Note: After this evaluation was completed, Friends of Karen used the findings to make improvements in the areas where families provided suggestions to service delivery.

Evaluation of the Friends of Karen Family Support Program

Final Report

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In collaboration with the Friends of Karen

September 1, 2015
# Evaluation of the Friends of Karen Family Support Program

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Executive Summary

Friends of Karen (FOK) is a non-profit organization that provides financial assistance, social and emotional support, and advocacy for children with life-threatening illnesses and their families in 22 counties in the Metro New York Tri-State area. Beginning in May 2014, the Center for Evaluation and Applied Research (CEAR) at the New York Academy of Medicine partnered with FOK to carry out the organization’s first formal evaluation. The evaluation utilized a mixed-methods approach to describe and assess the process of implementing FOK’s Family Support Program and program outcomes, and describe and disseminate best practices and lessons learned related to the provision of advocacy and financial and emotional support to children with life-threatening illnesses and their families.

The evaluation utilized a mixed-methods approach. Qualitative methods were used to understand this complex program from multiple perspectives, including those of staff members, social workers, and currently and formerly enrolled families. Quantitative methods were used to aggregate general characteristics of the populations served and also understand impacts and changes over time. Data collection methods were: a focus group with social work staff (n=9), interviews with Friends of Karen families (n=30), a survey of referring hospital social workers (n=15), review of Family Assessment Forms (n=42), interviews with key staff and stakeholders (n=6), and a review of program data. The evaluation was implemented over the course of 11 months and was reviewed and approved by NYAM’s Institutional Review Board.

Findings

Defining Success

FOK seeks to help families “function” through their child’s treatment and beyond, and does not want to turn away any families that could use help. Although FOK staff have a strong vision of success, the measures of success are seen as relative to the needs of families and no caps or limits are put on eligibility in terms of financial resources.
**Enrollment Figures and Participant Characteristics**

*Reported figures from 2014 FOK records*

- FOK largely serves low income families, with over 50% earning less than $35,000 per year.
- Families are mostly located in New York City and its surrounding counties.
- The majority are also considered to be racial and/or ethnic minorities, with 38% identified as Hispanic and 19% identified as being black.
- FOK serves children across the entire age range, with the bulk being between 4-11 years of age.

*Characteristics of New Families from Family Assessment Forms*

- Half of all households enrolled during September and October 2014 were headed by the mother.
- Similar to the figures obtained from FOK records, most families were low income and their child received Medicaid, a public insurance.
- Over a quarter of new families were Spanish speaking, indicating the importance of having bilingual staff or appropriate language access services to facilitate communication with this population.

*Participant Characteristics from Family Interviews*

For the most part the participants interviewed for this evaluation mirror official FOK statistics and those obtained from the family assessment form. Additional characteristics include:

- All but one of the participants in family interviews was female.
- A quarter of interviewees were Spanish speaking.
- Participants were more likely to be white than the general population of families served by FOK; however, 33% were Hispanic, reflecting the general characteristics of the families served.
- Income measures were not requested from the interview participants; however, the high proportion of individuals (27%) with less than a high school education suggests that many were low income.
**Enrollment Process**

Families are usually referred to FOK by a hospital social worker and although the social worker may provide some demographic information about the family directly to FOK, FOK waits for the family to initiate contact with them and express interest in their services. Families apply on their own, in some cases with the help of the hospital social worker, and then FOK social workers review the family’s application and develop a preliminary plan of how to help the families before meeting them. The plan can include financial assistance with household and/or medical expenses and emotional support and information about the plan is conveyed in the first meeting with the family. In the event that a family does not live within the 22 counties that FOK serves, FOK has an “umbrella program” that offers $500 to families living outside the FOK catchment areas.

**Staff perspective:**

- FOK social workers want families to contact FOK as soon after diagnosis as possible, as they stand to benefit more over the long run if they seek their services early rather than after the diagnosis has already deeply affected the family emotionally and financially.
- FOK social workers prefer to meet families for the first time in their homes, but do also meet in hospitals. They also prefer to meet alone with the parents or caregivers and not in the presence of their children.

**Enrollment Information from Family Assessment Form:**

- Among the cohort that had completed applications during the evaluation period, the average length of time between the referral and the completion of the application was about a month and a half and ranged from 4 days to about one year.
- On average, only 11 days passed between an application and the first visit by appointed FOK social worker.

**Hospital-based social worker perspective:**

There was high awareness of the services FOK offered and the eligibility criteria among hospital social workers surveyed (n=15). Below are several findings from the survey:

- The social workers surveyed generally had very positive things to say about FOK, stressing the collegial and collaborative relationship they have with FOK social workers.
- Six reported that the main reason they made referrals was for the families to receive financial assistance and 8 reported that they refer to FOK for the full range of services offered.
- Suggestions for improvement in the enrollment process included more support for families completing what the hospital-based social workers consider to be complex applications as well as support for limited English proficient patients.
Family perspective:

Overall, the families interviewed reported positive experiences with the application and enrollment process. Below are several findings from the interviews:

- The majority of families learned about FOK from the hospital social worker.
- Many families chose to apply to FOK for financial reasons, especially when one or more of the family members needed to leave their job in order to be with their child during treatments.
- Some families said that they hesitated to apply out of pride, and even when families were enrolled in the program, several families interviewed said that they tried not to “bother” their social worker much, and refrained from calling them or waited for their calls instead.

Assessment of needs at enrollment

By helping families that remain current on their household bills despite the loss of income due to their child’s illness, FOK believes it can prevent them from going into debt and help them build a cushion so that assistance can be reduced once the medical crisis has stabilized. Below is data from the family assessment forms analyzed for this evaluation regarding the level of economic insecurity among families first enrolled in FOK and the types of financial support they received.

- The majority of families (65.9%) enrolled in FOK during the two month study enrollment period had experienced a loss of income due to their child’s illness.
- The majority was current on household bills prior to their child’s diagnosis, and remained so afterward while seven families were behind on their bills prior to the diagnosis of their child.
- Nearly a quarter of the parents were on FMLA or unpaid leave.
- 45.2% of families were on food stamps.
- 21.4% of families were on public assistance.

Support to families that were behind on bills prior to their child’s diagnosis is generally limited to illness-related expenses, while those who were current on household bills at the time of diagnosis are generally eligible for household-related financial assistance, whether they were current on their bills at the time of the FOK assessment or not.
FOK Services

In 2014, FOK served 635 children with life-threatening illness and their families, including 990 siblings; 280 children were new to FOK in 2014 and the others had been enrolled in previous years. Below are the top three areas where FOK distributes its financial assistance:

<table>
<thead>
<tr>
<th>Type</th>
<th>FY'14 YTD</th>
<th>% total FY'14 Budget</th>
<th>FY'15 YTD</th>
<th>% total FY'15 Budget</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housing expenses</td>
<td>$335,686</td>
<td>25%</td>
<td>$360,383</td>
<td>24%</td>
</tr>
<tr>
<td>Utilities</td>
<td>$184,350</td>
<td>14%</td>
<td>$200,592</td>
<td>13%</td>
</tr>
<tr>
<td>Hospital travel</td>
<td>$126,376</td>
<td>9%</td>
<td>$177,143</td>
<td>12%</td>
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</tbody>
</table>

The goal of FOK is to stabilize a family during a health crisis and as a result, FOK seeks to reduce financial support to families once they have achieved that goal. Information gathered through the family assessment form indicates that the reduction in financial support can happen in as little as three months. Below are several trends in changing provision of services to families over the three month enrollment and follow up period of this evaluation:

- Nearly all families received illness related expenses, and the number decreased modestly within three months.
- Household expenses were offered to nearly 60% at the initial assessment and nearly 50% at follow up.
- Psychoeducational and emotional support was reduced by 16%.
- Referrals for emotional support for the ill child and his or her siblings remained stable, or increased over the three month period.

Family Perspectives on FOK Services:

Overwhelmingly, families that participated in interviews were very grateful for the services they received from FOK. In the words of one parent:

*Their consistency, they did what they said they would do. They helped the most, a couple of other organizations didn't offer as much. Besides the financial end of it, which I could not have done it without, they gave me such a sense of peace, not having to stress about my bills and worry about that. I was able to be with my daughter...*[My FOK social worker] truly they gave me the comfort of a friend that I knew she wasn’t going anywhere. I felt as if she was there. And they’re still inviting me to things... It’s like a constant hug.*

Bereaved Parent
Families reported that FOK:

- Allowed them to maintain their household as it was before the illness.
- Allowed them to spend more time with ill child in the last stage of life.
- Cheered the ill child and his or her siblings through gifts, and relieved some parents of having to buy them
- Helped siblings adapt to the circumstances.
  - Five families mentioned that the sibling of their sick child became seriously depressed or developed anxiety over the course of their child’s treatment and in three cases FOK helped the sibling adapt and manage their depression or anxiety.

Most families greatly valued the financial support provided by FOK, although only a few families said they valued this kind of support the most. For some families, emotional support was the most important aspect of the services they received.

**Perspectives on their FOK social worker:** Participating families described how their social workers helped them in myriad ways. In addition to providing financial and emotional support, they coordinated donations, benefits, and services that families received on a more limited basis from other sources. They were seen as being highly organized, thoughtful, and proactive. Ultimately, however, families mostly talked about how their social worker cared for them and their families and supported them in the process of seeking treatment for their child’s illness. Families interviewed also generally found their experiences with their FOK social worker to be much more personal and ongoing than the ones they had with social workers in hospital settings.

**Perception of Limitations to FOK Services:** Most participants reported that they understood that they could receive help from Friends of Karen only while their child was in treatment. Some parents recalled being given a specific timeline, while others did not. Most participants also intuitively understood that FOK must limit how much they give out to whom and that what they give each family depends on that family’s needs and existing lifestyle. Although people understood that there must be limitations, some families were uncertain as to why and how those limitations existed. One parent felt that she received more services than other families because FOK must have “really liked us.”

**Suggested Improvements:** While the predominant response from families interviewed was that nothing could be improved, a few had specific requests worth mentioning:

- More advanced warning that the amount or type of financial assistance they received was going to end.
- Better communication about what is covered or not covered.
- Allow hospital-based social workers to apply to FOK on behalf of families.
Facilitators of Success

Findings from staff and stakeholder interviews as well as the focus group with FOK social workers highlighted how FOK achieves success, challenges to that success and best practices and lessons learned.

The following were identifiable facilitators of success:

- Hiring well-qualified social workers who have the capacity to do home visits and perform well when interacting with a range of other high level professionals in a hospital setting.
- Hiring bilingual staff who can communicate effectively with Spanish-speaking families in the program.
- Providing supervision and support to social workers. Experienced supervisors are available for consultation and able to give clear guidance on the full range of services and also on its limits so that social workers meet the needs of the families and do not push their own agendas.
- FOK has been able to raise sufficient funds to serve all eligible families that seek their services.
- A compassionate and resilient workforce allows FOK to serve complex families in complicated situations.

Challenges

Two main challenges directly impact the implementation of the Family Support Program, both of which relate to funding. One relates to its allocation and the other acquisition. They are:

Difficulties budgeting:

- The budget is developed around the demands of the Family Support Programs, which includes a fixed amount based on staff and rent and one that varies with family need and includes covering families’ bills. Variation in how much is provided to each family makes it difficult to predict at the beginning of each year what the cost of serving families will be.
- Measuring and budgeting social work staff time was considered difficult, particularly since many were part time staff with benefits
- The most challenging issue with the budget is deciding on whether or not there should be limits on certain services provided to families and what those limits should be.

Difficulties Marketing FOK:

- The fundraising environment that FOK operates in was described as being competitive.
- FOK is hesitant to market the program too broadly because it does not want to attract more families than it can truly support, either financially or emotionally, through staff time.
Staff reported that FOK struggles with how to define and describe the work that it does in part because the name of the organization is not descriptive of its activities and because providing for families’ essential needs (housing, food, illness related travel) may not seem as appealing as sending a family on dream vacation (Make a Wish Foundation) or curing cancer (St. Jude Children’s Hospital).

**Best practices/ Lessons learned**

The following is a list and description of key features or best practices of the Family Support Program that allows it to function the way that it does:

- Hiring strong staff and building their capacity.
- Creating a financial cushion.
- Engaging voluntary and pro-bono services and other resources.
- Utilizing a differential diagnosis of financial need to serve families of different income levels.
- Recognizing limits to the services FOK can provide and encouraging autonomy in families.

**Discussion**

FOK is unique because it utilizes an approach to financial assistance that could be considered a differential diagnosis of financial need whereby amount of assistance offered is relative to the standard of living prior to the child’s diagnosis. Its social workers look at the socio-economic context of the family including their household expenses prior to and after diagnosis, their illness related expenses, and their resources in terms of income and other supports, and try to offer something to everyone. While they are able to serve those who are well off, they largely serve low income and working middle class families, which is virtually unheard of. The need for such assistance may be especially important in the New York City area, where the cost of living, particularly for housing, is among the highest in the nation.

Families interviewed for this evaluation were overwhelmingly grateful for FOK’s assistance, both emotionally and financially. FOK helped families as a whole and offered special assistance to vulnerable siblings of the ill child. Many families believed it helped sustain them through a difficult time. Even those who ultimately lost their children were able to look back on the experience and feel grateful that they were able to experience their child’s death the way they did because of Friends of Karen.

FOK’s generous approach was facilitated by having skilled social worker staff, some of whom were bilingual and able to assist the sizable Hispanic population in both linguistically and culturally appropriate ways. Staff reported that their passion for their families grew through their work, as they were inspired by and helped cultivate resilience. They also received guidance and support for difficult cases.
FOK faces several important challenges with respect to budgeting. Executing the differential diagnosis of need model proved difficult. In addition, treatments of childhood cancers vary widely so it is hard to predict how long a child will need services and therefore how much to budget for each family. Furthermore, staff did not believe adequate systems were in place to measure true labor costs in order to adequately budget staff time needed to assess families’ needs, allocate resources, and offer the emotional support. Efforts to check program services against budgets included modifying spending guidelines and changing service plans for families, sometimes causing confusion for both staff and families.

In order to sustain the Family Support Program, staff recognized the need for sound fiscal management. FOK’s board established an endowment and allows the program to draw from a Board Designated Fund annually in order to cover gaps in revenue generated through fundraising events, grants, and individual giving. It also tries to maximize resources it can attract for free or at low cost.

While there is ample evidence that FOK succeeds at its mission, more information is needed to determine the most critical components of it. Identifying the most critical components may help alleviate the stress of keeping up with demand and possibly even allow for the expansion of the model.

Founded 36 years ago after a community wide effort to help Karen, a terminally ill child, receive care at home, FOK’s Family Support Program has a well-established operating model. It engaged CEAR to conduct its first formal evaluation of its services. This initial evaluation work documents and describes the Family Support Program’s operating model, including a description of the demographic characteristics of the families served, challenges and opportunities for serving children with life-threatening illnesses and their families, best practices and lessons learned. It will also identify outcomes in terms of primary benefits for, and impacts on, those receiving FOK services.

Beginning in May 2014, CEAR conducted a mixed methods process and outcome evaluation focused on the FOK Family Support Program. The evaluation had three aims:

1) To describe and assess the process of implementing Friends of Karen Family Support Program.

2) To assess the outcomes of FOK program in terms of the number of families served, the types of services they received, and the impact of those services on the families.

3) To describe and disseminate best practices and lessons learned related to the provision of advocacy and financial and emotional support to children with life-threatening illnesses and their families.

It is hoped that the evaluation findings will result in a better articulation of the FOK model so that it could possibly be expanded within the metro New York area or replicated in other parts of the country. It may also help fill gaps in the literature by focusing on services received by diverse populations with varying household structures including many minority, non-English speaking families, and single or unmarried couple households. Furthermore, economic

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interventions for children with life-threatening illnesses and their families are rare, as are published evaluations focused on them.

**Methods**

The evaluation plan, methods and instruments for this evaluation were developed in collaboration with FOK staff and consultants in order to assure that the information gathered was relevant to their needs and interests and that the data collection methods were feasible and sensitive to both FOK staff time and caregiver burdens. CEAR utilized a mixed methods approach in order to gather reliable information to address the aims of the evaluation. Qualitative methods were useful in understanding this complex program from multiple perspectives, including those of staff members, social workers, and currently and formerly enrolled families. Qualitative methods were also helpful when gathering personal and sensitive information related to a child’s health status or a family’s receipt of financial assistance. Quantitative methods were used to aggregate general characteristics of the populations served and also impacts and changes over time. Using both qualitative and quantitative methods, or taking a mixed methods approach, allows for the triangulation of data from multiple sources, the corroboration of findings, and the reduction in bias.

The following is a description of the multiple data collection methods that were used throughout the study period (May 2014- March 2015). All instruments and information sheets developed and used in the evaluation are available in the Appendix A. This study was reviewed and approved by NYAM’s Institutional Review Board.

*Focus group with social work staff:* In order to learn about the services offered by the FOK Family Support Program, the process of enrolling and supporting families, and the ultimate completion of services, a focus group was conducted with 9 social workers and case managers, including the Director of the Family Support Program. The focus group took place at FOK’s Manhattan office and took approximately two hours to complete. It followed a semi-structured interview guide developed in collaboration with FOK staff and consultants. CEAR staff members facilitated the group and took notes, recording the interview as backup to the notes. Lunch was provided. This focus group was summarized in detail for the Interim Report. Findings from the focus group will be interspersed throughout this report as needed.

*Interviews with Friends of Karen Families:* Formal semi-structured interviews were conducted with family members who currently or previously received FOK services to learn about the services they received and their satisfaction with those services. To capture perspectives on the full range of services offered by Friends of Karen, a purposeful sample was drawn to include
10 families currently being served by FOK because their child is receiving medical treatment, and 20 families who no longer received FOK services either because their child died (n=10) or completed treatment (n=10), for a total of 30 interviews. Within each sub-sample, diversity was sought in terms of racial and ethnic background, languages spoken (English and Spanish) and residence within or outside of NYC. Families were identified by FOK's Director of the Family Support Program and social workers, then called to ask their permission to be included in this evaluation research. Upon consenting to be contacted, CEAR researchers called to arrange the date of the interview and location.

Interviews were conducted in English and in Spanish. Before each interview, families were asked to complete a brief and anonymous demographic survey. The interviews explored how they learned about FOK, their ease or difficulty in applying for and receiving its services, the extent to which they benefited from its services, the degree to which services could be improved or changed, and the extent to which FOK helped them cope with their child’s illness and develop or maintain family well-being and positive interpersonal relationships. It also asked about other services that families may have received from sources outside FOK, such as from hospital social workers, religious institutions, and/or other community based organizations, and the ways that FOK is similar or different.

Interviews followed a semi-structured interview guide and either took place in a family’s home or other location of their choice or over the phone. Interviews took approximately one hour and were audio recorded for note taking and transcription purposes. Families received $25 cash if in person, and a $25 gift card if over the phone to show appreciation for their time.

Survey of referring hospital social workers: A brief survey of social workers in the pediatric oncology units in 22 hospitals in the service areas of FOK was developed to ask about referral practices, including their knowledge of the eligibility guidelines for FOK, reasons for making referrals to FOK, and how the referral processes could be improved. It also asked for the length of time they had practiced in a particular facility. Surveys were distributed on-line and participants were asked to complete it anonymously. Participants could choose to be entered into a raffle to win one of two $75 cash gift cards. Fifteen social workers completed the survey.

Review of Family Assessment Forms: FOK social workers were asked to complete a form based on their initial assessment of their families upon enrollment in FOK and then repeat this form at a routine follow up session 3 months later. The forms were then analyzed to learn about the range of FOK services offered to this representative sample of families, and how the services changed over time. Assessments were completed for all newly enrolled families who applied in September and October, 2014; a total of 42 forms were completed during this period. An FOK
number was used to protect the confidentiality of the families while allowing for follow up surveys to be completed and compared with the initial assessments.

The assessment form documented demographic characteristics of the family and the status of the family with regard to their ability to pay household and medical expenses, seek appropriate medical care for their ill child, afford and arrange childcare for siblings of the ill child, and demonstrate knowledge about their child’s illness and its potential to impact the family. It asked for a description of the child’s illness, date of diagnosis, age, and gender, and household size/structure, when they were referred to FOK, when their application was received, and the date of FOK’s first visit.

The assessment forms were completed by the social workers shortly after the initial and follow up visits so that it would not take away time from FOK services during the visit or complicate already stressful encounters. CEAR worked with FOK’s Director of the Family Support Program to train all FOK social workers on how to complete the form and monitor any challenges they had completing it. They were completed on paper, scanned, and securely transmitted to CEAR staff using a secure server. CEAR staff entered the findings from the assessments into a Qualtrics database and transferred the entered data into SAS for quantitative statistical analysis.

**Interviews with key staff and stakeholders:** Formal semi-structured qualitative interviews were conducted with 6 key staff and stakeholders of FOK, including its leadership on staff and board, a sibling support specialist, and a social work consultant in order to learn about the process of implementing the FOK Family Support program and the major outcomes of the services it provides. Interviews followed a semi-structured interview guide that explored perceptions of the FOK service delivery model, its strengths and weaknesses as well as its successes and challenges or missed opportunities. Lessons learned and recommendations for reaching and serving its target population were discussed. Interviews took approximately one hour to complete and were all conducted in person except one, which was conducted over the phone. They were audio recorded for note taking purposes, and selective transcripts were made for quotes.

**Review of secondary data:** To both contextualize the FOK program and report aggregated outcomes, the evaluation reviewed secondary data such as annual reports, program guidelines, and literature related to interventions to support children with life-threatening illnesses and their families. Program statistics, such as the number of children and families served, their racial/ethnic backgrounds, income levels, place of residence, and the amount of household and medical expenses paid were gathered from FOK. A review of the literature allowed for greater contextualization of the extent to which FOK was similar to or different than other
interventions or support programs for ill children and their families, and the extent to which its outcomes were comparable to other interventions.

Analysis

Analysis of evaluation data was ongoing and involved the input of FOK staff. Early and ongoing analysis allowed CEAR to provide rapid feedback to FOK, ensure the evaluation methods were yielding useful data, allow for adjustments to the data collection protocol, and report on preliminary findings on a timely basis.

Analysis of Qualitative Interview and Focus Group Data: Interview notes were maintained and analyzed in NVivo, a popular software package for qualitative research. Notes were selectively transcribed when responses are believed to be particularly salient and likely to be quoted in reports. Notes from interviews conducted in Spanish were translated into English for analysis. NVivo is designed to hold and manage multiple project documents, as well as a hierarchical set of topical codes, any or all of which can be attributed to particular blocks of text. After study documents are coded, searches can extract appropriately coded excerpts (e.g., blocks of text coded for reference to “coping,” or “financial support”) into single theme based reports. Interview data were analyzed using standard qualitative techniques.

Analysis of Survey Data: Data collected from on-line social worker surveys and family assessment forms were transferred to SAS statistical software for analysis. Basic statistics, including frequencies and means, were developed. A comparison of changes in FOK goals and plans were made between the initial and follow up family assessments.

Open ended questions in the social worker survey were analyzed for the distribution of responses and summarized accordingly.
**Finding**

Findings from this report were derived from all forms of data collection described above. They are organized by topic and salient themes within those topics, blending multiple data sources to give the most complete and representative picture of FOK’s approach to its work and the way its services and benefits are perceived by its families. Names of staff and participants are not included in this report to protect their confidentiality; pseudonyms are used when needed to convey the intended meaning of the participant.

**Defining Success**

According to its website, FOK’s mission is:

> To provide emotional, financial and advocacy support for children with a life-threatening illness and their families, in order to help keep them strong, functioning and able to cope.

Friends of Karen is a registered 501(c)(3) charity and the only organization in the New York metropolitan area to provide a comprehensive range of services -- at no cost -- to families caring for a child with a life-threatening illness.²

FOK seeks to achieve its mission through its Family Support Program’s team of social workers. What success looks like in terms of outcomes for families was a topic for much discussion with staff and stakeholders participating in the evaluation. One stakeholder defined success in a very idealistic way:

> Giving the family more time to love, because, our goal is to come in and take away all the stresses that naturally falls on someone’s shoulders when they have a child with a life-threatening illness. Because that’s enough to deal with. The fact that Mom may have to quit a job, the fact that you can’t pay bills, the fact that the sibling needs... childcare... or counseling..., all the sort of administrative and logistical stuff that comes along or crops up because of the child’s illness, we are able to take that away from them, or help them get through it, or give them the resources to get through it.

One staff member expressed a practical approach to helping families, and highlighted the importance of recognizing limitations when offering assistance. She defined the steps to success as:

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We can only measure our success by our role in that family's life for that short period of time when that child is in treatment. We can make sure the child can get to treatment... We can make sure that they have food on their table. We can help them find other resources, we can assist them in having child care or sending their kid to school. Or whatever that is but that's a piece of their life. Some of the families come to us with big problems, and we can't help them with those big problems. But I do think that we know our limitations, and if we stay true to our mission, and we know our limitation, and we focus on what it is we know we do well, then we'll be fine. And we have boundaries, and we're really clear on what those boundaries are. And I think that's incredibly important.

Finally, another staff member again emphasized the importance of the family unit, but rather than stability, sought ongoing functionality throughout the health crisis:

Greatest impact is that the families are able to function and concentrate on their family... and at the end of the day that the parents can feel confident and secure and I think if we can provide a service that allows a parent or parents to feel confident in their journey that their children are going to feel safe, and they're not going feel like everybody's losing control here. And 'oh my God, what is going to happen to me physically, emotionally and my family financially.'

Defining success was essential for measuring it, both for their philanthropic purposes and for this evaluation. FOK is accountable to its donors for the distribution of its funds and is very intent on justifying its expenditures. It has experienced growth in the number of staff (now 26) and cases, and its budget has grown accordingly. However, there is constant concern over maximizing its resources to be able to help families effectively and efficiently.

Although FOK staff have a strong vision of success, the measures of success are seen as relative to the needs of families and no caps or limits are put on eligibility in terms of financial resources. All families have the same opportunities for financial assistance, no matter what their income level. The degree to which FOK will cover illness related expenses and household related expenses depends upon whether the family experienced a loss of income due to caring for their ill child, and/or whether debts resulted from the illness or preceded it. Those who had household-related debts prior to their child’s illness and those who did not have household-related financial needs are eligible for illness related assistance such as travel, parking, meals, and other medical expenses not covered by insurance, such as co-pays. Those who have financial needs resulting only from loss of income or additional expenses due to the child’s

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3 Children must also be 21 years of age or under, lawful permanent residents or citizens of the U.S., and live or seek treatment in one of 22 counties served by FOK in the tristate Metropolitan NY area.
Illness can receive assistance to maintain their household. This includes assistance with their rent or mortgage, utilities, food, auto expenses and insurance, and telephone.

Financial assistance plans are made at the initial visit and are reviewed and revised every three months. While FOK seeks to support families throughout the duration of their child’s treatment, they do not commit to paying a set amount for a certain amount of time at the beginning. They adjust based on the progress of the child in treatment, the other resources that they are able to direct to their families (i.e., Social Security Income for the sick child or other philanthropic support), the alternate resources that the families are able to obtain (i.e. support from fundraisers, family members, and their community) and the amount of money allocated for family expenses in its annual budget.

FOK strives to offer every family something and not refuse any family support, even if it is not financial. All families are offered emotional support and advocacy as they seek treatment for their child, often across multiple hospital systems and for multiple years. Siblings of ill children are also eligible to receive support from an FOK Sibling Support Specialist who will work with the child in addition to the support the family receives from their FOK social worker. While they seek to reduce the financial support to families over time, they often maintain contact with families beyond their child’s treatment, whether the child has died or completed treatment. For families whose child has died, FOK has institutionalized various forms of remembrance, from greeting cards on the anniversary of their child’s death and birthday to an annual ceremony for all bereaved families who were served by FOK.

In sum, FOK seeks to help families “function” through their child’s treatment and beyond, and per its policies, does not turn away any families that qualify for their assistance.
Enrollment Figures and Participant Characteristics

Reported Figures

FOK keeps rigorous records of the number of families they served and characteristics of those families. Appendix B contains breakdown of the number of children served by their distribution across their 22 county service area from 2012-2014. Their annual report contains what they call a “snapshot” of the families they serve in their fiscal year. In 2014, 635 children with life-threatening illnesses and 990 of their siblings were served by FOK across their service area. Figure 1 offers descriptive details of the families served from FOK’s Annual Report 2014.

![Figure 1: Descriptive Statistics of FOK Families from 2014 Annual Report](image)

These figures indicate that FOK largely serves low-income families, with over 50% earning less than $35,000 per year. The families are mostly located in New York City and its surrounding counties. The majority are also considered to be ethnic and/or racial minorities, with 38% identified as Hispanic and 19% identified as black. They serve children across the entire age range, with the bulk between 4-11 years of age.
Participant Characteristics from Family Assessment Forms

CEAR’s evaluation allowed for the collection and analysis of more detailed characteristics of the families served by FOK. Table 1 includes information gathered from the completion of Family Assessment forms for 42 families in a two-month enrollment period in the fall of 2014.

Table 1: Characteristics of New FOK Families during Two Month Enrollment Period (n=42)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child age (year) at diagnosis (mean, min-max)</td>
<td>7</td>
<td>0 to 20</td>
</tr>
<tr>
<td>Primary language</td>
<td></td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>30</td>
<td>71.4%</td>
</tr>
<tr>
<td>Spanish</td>
<td>11</td>
<td>26.2%</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>2.4%</td>
</tr>
<tr>
<td>Race/ ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>16</td>
<td>38%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>14</td>
<td>33%</td>
</tr>
<tr>
<td>Black</td>
<td>9</td>
<td>21%</td>
</tr>
<tr>
<td>Unsure</td>
<td>2</td>
<td>5%</td>
</tr>
<tr>
<td>Asian</td>
<td>1</td>
<td>2%</td>
</tr>
<tr>
<td>Household structure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother heads household</td>
<td>21</td>
<td>50%</td>
</tr>
<tr>
<td>Mother and father head household</td>
<td>19</td>
<td>45%</td>
</tr>
<tr>
<td>Father heads household</td>
<td>2</td>
<td>5%</td>
</tr>
<tr>
<td>Parental marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single/not married</td>
<td>11</td>
<td>26%</td>
</tr>
<tr>
<td>Married</td>
<td>15</td>
<td>36%</td>
</tr>
<tr>
<td>Separated/ divorce/ widowed</td>
<td>12</td>
<td>29%</td>
</tr>
<tr>
<td>Unknown</td>
<td>4</td>
<td>10%</td>
</tr>
<tr>
<td>Parents are US citizens/ LPRs</td>
<td>39</td>
<td>93%</td>
</tr>
<tr>
<td>Parent/grandparents/ guardians served in US military</td>
<td>5</td>
<td>13%</td>
</tr>
<tr>
<td>Number of sibling (mean, min-max)</td>
<td>2, 1 to 7</td>
<td></td>
</tr>
<tr>
<td>Household size (mean, min-max)</td>
<td>4, 2 to 11</td>
<td></td>
</tr>
<tr>
<td>Single-child households (no siblings)</td>
<td>11</td>
<td>26%</td>
</tr>
<tr>
<td>Household income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under $23,850</td>
<td>11</td>
<td>26%</td>
</tr>
<tr>
<td>$23,850-$50,000</td>
<td>17</td>
<td>40%</td>
</tr>
<tr>
<td>$50,001-$75,000</td>
<td>6</td>
<td>14%</td>
</tr>
<tr>
<td>Over $75,000</td>
<td>6</td>
<td>14%</td>
</tr>
<tr>
<td>Child's insurance status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td>27</td>
<td>64.3%</td>
</tr>
<tr>
<td>Private insurance</td>
<td>11</td>
<td>26.2%</td>
</tr>
<tr>
<td>Unknown</td>
<td>4</td>
<td>9.5%</td>
</tr>
</tbody>
</table>
These findings resonate with FOK’s 2014 Annual Report listing of characteristics of families served in 2013 in terms of race/ethnicity, income, and age of the first child. The assessment form did not document for the family’s place of residence. However, several indicators gathered through this form offer greater detail into typical families served by FOK.

In terms of family structure, half of all households were headed by the mother. Such households may include siblings and other relatives, such as grandparents, aunts and uncles, or cousins to the ill child. Forty five percent of the households were headed by the mother and father of the child, but only 36% of families were married. The majority (55%) were unmarried, including those who were never married (26%), and those who were divorced, separated, or widowed. Two households were headed by the father only. The average household size was 4, and ranged from 2-11; the average number of children was 2 (ranging from 1 to 7), and 11 of the ill children (26%) had no siblings. Similar to the figures obtained from the annual report, most families were low income, and their child received Medicaid, a public insurance.

In terms of the immigration status of the families served by FOK, the overwhelming majority (93%) of the parents were lawful permanent residents or citizens. The assessment form presented the first opportunity for FOK to document this information. Five of the parents/grandparents or guardians had served in the U.S. military. Over a quarter of new families were Spanish speaking, indicating the importance of having bilingual staff or appropriate language access services to facilitate communication with this population.

In sum, the majority of families could be considered “fragile” even before their child became ill. The phrase “fragile families” refers to family structures in which the mother is unmarried at the time of the child’s birth. This family structure is increasingly common in the U.S., particularly among blacks and Hispanics. In 2007, 40% of all children were born to unwed parents; unfortunately, research has shown that children born to unmarried couples generally fare worse academically, economically, and even in terms of their health. Therefore, philanthropic efforts to encourage stability in a child’s home over the course of a life-threatening illness and treatment among fragile families are likely to face difficulties that supersede the illness.

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4 FOK serves children with legal residence in the U.S. regardless of the immigration status of the parents.
**Participant Characteristics from Family Interviews**

The final snapshot of the characteristics of families in FOK comes from a demographic form completed by families who were interviewed (Table 2). For the most part, it mirrors the official statistics and those obtained from the family assessment form. All but one of the participants in family interviews was female, and their average age was 41, ranging from 29 to 61. A quarter were Spanish speaking, and over 60% were employed workers at the time of the interview. The interviewees were more likely to be white than the general population of families served by FOK; however 33% were Hispanic, reflecting the general characteristics of the families served.

Over half (16) were born outside the U.S., and nearly a third of grandparents of the ill children lived outside the U.S. Ten of the participants were from Central or South American, three were from the Caribbean, two were from Eastern Europe, and one was from Africa.

Income measures were not requested from the interview participants; however, the high proportion of individuals (27%) with less than a high school education suggests that many were low income.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FOK status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Active</td>
<td>10</td>
<td>33%</td>
</tr>
<tr>
<td>Bereaved</td>
<td>10</td>
<td>33%</td>
</tr>
<tr>
<td>Survivor</td>
<td>10</td>
<td>33%</td>
</tr>
<tr>
<td>Spanish speaking</td>
<td>8</td>
<td>27%</td>
</tr>
<tr>
<td><strong>Female/ mothers</strong></td>
<td>29</td>
<td>97%</td>
</tr>
<tr>
<td><strong>Average age (mean, min/ max)</strong></td>
<td>41</td>
<td>29 to 61</td>
</tr>
<tr>
<td>Working</td>
<td>20</td>
<td>67%</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>2</td>
<td>7%</td>
</tr>
<tr>
<td>Black</td>
<td>5</td>
<td>17%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>10</td>
<td>33%</td>
</tr>
<tr>
<td>White</td>
<td>12</td>
<td>40%</td>
</tr>
<tr>
<td>Born outside the US</td>
<td>16</td>
<td>53%</td>
</tr>
<tr>
<td>Child's grandparents outside US</td>
<td>9</td>
<td>30%</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>8</td>
<td>27%</td>
</tr>
<tr>
<td>Some college or higher</td>
<td>21</td>
<td>70%</td>
</tr>
</tbody>
</table>
Additionally, 13 out of the 30 interviewed lived in New York City (NYC), 12 lived in NY counties surrounding NYC, three lived in New Jersey, and two in Connecticut. Combined with the data presented above, the information gathered from this purposeful convenience sample of FOK families suggests that FOK works with highly diverse families. Among immigrant families, the lack of extended family, including grandparents of the sick child, may indicate lack of a strong support network in a time of crisis.

Enrollment Process

Staff Perspectives

FOK social workers that participated in a focus group walked CEAR researchers through the process by which they enroll families and decide upon the initial services that families will receive. They explained that families are usually referred to FOK by a hospital social worker. Though the social worker may provide some demographic information about the family directly to FOK, FOK waits for the family to initiate contact with them and express interest in their services. This is usually done by phone; families reach an FOK intake worker who explains the program and what it can possibly offer and then sends an application to their home. The intake worker primarily screens to make sure that the family lives within one of the 22 counties that FOK serves; participants explained that there is an “umbrella program” that offers $500 to families living outside the FOK catchment areas. Participants expressed their hope that families contact FOK as soon after diagnosis as possible, as they stand to benefit more over the long run if they seek their services early rather than after the diagnosis has already deeply affected the family emotionally and financially.

After contacting FOK, families are then expected to fill out an FOK application and return it with supporting documents, including tax returns and proof of income such as their last two pay stubs, SSI awards, or other support. Hospital-based social workers who work with the families are also asked to submit documentation on the child’s condition and expected length of treatment. If a family is in crisis, FOK may extend assistance to families before their application is complete. This could include a family whose child is at the end of their life. FOK also asks families to sign a release allowing them to speak with the hospital-based social worker. This is in order to collaborate in the interest of the patient’s care.

FOK social workers are assigned to families based on their home residence, not the hospital where their child is seeking treatment. The focus group participants reported that they study the applications and develop a preliminary plan of how to help the families before meeting them. This could include financial assistance with household and/or medical expenses and
emotional support. The plan is then confirmed upon meeting the families. They prefer to meet the families in their homes, but do also meet in hospitals. They also prefer to meet alone with the parents or care givers and not in the presence of their children.

**Enrollment Information from Family Assessment Form**

Findings from analysis of the family assessment forms offered information about how quickly the referral and intake process typically takes place (Table 3).

<table>
<thead>
<tr>
<th>Enrollment Stages</th>
<th>Days (Range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Days between 1st diagnosis and referral (n=30)</td>
<td>74, 7 to 348</td>
</tr>
<tr>
<td>Days between relapse and referral (n=6)</td>
<td>396, 26 to 997</td>
</tr>
<tr>
<td>Days between referral and application</td>
<td>44, 4 to 369</td>
</tr>
<tr>
<td>Days between application and first visit</td>
<td>11, 1 to 50</td>
</tr>
</tbody>
</table>

*Information about whether the referred child had an initial diagnosis or was referred upon relapse was not available for 6 of the families.

Ideally, FOK would like to help families as early in their treatment as possible so that families do not deplete their resources or become destabilized due to the financial pressures as a result of loss of income and additional illness-related expenses while their child undergoes treatment for a life-threatening illness. The findings were markedly different between those referred with a new diagnosis compared to those who had relapsed. Among families of children with a new diagnosis, the average length of time between diagnosis and referral was about 2.5 months, and ranged from a week to nearly a year. Among those families who were referred following their child’s relapse, the average was just over a year, and ranged from nearly one month to over 2.5 years. Of course, these figures only include families that actually completed applications and enrollment with FOK; no figures are available for those that were referred by a hospital-based social worker but never applied or followed up. That said, among the cohort that had completed applications during the evaluation period, the average length of time between the referral and the completion of the application was about a month and a half, and ranged from 4 days to about one year. This indicates that there is little lag between referrals and the submission of an application for most families that apply.

Upon receipt of an application, FOK was quick to respond. On average, only 11 days passed between an application and the first visit by appointed FOK social worker. The most time that passed between receipt of an application and the first visit was 50 days.
Hospital-based Social Worker Perspectives

Given that hospital-based social workers are a major determinant of who and when a family with an ill child is referred to FOK, the evaluation sought to learn more about their knowledge of FOK and their referral practices.

Among hospital-based social workers that completed CEAR’s on-line survey (n=15), there was high awareness of the services FOK offered and the eligibility criteria. For example, all knew that FOK provided emotional support and offered assistance paying for utilities for families of children under 21 years of age that had a life-threatening illness. Thirteen knew that eligibility for services depended on the extent to which the family’s financial situation was affected by the child’s illness. The hospital-based social workers were asked for a rough estimate of the number of families that they referred to FOK in a given week. Results varied from almost all, to very few (Table 4).

Table 4: Proportion of referrals made to FOK by hospital-based social workers (n=15)

<table>
<thead>
<tr>
<th>Proportion of families referred in a week</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Almost all</td>
<td>8</td>
<td>57.1%</td>
</tr>
<tr>
<td>Some</td>
<td>4</td>
<td>28.6%</td>
</tr>
<tr>
<td>Very few</td>
<td>2</td>
<td>14.3%</td>
</tr>
</tbody>
</table>

Six reported that the main reason they made referrals was for the families to receive financial assistance, and 8 reported that they refer to FOK for the full range of services offered. The majority made referrals by giving families a brochure and calling FOK to let them know about the family while encouraging the family to contact FOK for an application.

The social workers surveyed generally had very positive things to say about FOK, stressing the collegial and collaborative relationship they have with FOK social workers. For example, one wrote:

Friends of Karen is a reliable organization that I know when I refer my families to, they are getting quality support. I also know that I can reach out to the social workers there and discuss the family in greater detail, including my concerns and what I believe their needs might be based on my assessment, and their workers value this and also give their feedback based on their own assessments, which I also value. I know that together we can come up with a good plan for the patient and their families to get through the treatment.

While most comments were positive, one was critical of what was perceived to be disparities in the distribution of financial support, suggesting favoritism of some families over others.
Another suggested that the application refrain from asking families to use their pictures for future marketing materials, suggesting this might discourage families from applying for services.

Finally, several suggested room for improvements to the referral process through improved communication and greater consistency. More support for families completing what they consider to be complex applications was also suggested, including support for limited English proficient patients. One suggested allowing hospital-based social workers access to the application so that it could be started while the families were in the hospital.

**Family Perspectives on Enrollment**

Among the families interviewed, 28 out of 30 of them heard about FOK from a staff member at the hospital where their child was seeking treatment. Nineteen heard about it from a social worker, two from a nurse where there were no social workers, one from a child life specialist, and one from another parent; three didn’t specify who told them in the hospital. One person didn’t remember how they heard about it, and one heard about FOK from a television cable installer when he came to their home and saw the condition of their daughter. None had ever heard about FOK before their child’s illness, and many were reluctant to call at first. One person explained:

> We were at the cancer oncology ward, and the social worker had given me a brochure on FOK, ... but you know we’re proud people, we didn’t think we need help from anybody, we just didn't know where our path was taking us. And she had given us a couple groups to contact, and I just said 'I'm not going to call anybody, I don't need any help'. And then, one day, when things were a little calmer I sat down and opened up the brochures and read them and called, and I spoke, she was very pleasant and very sweet. And said she'd like to come out and visit with us, and she did, and she explained what their group could do for us, and again, we were still, like, ‘we don't need any help from anybody,’ but we really did, you know, we just didn't realize that we did...I didn't even know they existed before that. I mean, I didn't know many of these groups existed before this. Parent of Survivor

Many families decided not to apply to FOK when their child was first diagnosed, and only did so when one or more of the family members needed to leave their job in order to be with their child during treatments. One mother explained:

> Within a month of being here and not knowing where life was headed, I kind of said I'm not going to go to work, because I've always been the working parent, and I decided to stay home, and I think that's when, if my memory recollects correctly,
that's when [the hospital-based social worker] said to us, you know, FOK is a terrific fund and they're awesome, and also, we had a second recommendation from Katie’s pediatrician out of here, who's not affiliated with this hospital at all. Parent of Child in Active Treatment

Many families said they called because they had financial concerns after their child became ill and needed treatment. A few also mentioned needing childcare for the siblings of their ill child because their spouse worked and they needed to be in the hospital all the time. One explained:

When my son got sick, I wasn’t working, I wasn't able to work, and we were tight as it was with our mortgage, and bills medical bills (from my daughter’s ongoing medical treatment for cancer), never mind on top of the new medical bills (for my son), so we were freaking out, I just didn’t know what we were going to do, I thought we were going to lose the house, what was going to happen to other 2 kids while I'm in the hospital so it's just a lot at one time. So between social worker at [the hospital] and between the social worker at FOK they were wonderful at helping us figure everything out and taking step by step. Parent of Survivor

Many felt hesitant to apply out of pride, or not wanting to admit that they needed help.

I felt bad taking from them what I took from them, to be honest, we felt a lot of guilt, because it takes away your pride in some sort of way. It makes you feel like you can’t provide for your family. But we had no choice. Parent of Survivor

Out of pride and a sense of privacy, one Spanish speaking family refused FOK’s rent assistance when the mother stopped working to care for her son, and instead moved in with the mother’s sister. The child of that family was sensitive about people knowing he had an illness, and the mother tried to honor that by not seeking outside assistance. Ultimately, the child consented to letting his mother get help from FOK. She said:

I had to ask my son because he didn’t like for me to talk about his sickness with other people. I couldn’t do anything without him saying ok. He let me apply to FOK because I talked to him about it and told him what they would offer me. He said yes. At first he didn’t want to talk to the people from FOK, but then it seemed like he liked [the FOK social worker]. Bereaved Parent

Even when they were receiving FOK services, several families interviewed said that they tried not to “bother” their social worker much, and refrained from calling them or waited for their calls instead.
When asked to recall the application process, most explained that it was easy and straightforward. A few did not even remember completing it, and several explained that their hospital social worker filled it out for them, and they just signed the papers. Applications were available in English and in Spanish. One Spanish-speaking parent recalled help she received in filling it out. She said:

My daughter was already doing poorly at that point. Some things that I didn’t understand on the application she helped me with, but other things I filled out myself. She gave me instructions about how to do everything. She explained to me the whole application, so it was easy for me. I filled it out myself, though. Bereaved Parent

Most had applied while their child was in active treatment in the hospital, including two who had children receiving bone marrow transplants for sickle cell. Two only applied toward the end of their child’s life, when the child returned home and was receiving hospice.

Many people recalled having to provide proof of their income and needs and going over the application with the social worker at the first visit to confirm what they reported. One bereaved parent explained, “They really help the people who need it, because a lot of people try to take advantage, so they needed proof.”

Overall, the families interviewed reported positive experiences with the application and enrollment process.
Assessment of Needs at Enrollment

Since the family interviews were not used to assess the needs of the families at the time they enrolled in FOK, findings from the family assessment forms can be seen as a quasi-representative breakdown of the needs of families when applying to FOK. Table 5 shows the level of economic insecurity among families first enrolled in FOK and the types of financial support that they were already receiving.

Table 5: Assessment of Income/ Need at Initial FOK Assessment among New FOK Families During Two Month Enrollment Period (n=42)

<table>
<thead>
<tr>
<th>Assessment</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experienced loss of income due to child's illness</td>
<td>27</td>
<td>65.9%</td>
</tr>
<tr>
<td>Either parent/ guardian on FMLA*/ unpaid leave</td>
<td>10</td>
<td>23.8%</td>
</tr>
<tr>
<td>Family current on household bills:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prior to diagnosis</td>
<td>35</td>
<td>85.4%</td>
</tr>
<tr>
<td>At 1st assessment</td>
<td>30</td>
<td>73.2%</td>
</tr>
<tr>
<td>Current prior to diagnosis, not current at 1st assessment</td>
<td>6</td>
<td>14.6%</td>
</tr>
<tr>
<td>Other source of income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SSI</td>
<td>8</td>
<td>19.0%</td>
</tr>
<tr>
<td>Public assistance</td>
<td>9</td>
<td>21.4%</td>
</tr>
<tr>
<td>Food stamps</td>
<td>19</td>
<td>45.2%</td>
</tr>
<tr>
<td>Child support</td>
<td>8</td>
<td>19.0%</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>14.3%</td>
</tr>
</tbody>
</table>

* FMLA: Family Medical Leave Act

The majority of families (65.9%) enrolled in FOK during the two-month study enrollment period had experienced a loss of income due to their child’s illness. Nearly a quarter of the parents were on FMLA or unpaid leave. The majority of families were current on household bills prior to their child’s diagnosis, and remained so afterward. However, six (14.6%) had already fallen behind on bills by the time of the first assessment.
FOK Services

For an overview of the type of services FOK offers its families, secondary data was analyzed according the expense type for the fiscal years 2014 and 2015. Though families receive emotional as well as financial assistance, the difficulty quantifying such support leaves the aggregation of financial support as a good proxy for the range of services offered to FOK families. In 2014, FOK served 635 children with life-threatening illness and their families, including 990 siblings; 280 children were new to FOK in 2014, and the others had been enrolled in previous years. Table 6 provides a breakdown in the provision of financial support by type for 93% of all support offered. These expenses form the core of FOK’s 3.8 million dollar annual budget (FY2015) and are projected in addition to costs of social work staff, administration, and overhead.

<table>
<thead>
<tr>
<th>Type</th>
<th>FY'14 YTD</th>
<th>% total FY'14 Budget</th>
<th>FY'15 YTD</th>
<th>% total FY'15 Budget</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Housing expenses</td>
<td>$335,686</td>
<td>25%</td>
<td>$360,383</td>
<td>24%</td>
</tr>
<tr>
<td>2 Utilities</td>
<td>$184,350</td>
<td>14%</td>
<td>$200,592</td>
<td>13%</td>
</tr>
<tr>
<td>3 Hospital travel</td>
<td>$126,376</td>
<td>9%</td>
<td>$177,143</td>
<td>12%</td>
</tr>
<tr>
<td>4 Auto expenses</td>
<td>$125,436</td>
<td>9%</td>
<td>$124,114</td>
<td>8%</td>
</tr>
<tr>
<td>5 Telephone</td>
<td>$72,169</td>
<td>5%</td>
<td>$85,825</td>
<td>6%</td>
</tr>
<tr>
<td>6 Child care</td>
<td>$77,250</td>
<td>6%</td>
<td>$80,680</td>
<td>5%</td>
</tr>
<tr>
<td>7 Hospital &amp; lab expenses</td>
<td>$57,663</td>
<td>4%</td>
<td>$77,371</td>
<td>5%</td>
</tr>
<tr>
<td>8 Funeral expenses</td>
<td>$74,769</td>
<td>6%</td>
<td>$68,007</td>
<td>5%</td>
</tr>
<tr>
<td>9 Hospital meals</td>
<td>$50,913</td>
<td>4%</td>
<td>$59,096</td>
<td>4%</td>
</tr>
<tr>
<td>10 Physician &amp; nursing expenses</td>
<td>$60,216</td>
<td>4%</td>
<td>$59,007</td>
<td>4%</td>
</tr>
<tr>
<td>11 Medicines &amp; supplies</td>
<td>$53,523</td>
<td>4%</td>
<td>$49,095</td>
<td>3%</td>
</tr>
<tr>
<td>12 Food expenses</td>
<td>$28,365</td>
<td>2%</td>
<td>$29,772</td>
<td>2%</td>
</tr>
<tr>
<td>13 Health insurance</td>
<td>$8,258</td>
<td>1%</td>
<td>$26,014</td>
<td>2%</td>
</tr>
<tr>
<td>14 All other</td>
<td>$100,250</td>
<td>7%</td>
<td>$111,744</td>
<td>7%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>$1,355,224</strong></td>
<td></td>
<td><strong>$1,508,843</strong></td>
<td></td>
</tr>
</tbody>
</table>

Overall, the FY’15 budget was 11% higher than the FY’14 budget making the distribution of most expenses relatively consistent from FY2014 to FY2015. Health insurance-related costs saw the biggest absolute increase from just over $8,000 to over $26,000. This may reflect changes in health insurance premiums, deductibles, and co-pays brought about by national reforms under

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6 FOK’s fiscal year runs from April-March
the Affordable Care Act (ACA) enacted in 2014. Otherwise, expenses reflect the fact that FOK families live in one of the most expensive housing markets in the country. Nearly a quarter of the entire family support budget is dedicated to housing. When combined, travel related expenses, including hospital travel (i.e., parking and tolls) and auto expenses, make up the 2\textsuperscript{nd} largest expense category at 20% of the family support budget in FY2015.

While aggregated expenses provide a good overview of the distribution of support to FOK families, they do not reflect the way in which support changes over time depending on the needs of the family. Going back to the goal of the program to stabilize a family during a health crisis, FOK seeks to reduce the financial support to families once they have achieved that goal.

Information gathered through the family assessment form indicates that the reduction in financial support can happen within a three month period. Table 7 summarizes the type of support offered to FOK families newly enrolled during two consecutive months of the evaluation period and the change in the services offered to them three months later. Excluded from this analysis were three families whose ill child died within three months of enrollment, and three families that did not respond to outreach by social workers nor submit any expenses for reimbursement.

\footnote{The ACA established maximum deductible levels which were often higher than most had previously been; many insurers interpreted this change as setting a standard rather than a limit.}
Table 7: Change in FOK Services Plan between Initial and 3 Month Follow Up Visit among New FOK Families with a Child in Active Treatment (n=36)

<table>
<thead>
<tr>
<th>Service Components</th>
<th>Initial N</th>
<th>%</th>
<th>Follow-up N</th>
<th>%</th>
<th>Difference N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illness-related expenses</td>
<td>33</td>
<td>91.7%</td>
<td>31</td>
<td>86.1%</td>
<td>-2</td>
<td>-5.6%</td>
</tr>
<tr>
<td>Household expenses</td>
<td>21</td>
<td>58.3%</td>
<td>17</td>
<td>47.2%</td>
<td>-4</td>
<td>-11.1%</td>
</tr>
<tr>
<td>Psychoeducational/emotional support</td>
<td>22</td>
<td>61.1%</td>
<td>16</td>
<td>44.4%</td>
<td>-6</td>
<td>-16.7%</td>
</tr>
<tr>
<td>Sibling support</td>
<td>15</td>
<td>41.7%</td>
<td>9</td>
<td>25.0%</td>
<td>-6</td>
<td>-16.7%</td>
</tr>
<tr>
<td>Gifts</td>
<td>23</td>
<td>63.9%</td>
<td>12</td>
<td>33.3%</td>
<td>-11</td>
<td>-30.6%</td>
</tr>
<tr>
<td>Back to school supplies^8</td>
<td>17</td>
<td>47.2%</td>
<td>12</td>
<td>33.3%</td>
<td>-5</td>
<td>-13.9%</td>
</tr>
<tr>
<td>Advocacy/ resources</td>
<td>13</td>
<td>36.1%</td>
<td>11</td>
<td>30.6%</td>
<td>-2</td>
<td>-5.6%</td>
</tr>
<tr>
<td>Literature</td>
<td>15</td>
<td>41.7%</td>
<td>3</td>
<td>8.3%</td>
<td>-12</td>
<td>-33.3%</td>
</tr>
<tr>
<td>Go Bag</td>
<td>34</td>
<td>94.4%</td>
<td>1</td>
<td>2.8%</td>
<td>-33</td>
<td>-91.7%</td>
</tr>
<tr>
<td>Referral to other agency for financial support</td>
<td>11</td>
<td>30.6%</td>
<td>4</td>
<td>11.1%</td>
<td>-7</td>
<td>-19.4%</td>
</tr>
<tr>
<td>Referrals to additional emotional support:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>For parents</td>
<td>6</td>
<td>16.7%</td>
<td>2</td>
<td>5.6%</td>
<td>-4</td>
<td>-11.1%</td>
</tr>
<tr>
<td>For ill child</td>
<td>2</td>
<td>5.6%</td>
<td>2</td>
<td>5.6%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>For sibling</td>
<td>3</td>
<td>8.3%</td>
<td>4</td>
<td>11.1%</td>
<td>1</td>
<td>2.8%</td>
</tr>
</tbody>
</table>

Nearly all families received illness-related expenses, and the number decreased modestly within three months. Household expenses were offered to nearly 60% at the initial assessment and nearly 50% at follow up. Psychoeducational and emotional support was also reduced by 16%. Certain items, such as literature and Go Bags^9 occur at the first visit; the change in the provision of these services among this enrollment cohort corresponded to this programmatic reduction. Referrals for emotional support for the ill child and his or her siblings remained stable, or increased over the three-month period.

Family Perspectives on FOK Services

Overwhelmingly, families that participated in interviews were very grateful for the services they received from FOK. Families who were interviewed all received some form of financial support, and families varied in terms of how much they relied on the FOK social worker for emotional support. Participants tried to describe their gratitude in many ways.

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^8 Though its own line item, back to school supplies are considered to be part of the gifts program.

^9 Go Bags are bags prepared by FOK to help parents organize their paperwork and be ready for lengthy hospital stays and numerous encounters with health care providers.
The following quotes are examples of overall impressions of the FOK Family Support Program:

I don't know how we would have made it through our most difficult time without them, and that's financial, emotional, everything. That's a lot for somebody that doesn't know you to do, they're like our miracles. Parent of Child in Active Treatment

What they offered us was a relief and gave us tranquility. We only had to think about our son. And the financial part didn't have to asphyxiate us and create problems. What a child needs is that the family is united. Parent of Child in Active Treatment

Their consistency, they did what they said they would do. They helped the most, a couple of other organizations didn't offer as much. Besides the financial end of it, which I could not have done it without, they gave me such a sense of peace, not having to stress about my bills and worry about that. I was able to be with my daughter...[My FOK social worker] truly they gave me the comfort of a friend that I knew she wasn't going anywhere, I felt as if she was there. And they're still inviting me to things... It’s like a constant hug. Bereaved Parent

They hit every single piece and brought it together, so that at the end of the day, I could just be a mom and take care of my daughter (crying), and that’s really all I wanted in the end. I wanted all the professionals to do whatever they needed to do so I could just sit with my daughter...and that’s literally what they did... Hospice took care of the medical piece, and they took care of anything else. Bereaved Parent

We have pretty good medical coverage... so I wasn't that worried at first, I was more worried about how to take off work and now I'm going to have lost wages because we didn't really want to leave her alone in the hospital and overnight... she was pretty much every day [in the hospital]. It wasn't that much after she was diagnosed that I thought, ok, we have good insurance, bills came in, and I didn’t realize this, that even though my co-pay is only $20, it's not one co-pay. So every time, which was every day I would be at the doctor, it was a co-pay for labs, it was a co-pay for like blood transfusion, it was a co-pay for like doctors' visits, so that that $20 co-pay was like $60 times 4 days a week, and then it got to be like 2 car payments. So one of the nurse practitioners gave me a booklet with FOK, and then I took it upon myself to call, and I remember being so nervous, because, we're not rich people, but we're not poor people, we're typical, average middle class. ...We would have lost our house if [FOK] didn't step in....So they helped me, but in the bigger picture, they’re helping the economy of NY. Parent of Survivor
Gifts

FOK offers all families, regardless of financial need, gifts on holidays and birthdays. Age appropriate birthday gifts are offered to all children in a household with children receiving treatment for a life-threatening illness and for siblings of children who have died for some time after. Preferred gifts are communicated to their FOK social worker before birthdays or religious holidays and teens are typically offered a gift card to pick something of their own choosing. According to the families, gift cards do not exceed $100 and families with multiple children are offered no more than $500 in gifts at the holidays. Food baskets and birthday party bags are also sent as gifts for a child’s birthday and Thanksgiving.

FOK’s gift program was often viewed as a much appreciated surprise. Many reported how the gifts cheered their sick child, made the siblings feel valued, and relieved the parents of the responsibility of buying gifts. Gifts were also offered upon meeting a child for the first time, and when the social worker visits the child at the hospital. Many saw it as something extra and not the main thing they valued about the program. Survivors did not mention receiving ongoing gifts after their child’s treatment ended, though that did not always lessen the anticipation of more gifts from the children. One participant explained:

They were amazing. To this day every time a box is in front of the house, the kids are like, ‘[our FOK social worker] sent us something!’ Eventually, it’s like copy paper and the kids are like, ‘Oh [FOK] sent us something!’ [They sent us gifts] for Thanksgiving, for their birthdays, for Christmas, they’re amazing. Parent of a Survivor

Family Perspectives on FOK Social Workers

Participating families described how their social workers helped in a myriad of ways. Besides determining the extent to which FOK would provide financial and emotional support, they advised families on other resources for which they may be eligible. This included social security benefits for their ill child, housing subsidies, public assistance (welfare), and public insurance. They also helped negotiate financial assistance plans with hospitals for portions of their medical bills that would not be covered by their insurance and addressed errors in medical claims. They helped resolve financial challenges that may have existed prior to their child’s illness and that continued to negatively impact the family. This ranged from helping find a donor to pay for part of an expensive water bill, to helping find a lawyer who could help a mother with bad debt file for bankruptcy.
The social workers were described as having coordinated donations, benefits, and services that families received on a more limited basis from other sources. They were seen being highly organized and thoughtful; many people mentioned that they provided pre-addressed stamped envelopes so they could send bills to FOK for payment. They were also seen as taking action. One woman explained, “I needed someone to say, this is what we’re going to do.”

However, families mostly talked about how their social worker cared for them and their families and supported them in the process of seeking treatment for their child’s illness. People described FOK social workers as being steadfast, reliable, and responsive and as providing advice and guidance as support without telling families what to do. The following are examples of the ways FOK families described their social workers.

They're in your life when things are really down, and also when you are going through something really bad, a lot of people who were there for you before, they're not there for you anymore... they become your closest circle, and they know everything. Parent of Child in Active Treatment

What I noticed most and what inspired most confidence is that they are really nice. They make you feel free and able to trust them. I liked that the most. And their honesty. How they talk to you, with cariño (love). Bereaved Parent (Spanish-speaking)

I feel comfortable with her. Nothing makes me feel uncomfortable. Her treatment has been good. I trust her. Because sometimes I doubt whether it’s ok to send my daughter to school because a lot of people tell me it’s not. So I call her to get her opinion. And she tells me it’s ok because the doctor said it’s ok and I should just talk to the teachers so that she can leave a little early from school and get used to it again. Parent of Child in Active Treatment (Spanish-speaking)

FOK social workers helped at least two of the families interviewed come to terms with possibility of their child’s death. The participants explained that their social worker helped them come to terms with their emotions in order to admit that their child would die to the child and his or her siblings, and most importantly to themselves. One participant said:

She was just a very warm, loving, compassionate person, and she, being gone through this with so many other families, she knew exactly what I was feeling, better at times than what I was feeling you know what I'm saying... she would say key words, or guide me through my own emotions, and almost explain my emotions to me, because I'm not very good with my emotions. Bereaved Parent

Another participant who worked with a different social worker said:
[My social worker], she helped us a lot to go through this, for parents to realize they're losing their child, its, you don't know what to do, you've never managed with that before. So, almost till the end, she has so many cases, she has the experience, she felt that something is wrong given [I] was full of hope, yeah, but she came one day, and she was like, ‘we have to talk about the other side’, you know. And before that, we didn't even want to think about that. But when the time comes, you can't do everything [in] a day, you don't have a year to manage the funeral, all the expenses, and everything, so I'm so thankful to her. *Bereaved Parent*

This parent also described the way her social worker helped her talk to her other children and explain to them that her daughter would die. Her son’s reflections on his sister’s ultimate death greatly impressed his teacher, who praised his mother for the way that she handled it.

*FOK social workers’ efforts to keep in touch with bereaved families over time were much appreciated. One mother explained:*

> They get in touch on Mother’s Day, the anniversary of her death, on her birthday, there is always a card. And this time, in October, I got a card for my daughter’s birthday and it makes me feel like she is sending me letters from far away. It’s very beautiful. Thank God good people like them exist, and they don’t ask for anything in exchange. *Bereaved Parent (Spanish-speaking)*

Families interviewed generally found their experiences with their FOK social worker to be much more personal and ongoing than the ones they had with social workers in hospital settings. Many reported they had difficulty getting time or the attention of hospital social workers, whereas FOK social workers would call them and check up on them. Some had good things to say about all the social workers they encountered and one even began to encourage one of her daughters to become a social worker since they were so helpful regarding matters of importance.
Perception of Limitations to FOK Services

In terms of the participants’ understanding of how long they believe FOK could help them financially, most participants reported that they understood that they could receive help while their child was in treatment. Several of the participants with children in active treatment recalled more specific timelines, like 3-6 months, or 6 months, or month-to-month up to a year. Several participants reported receiving support for multiple years, with the highest being four years. The participants varied in their perception of limitations to FOK’s funding. Some felt the limitations were inconsequential. For example, one person explained:

I honestly don’t remember, they gave me the impression they would support me as long as I needed to get myself back financially stable. They didn’t say you have to go back to work in 2 weeks or anything, I mean if I said to them I need to take a month, fully believe they would have supported me. Bereaved Parent

Another reported:

No at the first meeting they said they would help with whatever they can and I said no problem, I’ll take what I can get. If I have $50 in electricity to pay and they put $20, great. I only have to pay $30. And they always helped me. With everything they gave me, I could make it. They even gave my son a computer. [The FOK social workers] were always thinking about my son. They never told me how much or for how long they were going to give, but they always, until the end, helped. Even for the casket, to send it to Santo Domingo. They helped in that way so I could bury him there. I’m telling you. I pray to God that he protects you all, there are no words to express what they did for me. Bereaved Parent (Spanish-speaking)

Others perceived that beyond their child’s health status, FOK support was dependent on their ability to provide for their family:

I don’t remember that [what they said about the length of time they would support me], but I know they said as long as I’m still out taking care of him, and they know, they have the proof that I’m not working, they will be able to help me till I get back to my feet, I remember, I think they tell me that. Parent of a Survivor

Another survivor described how FOK helped her with utilities after her child was not in treatment because she still wasn’t working.

Most participants intuitively understood that FOK must limit how much they give out to whom, and that what they give each family depends on their needs and existing lifestyle. A couple participants explained:
I am aware that they have been helping and are still helping thousands of families. They sort of have to limit what they give out to everybody so, whatever they do for us I'm grateful. *Parent of Child in Active Treatment*

I imagine that the people who are used to more things than me, for example, the people who have cars, and such things, I would assume they would want more help than I did, but for me it was all fine. *Bereaved Parent (Spanish-speaking)*

While people understood that there must be limitations, people were uncertain as to why. While one participant appreciated FOK’s offer, she would have appreciated more in order to achieve more financial stability. She explained:

I mean, don’t think that I’m being ungrateful, because I’m not, because they did the most important thing which is keep a roof over my kid’s head, but it would have been nice, if they would have paid the [utility] bills from [the beginning], so that when they do cut me off I have a leg to stand on. Say for example, I was saving all that money, the seven hundred dollars [in my son’s SSI benefits] that I got, [say] I was saving three hundred dollars out of it, then when they cut me off, I would have that extra cushion to continue to pay my rent until I get another job, that would have given me an extra cushion, I would have at least saved, at least twelve hundred dollars, I would have had twelve hundred dollars in the bank so when they cut me off at least I’ll have one month of rent, and then I can go job hunting and stuff like that. *Parent of Child in Active Treatment*

Another participant, knowing they received more benefits than others families receiving treatment at their child’s facility, guessed that FOK must have “really liked us.” She explained:

I don’t know why, but they were very generous with us, I don’t know if it’s because we were very hard working, and we had worked very hard for everything that we had. But they were just very generous with us. [Other families], they would just “Oh yeah, FOK, they said they couldn’t help us.” And I was like... oh my God, if they only knew what they did for us, you know what I mean? I kind of figured in my head, I knew obviously they weren’t going to help people that were on Medicaid, that were getting free insurance, or someone that only had a single working parent from the start. You know what I mean. In my head, I was like, well, obviously I can understand that. But I don’t know if there were other circumstances that came into play as to why but I just know that with us they were very generous very helpful. *Parent of a Survivor*
Suggested Improvements:

While the predominant response from families interviewed was that nothing could be improved, a few had specific requests worth mentioning.

Timing of when financial support is reduced or terminated:

While most knew the support couldn’t continue indefinitely, more than one were surprised when the time came that it would be reduced. Although given advance notice of the reduction, one participant wished that it could continue for at least a month longer. She explained:

If I was doing a survey on them, that's what they should do, and I think they should do the minimum six months, give the person a six months cushion, the minimum six months, the most one year, just to give the person a cushion so that [you don’t] have to think about stuff like that. It's really stressful, it adds to your stress. Parent of Child in Active Treatment

A bereaved parent was also critical of what she felt was an abrupt end to FOK’s support. She had been mostly receiving support to pay her rent throughout her child’s treatment. When she asked how long she would continue to receive support after her child died, she was told that the next month would be the last, giving her essentially one more month of rent assistance. She felt that was “a little harsh”:

I don’t know. I know you can't assist forever, but like, just, it was kind of like a shock, like, kind of like, ok, the kid isn't here anymore, so we can't help you anymore.

Bereaved Parent.

FOK helped pay for her child’s funeral expenses; and overall, the participant was very grateful to the program for their support.

Communication about what is covered or not covered

One interviewee reported that he learned that certain medical bills he expected would be covered were not because they had gone to collections. He assumed there was a change in FOK’s plan, but didn’t have a clear sense of what would be paid and what would not. He explained:

They’ve paid many bills, there are many they have not paid. And there is the only...they don’t have an obligation and I can’t feel upset that they don’t pay it, but the only thing I have to say to them is that they should tell me what they cannot pay. They should tell me they will pay this and this but not this. They should let us know
because... it’s the only point of difficulty I’ve had with FOK. I’ve received many collection letters, but I was relaxed because I thought FOK was paying, but they were sending those letters because they were not paying...I feel bad asking FOK about it because they’ve helped us. Parent of Child in Active Treatment (Spanish-speaking)

As a result, he started submitting smaller bills for reimbursement instead of many at one time in the hope that they will pay them if altogether they do not appear to be so large. The participant recommended better communication and clearer explanation of what would be offered and if policies or coverage had changed: “if they can’t do something they just have to let you know and not let things be fluid and you’re thinking that something is being paid for when it’s not and then all of a sudden you find out.”

Suggestions for more emotional support:

One bereaved family wished that her social worker could have come to her child’s funeral. She understood it was FOK policy that they do not. A parent of a survivor wished that there could have been a support group for parents.

Suggestions for an alternate application process:

One interviewee wished that the intake process could be changed so that the hospital-based social workers could enroll people on behalf of families. She explained:

Sometimes the family is too distraught or can’t, get to doing that, making that phone call, and they’re really missing out on a valuable foundation resource here, for them to say, I can’t help them unless they call. And it’s like, it’s really tough... speaking with the child life specialist at [a hospital], she said the same thing... ‘I just, don’t really refer too many people to FOK because of their intake system, because a lot of people get frustrated that I can’t do the referral process for them.’ And it’s true, why can’t I [as a parent] just pick up the phone and say, “hey, these people really need you.” Just go there and say, hey, this is what I do, and I help you. Then do the intake right there in person. Parent of a Survivor

Though this participant did not have the experience of FOK operating this way, several others described their enrollment as something similar to this, with FOK social workers inviting them to apply after meeting them in the hospital and explaining the program, and hospital-based social workers helping to fill out the application.
Impact on Families

Families who were interviewed described the overall impact that FOK made on their families in positive terms. Findings regarding impacts are first presented by the impact on the families as a whole and then on the siblings of the ill child.

On families as a whole:

One interviewee captured the impact of the program as it related to FOK’s own goals of maintaining their household as it was before the illness.

We thought it was a great plan because the ability to save that my family had at the moment all this started was basically zero. We lived day to day. We didn’t want for anything, but we didn’t waste anything. They told us that there would be many bills piling up. When you don’t see the bills at first, you don’t realize, but then they did begin to arrive. And what they proposed sounded excellent because one of the things that they mentioned was that our style of life shouldn’t change, that everything at home should stay the same, that they would take care of those costs and obviously that was really fantastic. *Parent of Child in Active Treatment (Spanish-speaking)*

Like other families, another participant appreciated that FOK allowed her to be with her child in the last stage of her life by offering her rent assistance. She explained:

[I felt] relieved. It definitely helped make my decision to stop work, because if I hadn’t had that option, even though [my daughter] wanted me there, I still would have been like, ‘heh, like what else am I supposed to do?’ And even when I gave up my full time job, I was able to just focus on her, and not realize that the stress went away, because I was kind of stressing like, ‘when am I going to go back to work? Can I go back to work this time, can I call and tell them that?’ Because they were calling me like every few days, ‘OK, do you think you’ll be back on Monday?’ *Bereaved Parent*

On siblings:

FOK takes into account the siblings of the sick children and offers support. Staff members explained that recently they’ve been offering 6 weeks of weekly sessions to children to help them adapt to their sibling’s illness. One participant explained that her daughter’s illness greatly affected her son, who at 7 years of age was just two years older than her daughter. She said:

[It] actually 100% had impact on him. Him and his sister are pretty much inseparable, they’re best friends, because they’re close in age...Part of the reason
she [the sick child] was so well adjusted was because of him, because they would still play while she’s getting her chemo... he did have a lot of changes that he wouldn't have gone through had she not had to go through this. So basically, the [Sibling Support Specialist] from FOK came, and she would play games. For example, he was scared of her hair falling out before it did, he would say ‘Oh, I don’t want it to fall out.’ They worked with him on those kinds of concerns that he had ... [He] always looked forward to it, she was wonderful with him. Parent of Child in Active Treatment

Another participant explained that the sibling support was very important for the sibling of a child who had received a transplant for his sickle cell anemia. She said:

Sam, he felt neglected because everything is about Mike, Mike Mike, and it’s been like that all of his life, and he's coming second fiddle to Mike and everybody goes crazy, ‘oh Mike, I'm so sorry,’ but they forget that he's standing there, too, and just to ask him how he's doing. But the [Sibling Support Specialist] now, she makes all her attention on him, and he likes it, he always talks about her. Parent of Child in Active Treatment

A couple of participants reported that FOK arranged for help with homework for the sibling of the sick child after they realized they had gotten behind when their parents were consumed by their other child’s treatment.

Five families mentioned that the sibling of their sick child, mostly teenagers, became seriously depressed or developed anxiety over the course of their child’s treatment. In three of the cases, the parents reported that sibling support helped the sibling adapt and manage their depression or anxiety and also to understand what was happening to their sibling and their family. One said her daughter learned most importantly when not to talk about her sibling’s illness and when it was ok to talk about it. However, for two siblings the outcomes were not so positive. One sibling refused sibling support, and, according to the mother, abandoned her during his sister’s treatment and went to live with his father, from whom she was divorced. Another participant’s son became seriously depressed and was able to seek psychiatric treatment through a referral from FOK, only to have died shortly before his sister. No explanation was offered as to the cause of his death. However, the shock of then losing her daughter to cancer shortly after her son died galvanized the mother to create a special fund for sibling support at FOK.

Although families who were served by the sibling support program appreciated it, those with older children did not qualify for it, and at least one wished that her son could have received some support. She said:
Because he was older, they were like, 'No, sorry, you’re on your own.' He had a good sense of humor. We would just leave him a can of soup on the counter and be like, there’s your dinner. ...Sometimes I felt bad for [him] because he was left out because he was 21/22 at the time. I understand where you have to draw the line. Because I know in their Christmas program and their back to school program, they always include siblings. So I felt, not that I should, he was 21, I felt a little bad for him anyway. They have to have a policy, so that was it. Parent of a Survivor

**Most Valued Aspect of FOK:**

Interviewees were asked what the most important aspect of FOK was for them. Most people valued the financial contributions of Friends of Karen, though few said it was the most valued. A couple who did said:

Um, the financial support definitely because it took a load off, like, stress wise, it helped a lot, to not have to stress about money during that kind of a process. It didn't cover everything, but that's fine. As long as the main one is rent, really. Bereaved Parent

Obviously, the most important part was the fact that we’re leaving this experience without any major medical bills that will follow us. Parent of a Survivor

While many listed the financial support as the most important, some emphasized the emotional part as well. Exemplary quotes are:

Oh my gosh, definitely the support, the financial support, yes, but they had a huge edge of just compassion, from their employees. They're really good at guiding, at guidance. The compassion, the guidance. And they were also very sympathetic. They just know you, and they deal with different people every day on such a high volume, yeah, that’s it. Parent of Child in Active Treatment

Everything. Everything, everything, there is no single one thing. Even coming here to talk to me. There are moments when you’re alone and if someone comes to talk to you, they say cheer up. They help you morally, they lift your spirits. These are things to be thankful for. Bereaved Parent (Spanish-speaking)

If I hadn’t had that help I wouldn’t have been able to do it. I told the doctor yes [to the transplant], but when I was in the hospital it was a shock, it was a mess. I wanted to go back in time and tell them not to do it. I was depressed, frustrated. I even broke a foot in the snow. I had to stop working entirely. They helped me emotionally and financially. Parent of a Survivor (Spanish-speaking)
Facilitators of Success

With such evidence of the success of the program in addressing major concerns and areas of need for families of children with life-threatening illnesses, the remainder of this report turns to findings from staff and stakeholder interviews and a focus group with FOK social workers to describe how FOK achieves this success, what are challenges to their success, and what are best practices or lessons learned that they could share with others interested in engaging in philanthropy for children with life-threatening illnesses. The following were identifiable facilitators of success:

- **Hiring Social Workers**

  The centerpiece of FOK is the Family Support Program, which is staffed by social workers. Among the nine participants in the focus group with FOK social workers, the average length they worked with FOK was nearly 8 years, ranging from 17 months to 25 years. Most reported that they were interested in their position because they liked working with children and families and a few had experience with pediatric oncology and with children and families facing life-threatening illnesses. One wanted a “gift to give back” since her friend had died from cancer.

  A stakeholder believed that the FOK model was built on the traditional role of the social worker doing home visits in order to understand and connect with families, and better understand their needs. A staff member affirmed this opinion by stating:

  "Generally speaking, I think that families benefit from the in home, us coming into the home, is incredibly helpful, and I'm not sure under the circumstances, I'm pretty confident these siblings would not be supported if we weren't able to. I think that's a really important aspect of the program. I think that looking at the whole family, we try very hard to, it's not, our focus is not just to come in there and work with the siblings, it's to figure out how we can improve the communication, the education within the whole family. So, using the parents, of, well, we're not going to be here forever, and it's time limited, so how can we teach parents how to talk to the sibling, and support them."

  In addition, a stakeholder felt that social workers have a level of professionalism that allows them to perform well when interacting with a range of other high level professionals in a hospital setting. Finally, she believed that standardizing the credentials helps clarify the roles and services offered to families.

  Beyond just being trained as social workers, a staff member stressed the importance of having a hardworking, down-to-earth attitude. She said:
Lot of hard work goes into this. You need certain people to work here. You need a social worker that doesn’t mind walking up 6 flights of steps... and doesn’t feel so skilled and so great, can’t bring yourself to be real... or say, I can never help them because problems way beyond me.

Staff must be willing to be able to assist with concrete tasks, such as helping a family apply for food stamps, and offer supportive social work services.

❖ Hiring Bilingual Staff

Given the diversity of the population served, it was important for FOK to have bilingual staff, especially staff that could speak Spanish. One staff member explained:

I find working with the Spanish families, many times the parents that don't speak any English fall through cracks, and they're not able to communicate with the social worker in the hospital many times. They're kind of on the fringe of things. Many times, we’ve been able to help families maneuver the system so to speak regarding Social Security Income, Medicare, Medicaid. They're so grateful that someone speaks in their language and they feel comfortable, and they feel supported and they feel safe working with us. So I think it's important.

❖ Providing Supervision and Support

FOK social workers who participated in a focus group talked about the importance of having an experienced supervisor to consult who can give clear guidance on the full range of services and also on its limits so that they are meeting the needs of the families and not pushing their own agendas. As one person explained:

I think having that supervision and the boundaries are there for a reason, and being able to work independently is huge in this, where you have supervision, but you're out on your own a lot, and that's very different than working in an agency or in a hospital where you have people around you 24 hours a day, so the experience of having [the Director] to start the program.

In order to meet their needs for supervision and support, the participants meet at least twice monthly to review cases and policies. Those who provide sibling support services reportedly meet once every other month, which one staff member found challenging. She would have preferred having more frequent meetings to discuss difficult cases.
Raising Sufficient Funds

Fundraising could be seen as both a facilitator of success and a challenge. However, FOK staff are proud to say that they have not had to turn anyone away and that they try to offer something to everybody who applies. However, they stressed the importance of funding for achieving success. One explained:

It all comes down to funding...two things: funding, and then making sure we can find everybody, or they find us. Because I think what we do we do really well, but we just have to be able to continue to do it, and be able to grow with the demand, and so, in my mind, that comes down to funding, and then we can build the rest.

Cultivating Passion and Resilience

The qualities of having passion and resilience were seen as facilitators of success for both FOK and the families they serve. Creating a passionate workforce was considered to be highly important for being able to serve complex families in complicated situations. Staff reported that passion grew and inspired them to do the best they could do for the families they served. One explained:

All of us as social workers are very passionate about social work in general. So when you come to Friends of Karen and you see what these people go through, and you see they believe what you're saying and they listen to you, and you are the only resource they have, your passion grows a hundred times more. You just feel you want to be there for them, and you want to do everything that you can to get this family to go through the illness. And when and if the child died, you will be there for them no matter what. It doesn't matter the nationality, it doesn't matter if they speak English or don't. It's just you're there for them, and what we do as an organization is unbelievable.

Resilience can be understood as the ability to thrive after a hardship. This quality was seen in the families served and even among staff, some of who had lost children to illness. One staff member explained:

I see the best in everyone. I see people open their hearts, their wallets, giving their time, caring, and they don’t have to. And even some of our staff who have lost children, who every day are faced with their own history and their own loss... yet... it renews their sense of purpose. They didn’t fall apart, they’ve come back to help others in that situation, with the kind of empathy and compassion, and teaches us that. So it’s the resilience of the family and the children in the face of what they're going through, the battles that they're facing. It's the people who support this organization on every single level.
By offering support, FOK seeks to cultivate the resilience that they felt all people are capable of. One staff member said:

People are resilient, because people have hope. And hope is huge. I think it goes back to...if you provide a support that gives someone confidence... Let’s face it, if you’re struggling with your own problem, and you feel really insecure, how can you be resilient? If you can’t pay bills, how can you be resilient? You can be resilient in the face of lots of challenges I think when you’ve got the support that you need, too. I think that people in general are resilient, and they rise to the occasion, especially these kids. They’re amazing.

Challenges

There are many mitigating factors that could affect whether or not FOK can successfully support a family with a life-threatening illness. Variations in disease progression, reactions to treatments, interpersonal relationships and family dynamics prior to the illness, and the financial status of families prior to the illness can all affect the outcomes for the child and his or her family. Multiple family members could even be facing life-threatening illnesses simultaneously, as was the case for one family interviewed. While these are important to consider when understanding the limitations of serving families of children with life-threatening illnesses, there are two main challenges that directly impact on the implementation of the Family Support Program, and both relate to funding. One relates to its allocation and the other its acquisition. They are:

- Difficulties Budgeting

By not turning any families away, budgets for the Family Support program have to be set without having a clear sense of the level of need among participants and how those needs may change over time. The budget is basically developed around the demands of the Family Support Programs, including a fixed amount and one that varies with family needs. The fixed costs include the staff and rent and the flexible amount are the family bills. As presented earlier, the budget for family bills in 2015 was $1.5 million, the largest amount ever. The budget for this amount is set based on what they can raise. It is somewhat flexible in that FOK can ask its board to contribute more from a board designated investment fund if there is increased needs, or if revenue from fundraising events, grants, and individual giving falls short of projections. Staff try to control the amount spent in the Family Support Budget by reviewing expenses on a weekly basis. However, the most challenging issue with the budget is deciding on whether or not there should be limits on certain line items, and what those should be. One said:
If I'm called upon to make these decisions, knowing that where do we use our scarce and precious resources, I want to know that we're going to make the most difference in every family's life at least to the best of our ability. So if we know paying bills is exactly what every family needs or sibling support is what made a difference in that life, that's what we're going to concentrate on it.

In order to stay within a budget without strict or exact limits on the amount that could be offered to each family, staff described having to assess whether they were “enabling” dependent behavior through their support, or whether their support would allow families to keep up or maintain their standard of living and thrive through or after the crisis. Those that are believed to lead to “dependency” are minimized, and those that could truly support ultimate independence are encouraged.

Staff are also discouraged from committing to cover certain expenses for long periods of time and instead are advised to revisit the provision of assistance every three months. As described earlier in the perspectives from family interviews, this could be perceived as lack of transparency in the services that will be offered and can cause some confusion and stress among families.

Besides the effect it has on families, the fluidity in budgeting can lead to over or “under” spending during the budget period, with overspending obviously being more problematic. To address this challenge, FOK maintains a financial “cushion,” or Board Designated Fund (described below), and revises spending guidelines for its social workers. Each approach to controlling the budget has its own challenge. Maintaining the Board Designated Fund requires successful fundraising and revising guidelines means training staff to fully understand and accept the new guidelines in order to implement them. One staff member felt that the guidelines changed often without much notice and she relied on other staff to try to figure out what they are. She explained:

    Things change all the time because they’re trying to juggle budgets and funding, and you just kind of want to make sure you’re doing the right thing. So it is a lot of checking in.

Though adapting guidelines on the distribution of funding on an ad hoc basis may not be ideal, staff struggled to find an accurate way to “forecast” the costs of delivering FOK services to families with varying needs and uncertain disease trajectories and health outcomes.

Finally, there was a concern that budget decisions were affected by the wide-ranging emotional needs of the families. Staff must adapt their schedules and time to their varying needs. One staff member reported difficulty in estimating “true labor hours” required to project staffing
needs over time due to family’s varying emotional needs. In an attempt to more efficiently manage staff time and budget for rapidly changing family needs, FOK has “modernized” its case management software to allow greater access to real-time data about the families that it serves in order to budget staff time more efficiently.10

켰 Difficulties Marketing FOK

The fundraising environment that FOK operates in was described as being competitive, and programs that are successful at attracting funds are generally well known through their work and also through marketing. Families generally do not learn about FOK until they have a sick child. However, FOK was well known in hospital systems and among those caring for children with life-threatening illnesses. Families that were served by FOK were also great representatives of the program and some give back financially or serve as volunteers. Most families interviewed wished that FOK would be more well-known so that it could raise even more funds to help families and some tried to do their part by speaking on behalf of the organization at events, or hosting their own fundraisers to help get the word out and raise funds. Others felt reluctant to “look back” on a difficult time once it had passed.

Staff reported that FOK has never paid for marketing the program beyond what it can do in-house through their marketing team. FOK’s marketing materials mostly seek to explain the program to the families they serve and encourage them with positive stories about how FOK can help them through a difficult time or “journey.” Furthermore, FOK is hesitant to market the program too broadly because it does not want to attract more families than it can truly support either financially or emotionally through staff time.

Beyond the practicalities of engaging in marketing, staff reported that FOK struggles with how to define and describe the work that it does. The fact that the name of the organization is not descriptive in terms of what it does has also been identified as a potential barrier to enlisting new supporters. Furthermore, they are neither trying to cure illnesses, like St. Jude Children’s Research Hospital, nor are they offering exciting dream vacations, such as Make a Wish. Staff believed that it seemed harder to generate support for paying someone’s rent, for example, than their vacation. This logic applied to families, too; one staff member believed that some families are too proud to accept financial support, but will still accept Make A Wish.

10 As of February 2015, FOK began implementing the transition to ETO Impact by Social Solutions for its case management tracking needs.
A staff member suggested that marketing offer a greater focus on the reasons why FOK does its work rather than how because the challenges that children face medically are so shocking and awe-inspiring that they would be likely to generate more sympathy and support for their cause.

She said:

I think that if we don’t step it up, and start clearly defining why we help people, we've got to quit telling people what we do, we need to tell the world why. My child was hospitalized for 10 months in a row never went home, had chemotherapy every 10 days, had four surgeries, had a leg amputated, and then had 3 transplants. That's all you need to say. Nobody's going to ask you why you paid the rent. Until we can get strong about this, and say what it is. Tell it like it is. It's shocking, people don’t get this. If you know that you have a parent that has been driving over 250 miles round trip 5 days a week ...for her child to go for radiation, and then at night she gets home at 7 o'clock at night, and then has to take care of her other two children who were with a babysitter, and now has to do homework with them, right, you will understand why they need emotional support to help them to adjust to the demands of their new life, and you'll understand why we need to pay over $400 and $500 a month on travel, and parking, tolls. Who has that kind of money? That's half a rent payment. So my point is let's tell why we're doing this, and people will say, I get it.
Best Practices/ Lessons Learned

While staff and stakeholders interviewed did not express interest in expanding its Family Support Program beyond its current service area, they were interested in being able to describe the best practices or lessons learned from engaging in their work so that they could possibly consider it in the future, or so that they could advise others on doing similar work. Some suggested building a tool kit or resource guide to help others develop programs like Friends of Karen, which, from the perspectives of at least the families interviewed, was very unique and rare! While families described receiving limited or even one-time support for particular items, like rent or parking, FOK offered a complete package of services for generous time periods.

The following is a list and description of key features or best practices of the Family Support Program that allows it to function the way that it does.

- **Hiring Strong Staff and Building Their Capacity**

As described earlier, FOK’s program is built around the work conducted by its social work staff. The extent to which they make sound assessments of families’ needs and offer appropriate service and do so in a reliable and honest way is important. One interviewee said:

> This is the kind of work that requires passion. Because it's not your typical go to an office, do work in a certain way... It seems to me in some ways the idea to hire people who become passionate and committed to the work because, like, it's really like you're coming in and doing crisis intervention around certain parameters. So in the lessons learned, hiring is a really important feature. [FOK’s] not in a position that you can hire too lightly because you give people a lot of responsibility reasonably quickly.

Beyond hiring, staff needed ongoing supervision and support to address difficult cases and understand the evolving guidelines for funding allocation and service delivery. FOK manages this through a Director of its Family Support Program and an outside social work consultant with more than 35 years in the pediatric oncology field. Their supervision and technical support are critical to providing consistent and adequate support to families of children with life-threatening illnesses and recognizing the limits of the support that can be offered.

- **Creating a Financial Cushion**

FOK has evolved from a local, grassroots effort to support families of children with life-threatening illnesses to a highly professionalized and formalized non-profit organization. In its
37 years it has formalized the roles of its board members and board-led committees, adapted to new regulatory mechanisms, formalized its budget, and developed fundraising plans. It has also established a Board Designated Fund, which it continues to grow over time. An interviewee reported that FOK has over $5 million in investments and that starting in 2010, its board has allowed FOK to draw upon it as needed for its programmatic expenses. The board agreed to maintain a year’s worth of operating expenses in the Fund as a “cushion” that should never be spent. Depending on how much funding has been raised in individual giving, grants, and special events, administrators work with the board to decide upon an amount of money to be drawn out of the Fund. Having this reserve of funding allows them to fill in gaps in fundraising and invest in new program activities as needed. This is particularly important given the competitive and challenging fundraising environment. One interviewee explained:

You know, the fundraising world is a fickle one. Every time you have grants, you can only get them for 3 years, or somebody’s funding is not renewed, or it was dependent upon a relationship that you no longer have, or funder changes their reasons, or the perception that you’re a $100 donation, not a $1000, so [funding] is not growing as fast. We sweat it out all the time. And we never stop. There is never a slow season, we never stop, and I would say the other thing we have to our advantage is our board was very prudent, and we've established a Board Designated Fund, and that has made all the difference in the world, because we have money to invest in our growth... By the same token we’ve been lucky because we’ve disciplined ourselves to save so that when we raise funds or we receive bequests -- that has been our strategy -- we put it back into our Board Designated Fund... And that has been huge. We'd be a different organization if we didn't have that.

While interviewees reported some debate about whether the entire Fund should be spent on meeting families’ needs, a decision was made to keep a reserve so that FOK could continue to provide for families in the future, thereby ensuring its sustainability.

➢ Engaging Voluntary and Pro-Bono Services and Other Resources.

FOK staff described themselves as being very resourceful in obtaining and utilizing free or low cost resources. This includes relying on volunteers, material donations (i.e., gifts, office supplies and furniture), and in-kind services. Examples include coordinating groups of volunteers to pack gifts around the holidays or maintain the property around their offices. Even highly skilled and sensitive tasks such as processing family bills were completed by long-standing volunteer labor, which saves on staff costs. Staff were more than grateful for the free or low cost resources; the entire operating model and budget is calculated with them in mind. One staff member said:
I feel I do my part, almost on the fundraising side by making sure to ask for help from vendors. I always price things out for the best price, then, if they're honest, dependable, and know who we are, I ask them to do better. We got our landscaper that way. I said, “This is my budget, can you do any better?” I find vendors who are my partners.11

Another interviewee said:

One thing I can say about myself is I’m very resourceful and I tap into every pro-bono resource that you possibly can. I think that I have a strength in working with volunteers, and getting people to help us, and I think many of the staff do as well. I think it’s our commitment and passion and [we're] able to give people substantive things to do that get us all of this. We try to never pay for anything we don’t have to. And that has been very helpful.

➤ Utilizing a Differential Diagnosis of Financial Need

As described earlier, FOK serves families of different income levels, and does not utilize an income threshold in deciding to whom it will offer its services. Instead it assesses financial needs based upon a family’s socio-economic context and tries to help families maintain a standard of living that they had before a child’s illness. One interviewee described this process as utilizing “a differential diagnosis of financial need.” Differential diagnosis is common in medicine, where medical providers seek to identify an illness based on a range of symptoms. In the case of FOK, social workers seek to identify financial need based on a range of factors, including current and ongoing household expenses; illness related expenses; debts prior to and after the diagnosis of a child’s illness; and resources, both existing and potential, that families can use to meet their expenses. As one interviewee explained, this novel approach may be challenging to some:

One of challenges in that mindset is to believe that it's ok to help people at all different levels, and then I believe, it's complicated to figure out ...and they've taken on a very honorable task in trying to help people at all levels.

Though financial assistance is dependent on many variables, the results are believed to be consistent across families and fair to the families it serves. Staff were encouraged to make these decisions fairly and act out of kindness. As one interviewee explained:

We've never put a cap on things. We've never put any income criteria. We've never said you have too much money, or you don't make enough money, because we look

11 Due to an error with the recording, this quote was taken from notes instead of a transcript.
at each family individually. I have to trust that my social workers are professional
enough and work hard enough to understand a family and are culturally sensitive,
and take into consideration socio-economic status, their capacity to work a certain
amount of time or hours, or their decisions they made for their family, and create a
plan that will assist them, but will be consistent. If you were to hold one case up
against the other... it will look consistent in terms of decision-making. But it could be
a family that makes 200 thousand up against an 18 thousand. But I believe we
found a way to be consistent in why we made that decision. And what is the factor
that pulls it all together is illness, has to be the illness.

➢ Recognizing Limits and Encouraging Autonomy in Families

Even in its generosity, FOK recognizes its limits in working with families. These limits are not
always financial, as described above, but rather they are about learning from families in order
to meet their needs respectfully and without interfering in their affairs.

However, setting limits is challenging and staff and stakeholders described ongoing learning
that is required in order to adapt the program accordingly. Changes in oncology treatments
alone have changed caseloads such that families survive but remain in treatment and in need of
support much longer. This required adaptation of the program to meet families’ needs for
longer.

In addition, learning from past mistakes was recognized as key to setting limits and better
serving families. Learning from experience includes learning from the families themselves. As
one interviewee said:

It’s important to have staff here for many years, now have staff that will stay a long time,
the more I can instill in them the stories I have, that I’ve had in the past, helps them realize
the struggles they’ll face, take that suggestion that a family made, use it moving forward.
When working with families, think about what that other family has taught you... that’s how
you get good.

By learning from families, FOK seeks to establish their program around their families’ needs
without dictating to families what they should or should not do in the course of their child’s
treatment.

That’s a best practice, and we help them because it’s their child... we’re not making
decisions about some child’s life, enabling them it’s their child, it’s not our decision. We
know what our role is, we know what we can and can’t do.
For example, while FOK can pay for illness related travel, they cannot decide whether the family should opt for treatment that requires travel that is out of their way and costly. They cannot decide whether a family should seek experimental treatment for a child, or whether they should accept hospice. They can only provide the resources for them to enact their decision once it has been made. As family interviews show, FOK support alone helped people make difficult decisions about how they would care for their child, whether it’s to leave a job and stay with their ill child full time, or to transfer to a facility that is further away from their home.

By setting limits to their involvement with families, FOK seeks to respect and even cultivate the autonomy of families as they seek treatment for their ill child.

Discussion

The findings from CEAR’s mixed methods evaluation provides a comprehensive overview of FOK’s Family Support Program, including its goals, the characteristics of the families it serves, multiple perspectives on its enrollment process, and impressions and impacts on families from their own perspectives. In addition, valuable information was gathered on facilitators of their success as a program, their challenges, and best practices and lessons learned in operating a unique philanthropic program to provide financial assistance, social and emotional support, and advocacy for families of children with life-threatening illnesses.

FOK is unique because it utilizes an approach to financial assistance that could be considered a differential diagnosis of financial need whereby the amount of assistance offered is relative to the standard of living prior to the child’s diagnosis. FOK does not limit its assistance to families based upon an established income threshold. Rather, its social workers look at the socio-economic context of the family including their household expenses prior to and after diagnosis, their illness related expenses, and their resources in terms of income and other supports, and tries to offer something to everyone. They believe a child’s illness dictates the approach, since most working families will suffer a loss of income due to the care-taking responsibilities of having a child with a life-threatening illness and there are also generally large expenses associated with having a catastrophic illness, even for the insured.

Their approach is considered quite remarkable, especially to the families it serves. While they are able to serve those who are well off, they largely serve low income and working middle class families. It is generally expected that financial assistance will be mean tested, or be based on and/or savings. All public benefits, including cash assistance (welfare), public insurance (Medicaid), food stamps, and housing subsidies are based on the premise that only those who are at or below a certain income threshold qualify. Financial assistance to middle class working
families is virtually unheard of, whether there is a medical crisis or not. The need for such assistance may be especially important in the New York City area, where the cost of living, particularly for housing, is among the highest in the nation.

Families interviewed for this evaluation were overwhelmingly grateful for FOK’s assistance, both emotionally and financially. They helped their families as a whole, and they offered special assistance to vulnerable siblings of the ill child. Many believed it helped sustain them through a difficult time. Even those who ultimately lost their children were able to look back on the experience and feel grateful that they were able to experience their child’s death the way they did because of Friends of Karen. Families were especially grateful that FOK relieved them of the typically burdensome tasks of maintaining and managing a household to allow them to concentrate on their ill child. Once their attention was solely focused on their child, FOK was able to help them emotionally confront and adapt to their child’s condition.

FOK’s generous approach was facilitated by having skilled social worker staff, some of whom were bilingual and able to assist the sizable Hispanic population in both linguistically and culturally appropriate ways. Staff reported that their passion for their families grew through their work, as they were inspired by and helped cultivate resilience. They also received guidance and support for difficult cases.

However, taking its generous approach had its own challenges. Aside from the expected challenges of raising funds in a competitive philanthropic environment, budgeting funds using the differential diagnosis of need model proved difficult. Besides varying levels of need based on the socio-economic status of the family, treatments of childhood cancers vary widely, as does a child’s response to those treatments. What could be expected to be six months of treatment could continue instead for years. In fact, advances in medicine have led to longer treatments and also higher survivorship. This makes predicting families’ needs over time highly challenging. Furthermore, staff did not believe adequate systems were in place to measure true labor costs in order to adequately budget staff time needed for the emotional support. Efforts to check program services against budgets included modifying spending guidelines and changing service plans for families, sometimes causing confusion for both staff and families.

In order to sustain the Family Support Program, staff recognized the need for sound fiscal management. FOK’s board established a Board Designated Fund and allows the program to draw from it annually in order to cover gaps in revenue generated through fundraising events, grants, and individual giving. It also tries to maximize resources it can attract for free or at low cost.

While there is ample evidence that FOK succeeds at its mission, more information is needed to determine the most critical components of it. Identifying the most critical components may
help alleviate the stress of keeping up with demand and possibly even allow for the expansion of the model.

In order to better identify core components, FOK may need to design a comparative study of families that receive their services and those that do not. Alternatively, they could track the effects of changes in their own services over time to determine the impact on families when a service was removed. The latter option may prove to be ethically challenging if families were found to fare worse if, for example, rent assistance were reduced or removed.

However, to some extent, making the difficult decision to restrict or even eliminate funding for certain services goes against the core of the program, which is to serve families holistically. It could be said that FOK supports social determinants of health, such housing, food, family dynamics and social support. By supporting aspects of a family’s life outside the medical system, FOK provides a complementary service that may synergistically help improve health.

This study is limited in that it does not provide evidence on the impact of FOK on the ill child’s health. Nor was it able to determine what types of assistance were more valuable than others. This is in part because it was a largely qualitative study focused more on process than outcome measures. In addition, small samples obtained through quantitative methods such as the social worker survey and the family assessment form do not allow for testing of hypotheses about the many components of FOK support through statistical means. The evaluation of the extent to which FOK met its goals was solely based on qualitative interviews with families; the family assessment form was not designed to capture whether the change in service plan was related to the accomplishment of a goal or not. Selection bias in recruitment of families for interviews must also be recognized; it is possible that FOK may have been more inclined to recruit families that had positive experiences with FOK, or that only those with positive experiences agreed. The evaluation had to balance the importance of establishing trust with families quickly with the potential for this bias. Finally, given the large amount of data collected through this evaluation, analysis was limited based on staff time and resources for analysis for evaluation purposes.

Though CEAR does not have expertise in potential areas of funding for philanthropic efforts for children with life-threatening illnesses, FOK may want to capitalize on trends in the health care industry to reduce costs through collaborative partnership with community based organizations to address non-medical social needs. Given the tremendous service that FOK offers childhood cancer patients and their families, hospitals may be able to formally partner with FOK through new funding streams such as DSRIP (Delivery System Reform Incentive Payment) in New York State, and possibly federal funding through the Centers for Medicaid and Medicare (CMS).
ACKNOWLEDGMENTS

CEAR would like to thank all of the families who participated in interviews for their time and openness in sharing their stories, and the Heckscher Foundation for Children for the generous grant to Friends of Karen to make this study possible. We also want to thank staff at Friends of Karen for being so forthcoming about their program and generous about their time. This evaluation was truly a collaborative effort and we hope that it is helpful in sustaining or even expanding the FOK model. May FOK be the cornerstone for families of children with life-threatening illnesses.
Appendices
Evaluation of the Friends of Karen Family Support Program

Focus Group Information Sheet

Overview: You are being asked to participate in a focus group about the Friends of Karen (FOK) Family Support Program. This interview is part of an evaluation about the process of enrolling and supporting families in this program, the outcomes of their enrollment, and the best practices and lessons learned about the program’s operating model. It is being conducted by the Center for Evaluation and Applied Research (CEAR) at the New York Academy of Medicine in collaboration with FOK. Funding is provided by the Heckscher Foundation for Children.

Interview procedures: You should expect the focus group to last approximately an hour and a half. You will be asked about your practice as a social worker, and your perspectives on serving children with life threatening illnesses and their families, including how the program benefits families, and ways that it could be improved. We will also ask about best practices for helping families cope with an ill child (both practically and emotionally), lessons learned, and recommendations for FOK management staff, in case they seek to replicate project activities. The focus group will be audio-taped as a back up to written notes taken during the interview by a note taker.

Participation is voluntary: Your participation is completely voluntary. You may choose not to participate or withdraw from the focus group at any time. If you decide to participate, you may still choose not to answer particular questions. Your refusal to participate or skipping individual questions will not impact your work with that agency.

Data are kept confidential: Any information obtained from you during this study will remain confidential. Audio recordings, notes and transcripts will be securely stored and analyzed by CEAR as part of this evaluation. Afterward, all notes, transcripts, and audio recordings will be shared with FOK for further analysis and reporting in the future. Your name will not appear in any notes, transcripts, reports, articles or presentations produced as a result of this work by CEAR or FOK. The recording of the focus group will be destroyed once analysis of the data is complete.

Questions? If you have any questions about this study please ask. If you have questions later, please contact:

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212-822-7287, ELL23@columbia.edu
Focus Group Guide for Friends of Karen Social Workers
Center for Evaluation and Applied Research
New York Academy of Medicine
Final Draft 07/16/14

We would first like to thank you for participating in this focus group. Your answers are important. As noted in the focus group information sheet, your participation is completely voluntary. You do not have to be part of the focus group and you can choose not to answer any question you do not wish to answer.

We would first like to mention some commonly used guidelines for the discussion:

- Information shared here should be treated as confidential by everyone present today.
- We may direct the conversation so that everyone has a chance to talk.
- It’s OK to ask each other questions. It’s also OK to disagree as long as we are all courteous. Please do not interrupt each other.

Are there any other guidelines or comments that anyone would like to add?

Background:

1. Please start by introducing yourself and telling me how long you’ve worked with Friends of Karen?

2. How did you come to be interested in working with children with life-threatening illnesses and their families?
   a. Have you worked with other populations?

3. In general, what are things you like about working with this population?
   a. What are some challenges of working with this population?

4. In general, do you see yourselves as serving the family members of the ill child, or as serving the child?
   a. To what extent do you interact with the ill child compared to the other family members?

FOK Services Life Cycle:
I’d like to talk about how you work with your families from beginning to end.

5. Could you please describe your initial visit with the family in terms of what you hope to accomplish, and what you are usually able to accomplish?
   a. What benefits do the families receive immediately upon enrollment?
   b. What are challenges to offering families services or benefits upon enrollment?
   c. Do you find any difference in meeting families for the first time in the hospital vs. their home?
   d. How do you manage discussing sensitive information, financial or emotional, in the presence of children (ill or siblings)?
6. How easy or difficult is it for you to earn the trust of the families you serve? How important is it to earn their trust?
   a. How do you establish it or what helps establish it?

7. After the initial visit, what services do the families receive over time?
   a. How frequently are you in contact through visits or phone calls?
   b. On average, how much time do you spend with families in person or over the phone?
   c. Do you create a schedule with families to offer education and social support, or do you offer immediate support, as needed?

8. What proportion of your time is spent on managing financial aspects (whether household or medical) for the families compared to emotional?
   a. Do you think this is a good balance? Do you wish you could help more either financially or emotionally?

9. To what extent do you feel like the families you serve were already under financial and emotional stress before their child’s life-threatening illness?
   a. How does having an ill child affect their situation?
   b. How do you advise families to handle the ongoing conversations that can often happen in front of children regarding financial, illness related, or emotional matters?

10. What role do you play when a child dies? How do you help afterward?

11. To what extent do you prepare families for the time when FOK services will end?
   a. Do you ever feel that the families are not prepared for the loss of financial assistance or emotional support received from FOK when their case is closed? How do you assist them?

Best Practices on Coping
As I understand it, FOK helps families adapt when they have a child with a life-threatening illness. I’d like to ask some questions to learn more about how you do so.

12. What are ways in which you help families anticipate the financial needs they may have as a result of having a child diagnosed with a life-threatening illness and its long-term effects?

13. To what extent do you help families plan long term, financially and emotionally?
   a. To what extent do you have them focus on gaining stability under the present circumstances and not worry about the long term?
   b. How can you help those that may not have had the best long term planning skills before their child became ill?
14. What kinds of suggestions or recommendations do you provide when helping a parent/sibling adjust to having a child or sibling with a life threatening illness?
   a. What about when the child is facing end of life?
   b. What kinds of strategies or signs of resilience do you see families adopt on their own?

15. To what extent do you assist with troubled interpersonal relationships as a result of the illness, whether between the parents, or between the parents and siblings?
   a. What do you find to be successful in improving interpersonal relationships?
   b. What do you find challenging about it?

16. To what extent do you help families advocate for better health care, either in the facilities that they are in, or to seek services in another facility?
   a. How do you find access to health care for those living in NYC compared to those outside?
   b. Do you see a difference in access to care depending on the type of insurance that the family or child has? Between Medicaid and privately insured patients?
   c. Do you see a difference in terms of the quality of care?

17. What is it like providing these services to diverse populations? To what extent do you adapt your advice or services to be culturally sensitive to the families you serve?

Referrals to FOK and Training/ Support for FOK Social Workers
Now, I’d like to get a little more practical information about the way families are referred to FOK, and also the extent to which you receive on the job training and support.

18. I understand that the majority of your families come to you through hospital based social workers. Do you have the sense of why they refer certain families to you and not others?
   a. Do you think that they are sending families that are appropriate for you to serve? Do you think that they could be sending more families to FOK?
   b. Once you start working with a family, do you maintain any kind of communication with the referring hospital based social worker, or any other kinds of case workers that the family has?
   c. Is there any way that the referral process to FOK could be improved?

19. What kind of training and support do you receive from FOK in terms of doing your job?
   a. How has that training or support helped you?
   b. Is there any way that you could be trained or supported more?
Final Questions on Lessons Learned:

20. How would you define success in terms of serving your families?
   a. Does it differ from family to family, or is there something essential you hope to
      be able to achieve with each family?

21. Do you think that there are ways that FOK could be helping your families more?

22. If FOK were to consider replicating its Family Support Program model in another part of
    the state or part of the U.S., what advice would you have for them?
    a. What elements of the program could be most easily replicated?
    b. What would you recommend that they do? Not do?
    c. What advice do you have for serving diverse populations in terms of race/
       ethnicity, income levels, and household structures?

23. Is there anything else you’d like us to know? Do you have any questions for me?

    Thank you for your time!
Friends of Karen Family Assessment

1. Child’s ID: _____________________________
2. Child’s Date of Birth: ______________________
3. Social Worker ____________________________
4. Date of Referral to FOK: ___________________
5. Date Application Received: ________________
6. Date of Visit: _____________________________
7. Location: ☐ Home ☐ Hospital

Family Demographic Information
14. Household Primary Language:
☐ English ☐ Spanish ☐ Other ____________________________
15. Child’s Race/ Ethnicity (check all that apply):
☐ Black ☐ White ☐ Asian ☐ Hispanic ☐ Native American ☐ Pacific Islander ☐ Unsure
16. Child lives with (check all that apply):
☐ Mother ☐ Father ☐ Guardian _____________
☐ Siblings, how many________  Ages: ________________
☐ Other. Please Describe: _________________________________________________________
17. Parents Living Arrangement: ☐ Living together ☐ Living Apart
18. a. Parents Marital Status: ☐ Married ☐ Separated ☐ Divorced ☐ Widowed ☐ Single
b. Biological Mother: ☐ Remarried ☐ Not Involved c. Biological Father: ☐ Remarried ☐ Not Involved
19. a. Other siblings not living with child: ☐ Yes ☐ No  b. If yes, how many __________
20. In Shelter: ☐ Yes ☐ No
22. a. Parent(s) US Citizen: ☐ Yes ☐ No  b. Parent (s) Lawful Permanent Resident: ☐ Yes ☐ No
23. a. Parents’ Country (-ies) of Origin_________________________ b. Emigrated _____ years ago
24. Are parents/ grandparent/ guardian a member or veteran of the US Military? ☐ Yes ☐ No

Financial
25. Was there a loss of income as a result of child’s illness? ☐ Yes ☐ No
26. a. Is either parent/guardian on FMLA/Unpaid leave: ☐ Yes ☐ No  b. Dates:_____________
27. Mom’s/ Guardian’s Income:  a. Before Dx______________  b. As of Assessment ________________
28. Dad’s / Guardian’s Income:  b. Before Dx______________  b. As of Assessment ________________
29. a. Other Income: ____________________________________ c. Source: _________________________
30. Household Income Level:
☐ UNDER $23,850 ☐ $23,850 - $35,000  ☐ $35,001 - $50,000  ☐ $50,001 - $75,000
☐ $75,001 - $100,000 ☐ OVER $100,000  ☐ Unknown
31. a. Was family current on household bills prior to diagnosis? ☐ Yes ☐ No  
b. If No: ☐ Expenses exceeded income ☐ Financial difficulty not the result of illness
   Please explain: ________________________________________________________________________
32. a. Is family current on household bills at assessment? ☐ Yes ☐ No  ☐ Other
   b. If No or other, please explain which bills are overdue and by how much:______________________________
Financial (continued)

33. □ Family unwilling to share financial information     □ Family unable to share financial information

34. a. Insurance Type: Private / Medicaid  
   b. Name of Insurance__________________________________________

35. Other sources of income or use of public benefits:

<table>
<thead>
<tr>
<th></th>
<th>Receives</th>
<th>Applied</th>
<th>Denied</th>
<th>Eligible to Apply</th>
<th>Refuses. Please specify reason for refusal:</th>
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<tr>
<td>SSI</td>
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<tr>
<td>Public Assistance</td>
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<td>Food Stamps</td>
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<td>Child Support</td>
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<tr>
<td>Other</td>
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36. What additional illness related expenses does the family have as of the most recent visit?
   □ Travel  □ Meals  □ Co-pays  □ Childcare  □ Lodging  □ Co-Insurance  □ Deductible
   □ Other: ____________________________

Family

Please check your assessment of various aspects of the family as it relates to the child’s illness.

<table>
<thead>
<tr>
<th>37. Understanding that child’s illness/treatment has an impact on family dynamics</th>
<th>Limited</th>
<th>Knowledgeable</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Parents</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. Siblings</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>c. Ill Child</td>
<td></td>
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</table>

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<tr>
<th>38. Understanding that child’s illness/treatment has an emotional impact on the well siblings</th>
<th>Limited</th>
<th>Knowledgeable</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Parents</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. Siblings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. Ill Child</td>
<td></td>
<td></td>
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<tr>
<th>39. Is the family comfortable with the information they’ve been given in the hospital regarding their child’s illness and treatment?</th>
<th>Yes</th>
<th>No</th>
<th>Not Applicable</th>
</tr>
</thead>
</table>

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<tr>
<th>40. Does family need guidance seeking medical information appropriately?</th>
<th>Yes</th>
<th>No</th>
<th>Not Applicable</th>
</tr>
</thead>
</table>

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<tr>
<th>41. Does family need assistance navigating the medical system?</th>
<th>Yes</th>
<th>No</th>
<th>Not Applicable</th>
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</table>

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<tr>
<th>42. Do the following members of the family appear to be adjusting to child’s illness/ treatment?</th>
<th>Yes</th>
<th>No</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Parents</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>b. Siblings</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>c. Ill Child</td>
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</tbody>
</table>
### Family (continued)

<table>
<thead>
<tr>
<th>43. Is there interest in Sibling Support Program</th>
<th>Yes</th>
<th>No</th>
<th>Please Explain</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Parents</td>
<td>☐</td>
<td>☐</td>
<td>______________________</td>
<td>☐</td>
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<tr>
<td>b. Siblings</td>
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<td>______________________</td>
<td>☐</td>
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<tr>
<td>c. Ill Child</td>
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<td>☐</td>
<td>______________________</td>
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#### 44. a. What type of support from the Sibling Support Program do you recommend?
- [ ] None
- [ ] Outreach
- [ ] Sessions up to 6 months
- [ ] Sessions Short Term
- [ ] Other

b. If no support is recommended: [ ] Parents/ family capable of addressing sibling concerns

- [ ] Other

- Please Explain Recommendation: _____________________________________________________________

#### 45. a. The family’s social support network is:
- [ ] Strong
- [ ] Adequate
- [ ] Limited

b. Please explain: _____________________________________________________________

Comments:

_______________________________________________________________________________________
_______________________________________________________________________________________
_______________________________________________________________________________________
_______________________________________________________________________________________
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To be reassessed in 3 months

Goals:

☐ Family will not fall behind on household bills identified as eligible for FOK assistance.
☐ Family will be given other resources and options if household bills are beyond family’s ability to pay before or after diagnosis.
☐ Family will receive FOK support to apply for benefits from government/insurance, or other agencies that they are eligible to receive based on financial/medical need.
☐ Family will be able to pay for illness related expenses with FOK assistance
☐ Family will receive FOK assistance to assure that the ill child will be able to travel for treatment.
☐ Parent will encouraged to reach out for FOK support as needed throughout treatment.
☐ Parent will be supported throughout treatment by their FOK Social Worker.
☐ Parents will receive psychoeducation support regarding child’s illness.
☐ Siblings will receive psychoeducation support regarding their brother or sister’s illness.
☐ Family will be receive FOK assistance to assure that siblings receive reliable/consistent childcare.
☐ Parent will be educated on how to communicate with their children about illness and how it impacts family dynamics.
☐ Children will be supported by FOK Sibling Support Specialist/Social Worker.
☐ Children will be supported on how to adjust to the impact of illness on self and family.
☐ Family will be supported throughout the dying process.

FOK Plan:

☐ Illness Related Expenses: Types: _______________________________________________________________
☐ Household Expenses: Type: _________________________  Amount: ________________________________ 

☐ Type: _________________________  Amount: _________________________________ 
☐ Type: _________________________  Amount: _________________________________ 
☐ Type: _________________________  Amount: _________________________________ 
☐ Type: _________________________  Amount: _________________________________

☐ Psychoeducation/ Emotional Support
  ☐ Parents ____________________________________________________________________________
  ☐ Siblings ____________________________________________________________________________
  ☐ Ill Child ____________________________________________________________________________

☐ Sibling Support______________________________________________________________________________
☐ Beth’s Buddies
☐ Gifts:

☐ Back to School
☐ Advocacy/Resources
☐ Literature
☐ Go Bag
☐ SMART Bag
☐ Referral to other agency for additional financial support
☐ Referral to other resources for additional emotional support for parents
☐ Referral to other resources for additional emotional support for ill child
☐ Referral to other resources for additional emotional support for sibling

Revised 08/29/14
Friends of Karen Family Support Program
Social Worker Survey

In partnership with Friends of Karen, the New York Academy of Medicine (NYAM) invites you to complete this brief survey about the Friends of Karen Family Support Program. Since many families are introduced to Friends of Karen by hospital based social workers, your knowledge and perspectives on Friends of Karen is vitally important to this program. By completing this brief survey, you will be helping Friends of Karen gain greater insight about its referral process and the way it communicates with others about its services.

Your responses will be anonymous. As our way of saying thank you, once you complete the survey you can enter into a raffle to receive one of two $75 gift cards for Amazon.com. You will also be able to sign up to receive more information about Friends of Karen. Your contact information will be kept separately and will not be linked with your responses.

Your participation in this survey by next Friday February 20, 2015 is greatly appreciated. If you have any questions about the survey, please contact Dr. Maysoun Freij at mfreij@nyam.org or 917-232-7326.

Thanks for your time!

1. How long have you been working as a pediatric oncology social worker or a hospital based social worker serving children with life-threatening illnesses?
   - [ ] New employee (1 month or less)
   - [ ] Less than 1 year
   - [ ] 1-4 years
   - [ ] 5-9 years
   - [ ] More than 10 years

2. Are you familiar with the organization Friends of Karen?
   - [ ] Yes
   - [ ] No

   Thank you for your participation. The remaining questions pertain to social workers who have some familiarity with the services of Friends of Karen.

   If you would like to receive more information on the Friends of Karen services, their eligibility guidelines and how to make a referral, please enter your contact information in the space below, and someone from Friends of Karen will be in touch.

3. On a scale of 1 – 5, how familiar would you say you are with the services offered through the Friends of Karen Family Support Program?
   - Not at all
   - Somewhat
   - Very

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<td>3</td>
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<td>4</td>
<td>5</td>
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</tbody>
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4. To your knowledge, what services does Friends of Karen offer participating families, depending on their needs? (Check all you are aware of)

- Emotional support
- Sibling support
- Rent/Mortgage assistance
- Travel reimbursement (mileage, tolls, parking) for medical care
- Assistance with utilities
- Assistance with phone bills
- Assistance with car insurance bills/car payments
- Medical expenses (co-pays, deductibles, prescriptions, out of network)
- Assistance with funeral expenses
- Lodging, i.e. Ronald McDonald House
- Food Cards, meal reimbursement
- Childcare expenses
- Medical equipment
- Other ____________________

5. How would you describe children and families that are eligible for Friends of Karen services?

- Child is under 21 years of age
- Child is U.S. citizen or lawful permanent resident
- Child is receiving treatment at one of the area hospitals served by Friends of Karen but does not live in one of 22 counties
- Child has a life threatening illness
- Family lives in one of 22 counties in NY, NJ and CT served by Friends of Karen for a year prior to diagnosis
- Family’s financial situation was affected by the child’s illness

6. In one week, roughly how many families that you come in contact with would you say you refer to Friends of Karen?

- All
- Almost all
- Some
- Very few
- None

7. Even though every family is different and unique, what would you say is the most common reason you refer families to Friends of Karen? (Check one)

- Emotional support
- Financial support
- Sibling support
- End of life support
- All of the above

8. How do you typically refer a family to Friends of Karen? (Check all that apply)

- Give them brochure
- Give them an application
- Tell the family to contact the agency themselves, I do not refer
- Call Friends of Karen and let them know about the family then tell the family they will need to contact the agency to complete an intake
- Other ________________________________
9. In your own words, please briefly describe why you would refer some families to Friends of Karen and not other organizations.
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

10. Thinking about all the families that you have referred to Friends of Karen, can you please briefly share an example of a family that has benefited from Friends of Karen? Please do not include any names or information that could be used to identify a child or family.
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

11. Do you have any suggestions for how the referral process to Friends of Karen could be improved?
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

Thank you for your participation in this survey!

If you would like to receive more information on the Friends of Karen services, their eligibility guidelines and how to make a referral, please enter your contact information in the space below, and someone from Friends of Karen will be in touch. ________________________________

Would you like to be entered into a raffle to win a $75 gift card for Amazon.com?
☐ Yes. What is your e-mail? _________________
☐ No.
Evaluation of Friends of Karen Family Support Program

Interview Information Sheet

Overview: You are being asked to be interviewed for an evaluation of the Friends of Karen Family Support Program. The purpose of this interview is to learn about your family’s experiences with Friends of Karen. This evaluation is being conducted by the New York Academy of Medicine (NYAM) in collaboration with Friends of Karen.

Interview: The interview will take about one hour. You will be asked a few questions about how you heard about Friends of Karen, and what effects it had on you and your family. You will also be asked for any suggestions on how services could be improved. The interview will be audio-recorded, and the interviewer will take written notes of your responses. You will receive $25 cash in appreciation for your time.

Participation is voluntary: Your participation is completely voluntary. You may refuse to participate or end the interview at any time. If you decide to participate, you may still choose not to answer any particular questions. Refusing to participate or skipping any questions will not impact the services that you receive from Friends of Karen.

Risks and benefits: You may feel emotional recalling your child’s health condition and the ways that Friends of Karen served your family. It may be difficult for you to share personal information about your family’s financial and emotional situation. However, taking part in this research may help Friends of Karen learn new things that could improve services for other families of children with life threatening illnesses in the future.

Data are kept confidential: Any information you share during this interview will remain confidential. Recordings and interview notes will only be available to NYAM and Friends of Karen staff involved in the research project, and results will be reported without names or identifying information. The audio recording of the interview will be destroyed once our analysis of the data is complete.

Questions: If you have any questions please ask. If you have questions later or feel that the research has had a negative impact in any way, please contact:

Maysoun Freij, PhD, MPH          Elaine Larson, RN, PhD, FAAN, CIC
Senior Researcher/ Evaluator     Chair, Institutional Review Board
New York Academy of Medicine     New York Academy of Medicine
1216 Fifth Avenue                1216 Fifth Avenue
New York, NY 100029             New York, NY 10029
212-822-7377, mfreij@nyam.org    212-822-7287, ELL23@columbia.edu

If the material in the interview raised any other issues for you, and you would like to speak with someone at Friends of Karen, please contact Rhonda Ryan at 914-617-4044.
Please take a minute to answer the question below, and do not write your name on this form.

1. Relationship of person being interviewed to ill child:
   - Mother
   - Father
   - Guardian: ______________________
   - Other: _______________________

2. Age ______________

3. Gender
   - Male
   - Female

4. Currently employed
   - Yes
   - No
   - On Family Medical Act Leave/ Unpaid Leave

5. What is your ethnicity/race? (Check all that apply)
   - American Indian or Alaskan Native
   - Hispanic/Latino, specify __________
   - Asian, specify __________
   - Black or African American
   - Native Hawaiian or other Pacific Islander
   - White
   - Other, specify __________
   - Prefer not to answer

6. Were you born outside the U.S.?
   - Yes, in _____________
   - No
   - Prefer not to answer

7. Do your parents (i.e. the child’s grandparents) live in the U.S.?
   - Yes
   - No, in where ______________
   - Prefer not to answer

8. How far have you gone in school?
   - Not a high school graduate
   - High school graduate or GED
   - Some college
   - College graduate
   - Graduate degree
   - Other, specify __________________
Evaluation of the Friends of Karen Family Support Program

Family Interview

Study Participation Incentive Receipt

I acknowledge receiving a $25 for participating in an interview being conducted by The New York Academy of Medicine.

Received By (study participant):

___________________________________________

Received From (interviewer):

___________________________________________

Date: ____________________
I’d like to start by learning a little bit about you and your family.

1. How long have you been living in this area?

2. How many children do you have? Can you tell me a bit about them?

3. What was (name of child) diagnosed with, and when was he/she diagnosed?
   a. How old was he/she at the time? And now?

4. How is (name of child) doing?

Now I’d like to talk about how you started to receive FOK services.

5. How did you hear about Friends of Karen?
   a. At what point in (name of child’s) illness did you hear about it?

6. What made you decide to call FOK, and was there a specific reason for your call?

7. Do you remember when you got the application for FOK? Was it easy to complete? Did you need any help completing it?
   a. How long did it take you to complete it?
   b. Was there anything about the application process that you found challenging or could be improved?

8. What was your first visit like with the Friends of Karen social worker?
   a. Could you please describe the first visit with the social worker?
      i. Where did she meet you? At your home? In the hospital?
      ii. Did she provide emotional support?
      iii. Did she provide information?
   b. How comfortable were you during the first visit?
      i. What made you feel comfortable?
      ii. Was there anything that made you feel uncomfortable?

9. Do you feel like you can trust your social worker, and what makes you feel that way?
   a. Have you become more comfortable with her over time?

10. I understand that a plan is made for the kinds of assistance that FOK will offer you after that first visit. What did you think about what they were offering?
    a. For example, were you surprised, grateful, disappointed?
    b. Did you have any questions about the kind of support that you would receive from FOK? Did you know what to expect?

11. How long did it take before you started to receive the assistance that FOK offered that first visit?
12. What kind of services and support are you receiving from FOK now?
   i. Household expenses?
   ii. Medical expenses, including travel, parking, and meals during treatments?
   iii. Emotional support for you as a parent?
   iv. Emotional support for (name of child) and his or her siblings?
   b. To what extent is FOK sensitive to your changing needs?

13. Has FOK helped you access any services or benefits that you were unaware that you qualified for? What were they?

14. What stands out in your mind about working with your FOK social worker?
   a. How is your FOK social worker different from any other social worker you worked with during your child’s illness?
   b. Did she offer different kinds of support? If so, what was she able to offer you that other social workers could not?

Now I’d like to talk about what you saw as the effect of Friends of Karen on your family.

15. To what extent have the FOK services made a difference to you and your family?
   a. How have they impacted you financially?
   b. How have they helped you emotionally?

16. Is there anything you learned from FOK about managing your finances that you found particularly helpful or useful?
   a. Has FOK been able to help you anticipate some of the financial complications/issues that can occur when you have a child diagnosed with a life-threatening illness?

17. When (name of child) became ill, did you know much about that illness and what it could mean for him/ her or your family?
   a. Was your FOK social worker able to help you seek information about the illness or treatments?
   b. To what extent did FOK help you understand the impact the illness could have on your family?
   c. To what extent did FOK change the way you discussed (name of child’s) illness with your family?
      i. To what extent did FOK help with communication among family members more generally?

18. [For those with siblings] How did having an ill child affect the other children in your family?
   a. Have you received any special services for the siblings through FOK?
   b. To what extent has FOK helped the siblings learn about the illness?
   c. To what extent has FOK helped the siblings understand the effects it could have on the family?
   d. Has FOK been able to help your children adjust to living with a sibling with a life threatening illness? If yes, what were some of the changes you saw?
19. Have you received any other emotional, social, or financial support from your community during (name of child’s) illness and treatment?
   a. i.e., hospitals, religious institutions, family, friends, neighbors, other social service orgs?
   b. How is FOK similar or different from those sources of support?

20. [If they haven’t discussed it already], what do you think about the gift program of FOK?
   a. What kinds of things have your children received? What does that mean to you or your kids?

Just a few final questions about Friends of Karen.

21. What’s the most important aspect of FOK’s support or what stands out most to you about FOK’s support?

22. What do you think it would be like to go through the experience of your child’s illness if you didn’t have FOK’s support and services?

23. Is there anything about what they offer you that could be improved?

24. Is there any else that you wish that they offered?

25. Anything else you’d like to share with me about FOK?

Thank you for your time!
I'd like to start by learning a little bit about you and your family.

1. How long have you been living in this area?

2. How many children do you have? Can you tell me a bit about them?

3. Offer condolences, what was your child diagnosed with and when?
   a. How old was he/she when diagnosed?
   b. When did (name of child) pass away?

Now I’d like to talk about how you started to receive FOK services.

4. How did you hear about Friends of Karen?
   a. At what point in (name of child’s) illness did you hear about it?

5. What made you decide to call FOK, and was there a specific reason for your call?

6. Do you remember when you got the application for FOK? Was it easy to complete? Did you need any help completing it?
   a. How long did it take you to complete it?
   b. Was there anything about the application process that you found challenging or could be improved?

7. What was your first visit like with the Friends of Karen social worker?
   a. Could you please describe the first visit with the social worker?
       i. Where did she meet you? At your home? In the hospital?
       ii. Did she provide emotional support?
       iii. Did she provide information?
   b. How comfortable were you during the first visit?
       i. What made you feel comfortable?
       ii. Was there anything that made you feel uncomfortable?

8. Did you feel like you could trust your social worker, and what made you feel that way?
   a. Did you become more comfortable with her over time?

9. I understand that a plan is made for the kind of assistance that FOK will offer you after that first visit. What did you think about what they were offering?
   a. For example, were you surprised, grateful, disappointed?
   b. Did you have any questions about the kind of support that you would receive from FOK? Did you know what to expect?

10. How long did it take before you started to receive the assistance that FOK offered that first visit?
11. What kind of services did the social workers offer you throughout your child’s treatment, and for how long?
   i. Household expenses?
   ii. Medical expenses, including travel, parking, and meals during treatments?
   iii. Emotional support for you as a parent?
   iv. Emotional support for (name of child) and his or her siblings?

b. How was FOK sensitive to your changing needs over time?

12. Did FOK help you access any services or benefits that you were unaware that you qualified for? What were they?

13. What stands out in your mind about working with your FOK social worker?
   a. How was your FOK social worker different from any other social worker you worked with during your child’s illness?
   b. Did they offer different kinds of support? If so, what were they able to offer you that other social workers could not?

Now I’d like to talk about what you saw as the effect of Friends of Karen on your family.

14. To what extent did the FOK services make a difference to you and your family?
   a. How did they impact you financially?
   b. How did they help you emotionally?

15. Is there anything you learned from FOK about managing your finances that you found particularly helpful or useful?
   a. Was FOK able to help you anticipate some of the financial complications/issues that can occur when you have a child diagnosed with a life threatening illness?

16. When (name of child) became ill, did you know much about that illness and what it could mean for him/her or your family?
   a. Was your FOK social worker able to help you seek information about the illness or treatments?
   b. To what extent did FOK help you understand the impact the illness could have on your family?
   c. To what extent did FOK change the way you discussed (name of child’s) illness with your family?
      i. To what extent did FOK help with communication among family members more generally?

17. [For those with siblings] How did having an ill child affect the other children in your family?
   a. Did you receive any special services for the siblings through FOK?
   b. To what extent did FOK help the siblings learn about the illness?
   c. To what extent did FOK help the siblings understand the effects it could have on the family?
   d. Was FOK able to help your children adjust to living with a sibling with a life-threatening illness? If yes, what were some of the changes you saw?
18. Did you receive any other emotional, social, or financial support aside from FOK during (name of child’s) illness?
   a. i.e., hospitals, religious institutions, family, friends, neighbors, other social service orgs?
   b. How was FOK similar or different from those sources of support?

19. [If they haven’t discussed it already], what did you think about the gift program of FOK?
   a. What kinds of things did the children receive? What did that mean to you or your kids?

I understand that Friends of Karen offers most of their services while your child is in active treatment, and so I’d like to discuss how they prepared you for when their services would be reduced.

20. [If not already asked] How long did you receive services from Friends of Karen?

21. Again, I want to offer my condolences, and I want to ask you to describe how FOK helped you around the time of (name of child’s) death?
   a. To what extent did FOK support you through that process?
      i. Did they help with the funeral or memorial services?
   b. In what ways does FOK continue to remember your child? What does that mean to you?
   c. [For those who received financial assistance] Did the financial assistance you received from FOK taper off, or did it end all at once?
      i. To what extent did the loss of financial assistance present a challenge to your family? How did you manage?

Just a few final questions about Friends of Karen.

22. What was the most important aspect of FOK’s support or what stands out most to you about FOK’s support?

23. What do you think it would have been like to go through the experience of your child’s illness if you didn’t have FOK’s support and services?

24. Is there anything about what they offered you that could have been improved?
   a. Is there any else that you wish that they had offered?

25. Have you kept up a connection to FOK since your child passed away?

26. Anything else you’d like to share with me about FOK?

   Thank you for your time!
I’d like to start by learning a little bit about you and your family.

1. How long have you been living in this area?

2. How many children do you have? Can you tell me a bit about them?

3. What was (name of child) diagnosed with, and when was he/she diagnosed?
   a. How old was he/she at the time? And now?

4. How is (name of child) doing?

Now I’d like to talk about how you started to receive FOK services.

5. How did you hear about Friends of Karen?
   a. At what point in (name of child’s) illness did you hear about it?

6. What made you decide to call FOK, and was there a specific reason for your call?

7. Do you remember when you got the application for FOK? Was it easy to complete? Did you need any help completing it?
   a. How long did it take you to complete it?
   b. Was there anything about the application process that you found challenging or could be improved?

8. What was your first visit like with the Friends of Karen social worker?
   a. Could you please describe the first visit with the social worker?
      i. Where did she meet you? At your home? In the hospital?
      ii. Did she provide emotional support?
      iii. Did she provide information?
   b. How comfortable were you during the first visit?
      i. What made you feel comfortable?
      ii. Was there anything that made you feel uncomfortable?

9. Did you feel like you could trust your social worker, and what made you feel that way?
   a. Did you become more comfortable with her over time?

10. I understand that a plan is made for the kind of assistance that FOK will offer you after that first visit. What did you think about what they were offering?
    a. Were you surprised, grateful, disappointed?
    b. Did you have any questions about the kind of support that you would receive from FOK? Did you know what to expect?

11. How long did it take before you started to receive the assistance that FOK offered that first visit?
12. What kind of ongoing services did the social workers offer you throughout your child’s treatment, and for how long?
   i. Household expenses?
   ii. Medical expenses, including travel, parking, and meals during treatments?
   iii. Emotional support for you as a parent?
   iv. Emotional support for (name of child) and his or her siblings?

b. How was FOK sensitive to your changing needs over time?

13. Did FOK help you access any services or benefits that you were unaware that you qualified for? What were they?

14. What stands out in your mind about working with your FOK social worker?
   a. How was your FOK social worker different from any other social worker you worked with during your child’s illness?
   b. Did they offer different kinds of support? If so, what were they able to offer you that other social workers could not?

Now I’d like to talk about what you saw as the effect of Friends of Karen on your family.

15. To what extent did the FOK services make a difference to you and your family?
   a. How did they impact you financially?
   b. How did they help you emotionally?

16. Is there anything you learned from FOK about managing your finances that you found particularly helpful or useful?
   a. Was FOK able to help you anticipate some of the financial complications/issues that can occur when you have a child diagnosed with a life threatening illness?

17. When (name of child) became ill, did you know much about that illness and what it could mean for him/her or your family?
   a. Was your FOK social worker able to help you seek information about the illness or treatments?
   b. To what extent did FOK help you understand the impact the illness could have on your family?
   c. To what extent did FOK change the way you discussed (name of child’s) illness with your family?
      i. To what extent did FOK help with communication among family members more generally?

18. [For those with siblings] How did having an ill child affect the other children in your family?
   a. Did you receive any special services for the siblings through FOK?
   b. To what extent did FOK help the siblings learn about the illness?
   c. To what extent did FOK help the siblings understand the effects it could have on the family?
   d. Was FOK able to help your children adjust to living with a sibling with a life threatening illness? If yes, what were some of the changes you saw?
19. Did you receive any other emotional, social, or financial support from your community during (name of child’s) illness?
   a. i.e., hospitals, religious institutions, family, friends, neighbors, other social service orgs?
   b. How was FOK similar or different from those sources of support?

20. [If they haven’t discussed it already], what did you think about the gift program of FOK?
   a. What kinds of things did the children receive? What did that mean to you or your kids?

I understand that Friends of Karen offers most of their services while your child is in active treatment, and so I’d like to discuss how they prepared you for when their services would be reduced.

21. [If not already asked] How long did you receive services from Friends of Karen?

22. To what extent did FOK prepare you for the time when they would no longer offer you as many services?
   a. [For those who received financial assistance] Did the financial assistance you received from FOK taper off, or did it end all at once?
   b. Did the social workers continue to provide some emotional support or education as the child’s condition improved?
   c. To what extent did the loss of financial assistance present a challenge to your family after your child was no longer in treatment? How did/do you manage?

Just a few final questions about Friends of Karen.

23. What was the most important aspect of FOK’s support or what stands out most to you about FOK’s support?

24. What do you think it would have been like to go through the experience of your child’s illness if you didn’t have FOK’s support and services?

25. Is there anything about what they offered you that could have been improved?

26. Is there anything else that you wish that they had offered?

27. Have you kept up a connection with FOK since your child was off treatment? Do you think you’ll stay connected in the future?

28. Anything else you’d like to share with me about FOK?
   
   Thank you for your time!
Evaluation of Friends of Karen Family Support Program

Key Informant Interview Information Sheet

Overview: You are being asked to be interviewed for an evaluation of the Friends of Karen Family Support Program. The purpose of this interview is to learn more about its mission, the implementation of its Family Support Program, and its outcomes. This evaluation is being conducted by the New York Academy of Medicine (NYAM) in collaboration with Friends of Karen.

Interview: The interview will take about one hour. You will be asked a few questions about your role at Friends of Karen, and the implementation of its Family Support Program, including its successes and challenges. You will also be asked for lessons learned, and for recommendations for others trying to do similar work. The interview will be audio-recorded, and the interviewer will take written notes of your responses.

Participation is voluntary: Your participation is completely voluntary. You may refuse to participate or end the interview at any time. If you decide to participate, you may still choose not to answer any particular questions. Refusing to participate or skipping any questions will not impact on your employment or involvement with Friends of Karen.

Risks and benefits: Direct discussion about the work of Friends of Karen and its benefits through this open dialogue is not intended to serve as an evaluation of any individual but rather to give insight into the program. It may have an emotional component, but is not perceived or intended to raise uncomfortable issues. However, taking part in this research may help Friends of Karen learn new things that could improve or expand upon its services for families of children with life threatening illnesses in the future.

Data are kept confidential: Any information you share during this interview will remain confidential. Recordings and interview notes will only be available to NYAM and Friends of Karen staff involved in the research project, and results will be reported without names or identifying information when disseminated to funders, the board, or the public more generally. The audio recording of the interview will be destroyed once our analysis of the data is complete.

Questions: If you have any questions please ask. If you have questions later or feel that the research has had a negative impact in any way, please contact:

Maysoun Freij, PhD, MPH
Senior Researcher/ Evaluator
New York Academy of Medicine
1216 Fifth Avenue
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Elaine Larson, RN, PhD, FAAN, CIC
Chair, Institutional Review Board
New York Academy of Medicine
1216 Fifth Avenue
New York, NY 10029
212-822-7287, ELL23@columbia.edu
Friends of Karen Staff and Stakeholder Interview Guide

1. Could you please start by telling me about your role with Friends of Karen, and how long you’ve worked with this organization?
   a. How did you come to work with FOK?
   b. What are your responsibilities within the organization?
   c. Who do you work most closely with in order to do your work?

2. Could you describe a typical day in your role?

3. In what ways do other departments or activities of Friends of Karen support or compliment the Family Support Program?

4. For sibling support specialist: Could you please tell me about the types of services that you offer and who generally receives your services?
   a. How many families or children do you serve at any given time?
   b. Who determines how much a family will receive in terms of your services?
   c. In what ways do you see families benefiting from your services?

5. To the extent that you are familiar, please tell me how the eligibility criteria were developed for the Family Support Program?
   a. How often are they or have they been revised?
   b. Who has input into what those criteria are?
   c. How are decisions made about those criteria? (i.e., through consensus, by leadership, with board approval)

6. Do you feel that there is a high demand or interest in the Family Support Program within the current service area?
   a. Do you feel that Friends of Karen is able to serve all those who request it (in some capacity)?
   b. Do you feel like Friends of Karen would be able to expand to other areas, beyond the 22 county service areas?
      i. Is that something you would be interested in? And why or why not?

7. To what extent do you feel that people know about Friends of Karen in its service areas?
   a. Do you feel that people learn about it only when they need it, like when their child becomes ill, or that it is generally recognized as a resource for children with life threatening illnesses and their families?
   b. Would you like it to be more widely recognized, and why or why not?
   c. How do you think you could receive greater recognition for your work?

8. What is the fundraising environment like now for Friends of Karen?
   a. How easy or difficult is it to raise funds to support your programs?
b. How has it varied over time? What impacts on your ability to raise funds for your programs?

c. To what extent does the philanthropy offered by FOK to families depend on the amount raised by FOK in a given year?
   i. When is the budget developed in relationship to fundraising efforts?
   ii. To what extent does the operating budget drive the fund raising efforts, or vice versa?

9. To the extent that you are familiar, could you please tell me how the relationships with the participating hospitals were established?
   a. How important is it to the FOK model to be able to give people information about the program when their child is in the hospital?
   b. How are relationships with hospital staff maintained?
      i. Do they receive any incentives or recognition for promoting your services?

10. To what extent do you feel like hospital based social workers in your area are knowledgeable about the FOK Family Support Program?
    a. To what extent do you feel like they are good at making referrals of families to FOK?
    b. What are successes and challenges of working with hospital based social workers?
       i. How do you think it could be improved?

11. What are the ways that you technically measure the success of the Family Support Program?
    a. What kinds of information do you gather about the families that are served?
    b. How do you manage it?
    c. How often do you report on it, and to whom?

12. What are the challenges to offering services to such a diverse range of people in terms of income, education, race, and ethnicity?
    a. Is there anything that you think others could learn from you or Friends of Karen about working with diverse families?

13. To what extent do you maintain relationships with families served by FOK after they no longer receive services?
    a. How important is it to the organization to maintain those relationships?

14. In what ways does FOK contribute to the resilience of families and individuals in the face of hardships?
    a. Is there anything you have learned about resilience from working at FOK or with the families it serves?
Just a few final questions:

15. What do you feel is the greatest impact of the Friends of Karen Family Support Program?
   a. What are the biggest barriers to achieving its mission, which is “to provide emotional, financial, and advocacy support to children with a life-threatening illness and their families in order to keep them strong, functioning, and able to cope”?
   b. How do you think they could be overcome?

16. What key lessons have you learned about implementing or facilitating the Family Support Program?

17. What advice or recommendations would you give to others trying to do similar work?

18. Is there anything else you would like us to know?

19. Do you have any questions for me?

   Thank you for your time!
## FRIENDS OF KAREN, INC.  
**NUMBER OF CHILDREN SERVED 2012-2014**

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</tr>
<tr>
<td><strong>New Jersey</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bergen</td>
<td>7</td>
<td>16</td>
<td>16</td>
</tr>
<tr>
<td>Essex</td>
<td>11</td>
<td>17</td>
<td>14</td>
</tr>
<tr>
<td>Hudson</td>
<td>9</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>Passaic</td>
<td>16</td>
<td>14</td>
<td>13</td>
</tr>
<tr>
<td>Union</td>
<td>11</td>
<td>11</td>
<td>15</td>
</tr>
<tr>
<td><strong>Subtotal:</strong></td>
<td>54</td>
<td>64</td>
<td>70</td>
</tr>
<tr>
<td><strong>Connecticut</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fairfield</td>
<td>29</td>
<td>30</td>
<td>40</td>
</tr>
<tr>
<td>Middlesex</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>New Haven</td>
<td>15</td>
<td>24</td>
<td>20</td>
</tr>
<tr>
<td><strong>Subtotal:</strong></td>
<td>46</td>
<td>54</td>
<td>62</td>
</tr>
<tr>
<td><strong>Children living outside guideline area but treated in NY area hospitals</strong></td>
<td>13</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>554</td>
<td>581</td>
<td>635 *</td>
</tr>
<tr>
<td><strong>Siblings</strong></td>
<td>821</td>
<td>899</td>
<td>990</td>
</tr>
<tr>
<td><strong>GRAND TOTAL (Children Receiving Comprehensive Services)</strong></td>
<td>1,375</td>
<td>1,480</td>
<td>1625</td>
</tr>
<tr>
<td><strong>Number of children who died</strong></td>
<td>55</td>
<td>52</td>
<td>68</td>
</tr>
</tbody>
</table>

*Of this total, 280 children were new intakes to Friends of Karen in 2014.*