Vision for 2020

Families will experience trust, safety, security and connections with one another. Families will know and trust Jacob’s Heart staff beyond their Family Support Specialist.
Jacob’s Heart Children’s Cancer Support Services exists to improve the quality of life for children with cancer and support their families in the challenges they face. We provide family-centered care that addresses the emotional, practical and financial struggles for families of children and teens during treatment, families experiencing anticipatory grief and those who are bereaved.

Since 1998, Jacob’s Heart has provided emotional, practical, financial and peer support to hundreds of local children with cancer and thousands of their family members.

We envision a community where every child with a serious or life-threatening condition has a strong, supported and informed family empowered to fully participate in their care. We strive to inspire compassionate action within local communities to create a safety net of support for the unique needs of each child and family.

Mission and Vision

Family Support Services

Staff Mission Statements

Daniela… To address the families unique needs by taking the time to listen to them and support them through the challenges of childhood cancer.

Benito… To support the families through the challenges they face by creating a caring and loving environment.

Mariela… To support teens through treatment by honoring their individual needs and tailor care to better serve their family.

Mary… To empower children affected by childhood cancer by advocating, educating and providing support to the families and the FSS team.

Lily… To improve the quality of life for Jacob’s Heart children and their families by providing emotional support, as well as opportunities for families to come together in a meaningful way to support each other and build community. And to provide emotional support to JH staff.
Goals

By the end of 2020, 330 families will experience connection, trust, support and safety evidenced by:

- A 20% increase in families attending small scale events
- 20 families making deep connections
- Feedback from families and seeing an increase in deep sharing of thoughts and experiences

Strategies

- Visiting a family once a week (per FSS) and bringing engaging & structured activities
- Try different locations for English Bereaved and In Treatment support groups
- Being more selective & thoughtful when scheduling internal and external events
- Contacting families in the way that is best for them
- Hosting more events that foster connection
- Providing Spanish speaking counseling
Mission and Purpose
Jacob's Heart Children's Cancer Support Services exists to improve the quality of life for children with cancer and support their families in the challenges they face. We provide family-centered care that addresses the emotional, practical and financial struggles for families of children and teens during treatment, families experiencing anticipatory grief and those who are bereaved.

Since 1998, Jacob's Heart has provided emotional, practical, financial and peer support to hundreds of local children with cancer and thousands of their family members.

We envision a community where every child with a serious or life-threatening condition has a strong, supported and informed family empowered to fully participate in their care. We strive to inspire compassionate action within local communities to create a safety net of support for the unique needs of each child and family.

Demographics
The majority of Jacob’s Heart children come from low-income homes with high levels of unmet, basic needs. A recent census revealed: 79% of our families are enrolled in full-scope Medi-Cal, indicating low-income status; 60% qualify as high-financial need; 37% are experiencing housing insecurity; and 45% are subject to other major stresses (unrelated to their child’s condition) that have a significant impact on the quality of life for the seriously ill child.

Gender
- Male: 49%
- Female: 51%

Race/Ethnicity
- Caucasian: 16%
- Hispanic/Latino: 76%
- Asian American: 1%
- Black: 1%
- Other/Bi-Racial: 6%
2020 Goals for Data Collection and Program Evaluation

Jacob’s Heart will use a rigorous evaluation system to adjust program goals and activities. Quantitative and qualitative data collection mechanisms include: 1) Salesforce census data, which tracks family services and demographic information; 2) Service delivery statistics, which tracks the frequency and type of contact with children, parents, and siblings; 3) Personalized case files detailing assessment of need: psychosocial, emotional, and bereavement support delivered; 4) Internal or external referrals to collaborating partners documented in case files; 5) Informal family satisfaction queries conducted by Family Support Specialists at key points in the treatment trajectory; and 6) Written Family Quality of Life Survey distributed and collected immediately after Camp and on a rolling basis with sensitivity for a family’s emotional and mental state. Data is analyzed on a monthly basis and disseminated and evaluated by the Board of Directors on a quarterly basis.

From a quality-of-care perspective, families served by Jacob’s Heart will exhibit a reduction in the internal and external stressors that accompany a child’s life-threatening and/or terminal illness. We anticipate that quantitative and qualitative data collected by the Family Quality of Life Survey will reflect the following:

1. Families will rate the impact of emotional support services as or “very impactful” or better based on a 5-point scale.
2. Bereaved parents and parents of children in treatment and will indicate a reduction in stress and anxiety.
3. Parents will report feeling empowered in their decision-making around their child’s care.
4. Parents will acknowledge that their basic survival needs were addressed during the
5. COVID-19 and in transition after the virus threat.
6. Families will report that their needs for transportation to and from medical treatment were met, and that they felt safe and supported.

Qualitative data from families is gathered from parents through interviews in a safe and supportive environment, as a follow-up to our study on bereaved parents’ perspectives. 20 randomly selected parents will participate in qualitative interviews about Jacob’s Heart’s effectiveness in addressing stressors associated with childhood cancer. Qualitative data markers will be used to share the outcomes experienced on a deep human level within a trusted relationship.

Upgrade Salesforce for tracking the quantitative data such as:
1. Direct financial assistance provided to each family
2. Number of rides provided to medical appointments
3. Pick-up and drop off times - timeliness with appointment schedules
4. Number of bags of groceries delivered to home/hospital
5. Response time for meeting financial and practical needs
6. Home and hospital visits made
7. Counseling sessions & modalities used
8. Thematic group support sessions
9. Teen group activities and levels of participation
10. Referrals to additional resources
11. Peer mentorship matches and one-to-one family connections

Qualitative/experiential data is tracked and reported in quarterly quality of life surveys, interviews with family members, and feedback from oncology social workers at specialty hospitals.

Program Outcomes for 2020 All Counties
In 2020 Jacob’s Heart provided essential, daily support for **325 seriously ill children** and **1,189 of their family members.** Here is a snapshot of what we provided in 2020:

- **11,363 hours of counseling, coaching and care management** to families of children in treatment for cancer and other life-threatening illnesses (2019: 6,234 hours)
- **1,875 hours of emotional support** to families bereaved by child loss (2019: 1,075 hours)
- **$255,291 in direct financial assistance** for rent, utilities, food, meals, fuel and funeral expenses (2019: $192,305)
- **4,920 bags of groceries were** delivered by compassionate volunteers to families’ doorsteps (2019: 2,872 bags)
- 447 care packages with personalized gifts and essentials including items such as diapers, hand sanitizer, clothing, toys and household items (2019: 401)
- **504 door-to-door rides** so children were able to get to treatment with comfort, companionship, and safety (2019: 536) down slightly due to COVID; our transportation program has since been upgraded with additional safety measures
- **258 home and hospital visits** to help parents make informed decisions for their children
● **4,206 cards, gifts and remembrances** to honor milestones, birthdays and anniversaries

● **Personalized gifts and celebrations valued at $72,333** which alleviated stress and delivered joy to 403 family members through Holiday Hearts Adopt-a-Family

**Program Outcomes for 2020 Monterey County**

● **6,582 hours of counseling, coaching and care management** to families of children in treatment for cancer and other life-threatening illnesses (2019: 3,288 hours)

● **1,544 hours of emotional support** to families bereaved by child loss (2019: 509 hours)

● **$155,207 in direct financial assistance** for rent, utilities, food, meals, fuel and funeral expenses (2019: $106,141)

● **2,415 bags of groceries and supplies** delivered by compassionate volunteers to families’ doorsteps (2019: 1,354 bags)

● **237 door-to-door rides** so children were able to get to treatment with comfort, companionship, and safety (2019: 342) down slightly due to COVID; our transportation program has since been upgraded with additional safety measures

● **116 home and hospital visits** to help parents make informed decisions for their children

● **2,540 cards, gifts and remembrances** to honor milestones, birthdays and anniversaries

● **Personalized gifts and celebrations valued at $41,953**, which alleviated stress and delivered joy to 246 family members through Holiday Hearts Adopt-a-Family

**Program Outcomes for 2020 Monterey and San Benito Counties:**

● **7,103 hours of counseling, coaching and care management** to families of children in treatment for cancer and other life-threatening illnesses (2019: 3,545 hours)

● **1,743 hours of emotional support** to families bereaved by child loss (2019: 487 hours)

● **$171,376 in direct financial assistance** for rent, utilities, food, meals, fuel and funeral expenses (2019: $110,399)
- **2,881 bags of groceries and supplies** delivered by compassionate volunteers to families’ doorsteps (2019: 1,452 bags)
- **249 door-to-door rides** so children were able to get to treatment with comfort, companionship, and safety (2019: 344) down slightly due to COVID; our transportation program has since been upgraded with additional safety measures
- **120 home and hospital visits** to help parents make informed decisions for their children
- **2,740 cards, gifts and remembrances** to honor milestones, birthdays and anniversaries
- **Personalized gifts and celebrations valued at $46,923**, which alleviated stress and delivered joy to 268 family members through Holiday Hearts Adopt-a-Family

**Program Outcomes for 2020 Santa Cruz County**
- **3,583 hours of counseling, coaching and care management** to families of children in treatment for cancer and other life-threatening illnesses (2019: 2,211 hours)
- **1,023 hours of emotional support** to families bereaved by child loss (2019: 397 hours)
- **$56,964 in direct financial assistance** for rent, utilities, food, meals, fuel and funeral expenses (2019: $47,813)
- **1,802 bags of groceries and supplies** delivered by compassionate volunteers to families’ doorsteps (2019: 1,338 bags)
- **160 door-to-door rides** so children were able to get to treatment with comfort, companionship, and safety (2019: 180) down slightly due to COVID; our transportation program has since been upgraded with additional safety measures
- **122 home and hospital visits** to help parents make informed decisions for their children
- **1,326 cards, gifts and remembrances** to honor milestones, birthdays and anniversaries
- **Personalized gifts and celebrations valued at $20,253**, which alleviated stress and delivered joy to 106 family members through Holiday Hearts Adopt-a-Family

**Program Outcomes for 2020 San Benito County**
• **521 hours of counseling, coaching and care management** to families of children in treatment for cancer and other life-threatening illnesses (2019: 257 hours)

• **199 hours of emotional support** to families bereaved by child loss (2019: 90 hours)

• **$16,169 in direct financial assistance** for rent, utilities, food, meals, fuel and funeral expenses (2019: $4,258)

• **466 bags of groceries and supplies** delivered by compassionate volunteers to families’ doorsteps (2019: 98 bags)

• **12 door-to-door rides** so children were able to get to treatment with comfort, companionship, and safety (2019: 2)

• **4 home and hospital visits** to help parents make informed decisions for their children

• **200 cards, gifts and remembrances** to honor milestones, birthdays and anniversaries

• **Personalized gifts and celebrations valued at $4,340**, which alleviated stress and delivered joy to 22 family members through Holiday Hearts Adopt-a-Family

**Projected Goals for 2021**

**Monterey County**

• **6550 hours of counseling, coaching and care management** to families of children in treatment for cancer and other life-threatening illnesses

• **1500 hours of emotional support** to families bereaved by child loss

• **$135,000 in direct financial assistance** for rent, utilities, food, meals, fuel and funeral expenses

• **2000 bags of groceries and supplies** delivered by compassionate volunteers to families’ doorsteps

• **250 door-to-door rides** so children are able to get to treatment with comfort, companionship, and safety

• **100 home and hospital visits** to help parents make informed decisions for their children

• **2500 cards, gifts and remembrances** to honor milestones, birthdays and anniversaries
<table>
<thead>
<tr>
<th>Data Point</th>
<th>Description</th>
<th>Counties</th>
<th>2021 Projections</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of Individuals (Children and Family Members) Receiving Services</strong></td>
<td>Level 2-5</td>
<td>Monterey</td>
<td>850</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Santa Cruz</td>
<td>450</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Santa Clara</td>
<td>75</td>
</tr>
<tr>
<td></td>
<td></td>
<td>San Benito</td>
<td>75</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Total</td>
<td>1450</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Direct Support Hours - In Treatment/ Surviving</th>
<th>Monterey</th>
<th>Santa Cruz</th>
<th>Santa Clara</th>
<th>San Benito</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home visit time, hospital visit time, phone calls, creating a care package, text messages, time spent on DFA, time spent on gas assistance/coordinating rides, doing rides, office visits, event visits (meaningful time), Lily/Lori’s time, prepping materials for camp, newsletter, etc. (Not included: support groups, teen days, Art from the Heart, families attending an event)</td>
<td>6550</td>
<td>3550</td>
<td>650</td>
<td>500</td>
<td>11250</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Direct Support Hours - Bereaved</th>
<th>Monterey</th>
<th>Santa Cruz</th>
<th>Santa Clara</th>
<th>San Benito</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home visit time, hospital visit time, phone calls, creating a care package, text messages, time spent on DFA, time spent on gas assistance/coordinating rides, doing rides, office visits, event visits (meaningful time), Lily/Lori’s time, prepping materials for camp, newsletter, etc. (Not included: support groups, teen days, Art from the Heart, families attending an event)</td>
<td>1500</td>
<td>1000</td>
<td>175</td>
<td>200</td>
<td>2875</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Home/Hospital Visits/ Office - Case Management, Emotional Support</th>
<th>Monterey</th>
<th>Santa Cruz</th>
<th>Santa Clara</th>
<th>San Benito</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>A visit is constituted by a meaningful conversation with a family in person. A visit can be during an event, dropping off groceries/care packages, a visit to Heart Mart, etc. as long as the conversation is meaningful and lasts at least 15 minutes.</td>
<td>100</td>
<td>100</td>
<td>20</td>
<td>20</td>
<td>240</td>
</tr>
<tr>
<td>Description</td>
<td>Monterey</td>
<td>Santa Cruz</td>
<td>Santa Clara</td>
<td>San Benito</td>
<td>Other/Emergency</td>
</tr>
<tr>
<td>----------------------------------------------------------------------------</td>
<td>----------</td>
<td>------------</td>
<td>------------</td>
<td>------------</td>
<td>----------------</td>
</tr>
<tr>
<td>Direct Financial Assistance (rent, utilities, funerals, etc.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Monterey</td>
<td>$135,000</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Santa Cruz</td>
<td>$35,000</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Santa Clara</td>
<td>$10,000</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>San Benito</td>
<td>$10,000</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other/Emergency</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Groceries Bags (delivered to home or hospital)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Monterey</td>
<td>2000</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Santa Cruz</td>
<td>1750</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Santa Clara</td>
<td>200</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>San Benito</td>
<td>450</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mobile Pantry</td>
<td>200</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Bags</td>
<td>4600</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Value of Bags</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care Packages</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Monterey</td>
<td>250</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Santa Cruz</td>
<td>125</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Santa Clara</td>
<td>25</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>San Benito</td>
<td>5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>405</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Celebrations and Remembrances</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Monterey</td>
<td>2500</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Santa Cruz</td>
<td>1250</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Santa Clara</td>
<td>125</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resource Referrals Made</td>
<td>Monterey</td>
<td>Santa Cruz</td>
<td>Santa Clara</td>
<td>San Benito</td>
<td>Total</td>
</tr>
<tr>
<td>-------------------------</td>
<td>----------</td>
<td>------------</td>
<td>-------------</td>
<td>------------</td>
<td>-------</td>
</tr>
<tr>
<td># of resource referrals made</td>
<td>30</td>
<td>10</td>
<td>5</td>
<td>5</td>
<td>50</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rides Given (One Way)</td>
<td>Monterey</td>
<td>Santa Cruz</td>
<td>Santa Clara</td>
<td>San Benito</td>
<td>Total</td>
</tr>
<tr>
<td></td>
<td>250</td>
<td>175</td>
<td>100</td>
<td>20</td>
<td>545</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Families on Service</td>
<td>Monterey</td>
<td>Santa Cruz</td>
<td>Santa Clara</td>
<td>San Benito</td>
<td>Total</td>
</tr>
<tr>
<td>Level 2-5 families receiving services (includes high-need families and bereaved families)</td>
<td>180</td>
<td>100</td>
<td>20</td>
<td>15</td>
<td>315</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High-Need Families Receiving Comprehensive Support</td>
<td>Monterey</td>
<td>Santa Cruz</td>
<td>Santa Clara</td>
<td>San Benito</td>
<td>Total</td>
</tr>
<tr>
<td>Level 4 and 5 families receiving services</td>
<td>55</td>
<td>25</td>
<td>10</td>
<td>5</td>
<td>95</td>
</tr>
</tbody>
</table>
April 2020 - Modification of Core Four Services During COVID-19

1) Emergency Financial Assistance. Our families need immediate rent assistance to keep seriously ill children in their homes, a need that is burgeoning by the day - we are reassessing this need monthly as the pandemic evolves. We have been working with families whose children are likely to die during the COVID-19 pandemic for online memorial services and other creative options.

2) Food and Living Supplies. Going to the grocery store is not an option for our families, so we have doubled our deliveries of groceries and basic living supplies - no volunteers, only staff - including an increase in deliveries of groceries and supplies to their doorsteps. At the request of and in partnership with Lucile Packard Children’s Hospital Stanford, we recently added 24 new families of children with complex medical conditions who were suffering from COVID-related stressors to our program.

3) We are continuing to provide safe, reliable transportation to essential medical appointments as the only pediatric medical transportation provider in our service area. We have been approved by contract with the Central California Alliance for Health to provide medical transportation to children. Per our contract with CCAH, special COVID-19 precautions N95 masks, gloves, vehicle sanitization are in place.

4) We are increasing crisis counseling hours by phone or in person and have hired additional psychotherapists with expertise in children’s complex grief and trauma. Other services such as home and hospital visits support groups, camps, outings, group expressive therapies, family counseling and peer will resume when it is safe.
Results - Goals
As a result, children impacted by serious illness including children battling COVID and cancer:
1. Felt safe, supported, and loved through ongoing counseling and psychotherapy from professional counselors trained in complex grief and trauma in children.
2. Remained safe in their homes, because Jacob's Heart helped their families with rent and living expenses, and fresh, nutritious bags of groceries ensuring parents didn’t have to risk going to the grocery store.
3. Never missed a medical appointment during COVID, because Jacob's Heart was there with a safe, door-to-door ride.