The RYR-1 Foundation

2017-2021

www.ryr1.org
EIN: 47-1094057
Report generation on: 11/03/2023

Mission Statement

The RYR-1 Foundation’s mission is to support research leading to an effective treatment or a cure for RYR-1-related diseases by:
1) Research: We make grants to researchers interested in RYR-1-related diseases and developing a patient registry.
2) Medical Professional Education: The vast majority of medical professionals have never heard of RYR-1-related diseases. We raise awareness through resources on our website, as well as direct meetings with medical professionals around the world.
3) Patient/Family Support and Advocacy: We serve as a resource for patients and their families through our website, other forms of social media, and biennial International Family Conferences.

Table of Contents

Financial Trends Analysis ........................................ 2
Profitability .................................................. 4
Revenue Composition ........................................ 5
Expense Composition ......................................... 6
Full Cost Components ......................................... 7
Months of Liquidity ............................................. 8
Asset Composition .............................................. 9
Liability Composition .......................................... 10
Net Asset Composition ......................................... 11

HELPFUL LINKS

Nonprofitfinancefund.org
Guidestar.org
Glossary & Formulas

This report uses IRS Form 990 data to provide a comprehensive overview of the selected organization’s financial performance and condition, according to Nonprofit Finance Fund’s (NFF) philosophy and analysis. It aims to demystify nonprofit finance, helping users understand what financial data matters most, how to interpret the information. It can be used by nonprofit leaders, board members, funders, consultants, and other stakeholders to plan for the future, communicate resource needs, and inform financial, program, and strategic decisions.

Remember that no one ratio or metric defines financial health for all nonprofits. When assessing a nonprofit’s financial health, NFF recommends discussing financial performance and additional context with organizational leadership and/or enlisting the help of experts to interpret the numbers and draw the right conclusions. While the numbers always tell a story, it is incomplete without an understanding of internal and external context beyond the data.
Financial Trends Analysis

The dashboard below provides a snapshot of key financial trends and ratios, drawing from up to five years of the most recent Form 990 data available on GuideStar.org.

**Business Model Indicators**

<table>
<thead>
<tr>
<th>Profitability</th>
<th>2017</th>
<th>2018</th>
<th>2019</th>
<th>2020</th>
<th>2021</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unrestricted surplus (deficit) before depreciation</td>
<td>$674,799</td>
<td>$36,173</td>
<td>$75,935</td>
<td>$163,384</td>
<td>$34,914</td>
</tr>
<tr>
<td>As a % of expenses</td>
<td>175.6%</td>
<td>8.6%</td>
<td>21.8%</td>
<td>49.5%</td>
<td>13.5%</td>
</tr>
<tr>
<td>Unrestricted surplus (deficit) after depreciation</td>
<td>$674,799</td>
<td>$36,173</td>
<td>$75,935</td>
<td>$163,384</td>
<td>$34,914</td>
</tr>
<tr>
<td>As a % of expenses</td>
<td>175.6%</td>
<td>8.6%</td>
<td>21.8%</td>
<td>49.5%</td>
<td>13.5%</td>
</tr>
</tbody>
</table>

**Revenue Composition**

| Total revenue (unrestricted & restricted)         | $1,059,068| $778,647 | $744,214 | $393,570  | $519,685  |
| Total revenue, % change over prior year           | 248.2%    | -26.5%   | -4.4%    | -47.1%    | 32.0%     |
| Program services revenue                          | 0.4%      | 4.2%     | 4.9%     | 21.7%     | 29.3%     |
| Membership dues                                   | 0.0%      | 0.0%     | 0.0%     | 0.0%      | 0.0%      |
| Investment income                                 | 0.2%      | 0.8%     | 3.3%     | 3.2%      | 0.4%      |
| Government grants                                 | 0.0%      | 0.0%     | 0.0%     | 0.0%      | 2.7%      |
| All other grants and contributions                 | 99.1%     | 94.8%    | 84.6%    | 72.6%     | 65.8%     |
| Other revenue                                     | 0.2%      | 0.2%     | 7.2%     | 2.6%      | 1.7%      |

**Expense Composition**

| Total expenses before depreciation                | $384,269  | $421,185 | $349,004 | $330,396  | $257,682  |
| Total expenses, % change over prior year          | 282.4%    | 9.6%     | -17.1%   | -5.3%     | -22.0%    |
| Personnel                                         | 11.4%     | 12.3%    | 17.6%    | 17.7%     | 22.3%     |
| Professional Fees                                 | 4.8%      | 8.1%     | 11.6%    | 11.2%     | 16.8%     |
| Occupancy                                         | 0.0%      | 0.0%     | 0.0%     | 0.0%      | 0.0%      |
| Interest                                          | 0.0%      | 0.0%     | 0.0%     | 0.0%      | 0.0%      |
| Pass-Through                                      | 70.8%     | 41.0%    | 51.8%    | 55.3%     | 44.7%     |
| All other expenses                                | 13.1%     | 38.6%    | 18.9%    | 15.8%     | 16.2%     |

**Full Cost Components (estimated)**

| Total Expenses (after depreciation)               | $384,269  | $421,185 | $349,004 | $330,396  | $257,682  |
| One Month of Savings                              | $32,022   | $35,099  | $29,084  | $27,533   | $21,474   |
| Debt Principal Repayment                          | $0        | $0       | $0       | $0        | $0        |
| Fixed Asset Additions                             | $0        | $0       | $0       | $0        | $0        |
| Total Full Costs (estimated)                      | $416,291  | $456,284 | $378,088 | $357,929  | $279,156  |
## Capital Structure Indicators

### Liquidity

<table>
<thead>
<tr>
<th></th>
<th>2017</th>
<th>2018</th>
<th>2019</th>
<th>2020</th>
<th>2021</th>
</tr>
</thead>
<tbody>
<tr>
<td>Months of cash</td>
<td>28.7</td>
<td>33.7</td>
<td>51.5</td>
<td>34.0</td>
<td>49.1</td>
</tr>
<tr>
<td>Months of cash and investments</td>
<td>37.0</td>
<td>43.1</td>
<td>63.5</td>
<td>70.4</td>
<td>98.8</td>
</tr>
<tr>
<td>Months of estimated liquid unrestricted net assets</td>
<td>35.3</td>
<td>33.2</td>
<td>42.7</td>
<td>51.0</td>
<td>67.0</td>
</tr>
</tbody>
</table>

### Balance Sheet Composition

<table>
<thead>
<tr>
<th></th>
<th>2017</th>
<th>2018</th>
<th>2019</th>
<th>2020</th>
<th>2021</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash</td>
<td>$917,695</td>
<td>$1,181,163</td>
<td>$1,498,917</td>
<td>$935,646</td>
<td>$1,054,536</td>
</tr>
<tr>
<td>Investments</td>
<td>$267,393</td>
<td>$331,993</td>
<td>$349,030</td>
<td>$1,002,860</td>
<td>$1,066,033</td>
</tr>
<tr>
<td>Receivables</td>
<td>$50,000</td>
<td>$0</td>
<td>$50,000</td>
<td>$13,000</td>
<td>$116,290</td>
</tr>
<tr>
<td>Gross land, buildings, and equipment (LBE)</td>
<td>$0</td>
<td>$0</td>
<td>$0</td>
<td>$0</td>
<td>$0</td>
</tr>
<tr>
<td>Accumulated depreciation (% of LBE)</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Liabilities (as % of assets)</td>
<td>8.9%</td>
<td>1.5%</td>
<td>1.1%</td>
<td>0.1%</td>
<td>0.4%</td>
</tr>
<tr>
<td>Unrestricted net assets</td>
<td>$1,128,894</td>
<td>$1,165,067</td>
<td>$1,241,002</td>
<td>$1,404,386</td>
<td>$1,439,300</td>
</tr>
<tr>
<td>Temporarily restricted net assets</td>
<td>$0</td>
<td>$324,845</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Permanently restricted net assets</td>
<td>$0</td>
<td>$0</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Total restricted net assets</td>
<td>$0</td>
<td>$324,845</td>
<td>$646,362</td>
<td>$545,027</td>
<td>$788,737</td>
</tr>
<tr>
<td>Total net assets</td>
<td>$1,128,894</td>
<td>$1,489,912</td>
<td>$1,887,364</td>
<td>$1,949,413</td>
<td>$2,228,037</td>
</tr>
</tbody>
</table>

### Key Data Checks

#### Material Data Errors

<table>
<thead>
<tr>
<th></th>
<th>2017</th>
<th>2018</th>
<th>2019</th>
<th>2020</th>
<th>2021</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

Note: This issue is relevant to a small number of organizations: The nonprofit subject(s) of this report may have affiliates. The Form 990 data may not include information about any or all potential affiliates. If an organization does have affiliates and these affiliates have substantial financial activity, the financial data in this report may not present a comprehensive picture of the nonprofit's financial condition. Please consult the 990s of any potentially related affiliates for additional information.
Profitability

Breaking even every year is rarely enough. Nonprofits need surpluses – profits – to survive, to build financial health, to advance their missions. The unrestricted surplus (or deficit) shown here as “profitability” reflects the ability to generate consistent surpluses and cover full costs beyond operating expenses (see Moving Toward Full Cost Coverage on Page 7). Note: Depreciation is a non-cash expense used to approximate normal wear and tear on fixed assets, so we show a before and after picture to highlight its impact on surpluses or deficits.

Unrestricted Surplus (Deficit)

WHAT TO LOOK FOR:

- **Vital signs and change over time:** surplus (deficit) trends over time are a key indicator of financial health that reflects the strength of the organization’s business model. Consistent or growing deficits can potentially be a sign of concern, while regular surpluses help an organization save money to respond to risks and opportunities.

- **Surplus (deficit) size:** reviewing annual surpluses (deficits) both as a dollar amount and as a percent of annual expenses indicates performance relative to the size of the organization’s operations.

- **Business cycles:** some organizations have programming cycles that lead to surpluses only in certain years. Organizations with this dynamic should ask whether the revenue generated in surplus years is sufficient to cover the losses in deficit years, while also contributing to necessary savings.

- **Planned deficits:** there are times when deficits are unavoidable (e.g. in economic downturns or due to unexpected funding losses), and times when they are strategically planned with the expectation of future revenue (e.g. during periods of change or growth). In either case, dialogue with the organization’s leadership can help provide context for operating results.

QUESTIONS TO CONSIDER

- How consistent have unrestricted surpluses (deficits) been over time? Have results been improving or getting worse?
- Does the organization manage to regular surpluses in anticipation of future challenges or opportunities?

DATA LIMITATIONS

The IRS Form 990 does not distinguish between revenue and expenses for ongoing operations from those that are more episodic in nature (e.g. revenue earmarked for the purchase of a facility or significant program change/expansion, gains/losses on sale of investments or fixed assets, a one-time bequest). If such periodic or one-time revenue and expenses are present, the surplus or deficit line on the Form 990 may be misleading as a definitive measure of profitability. Dialogue with the organization’s leadership can help clarify any unusual or one-time activities.
Revenue Composition

The ideal revenue mix is reliable, repeatable, and/or replaceable, and can adequately cover a nonprofit's full costs. That “ideal” looks different for each nonprofit according to its mission, business model, market environment, strategy, balance sheet needs, and other factors. Because the Form 990 doesn’t distinguish between restricted and unrestricted revenue, the categories shown here may include some revenues that have donor-imposed restrictions for future use.

WHAT TO LOOK FOR:

- **Change over time**: multi-year trends show how the sources and amount of the organization’s revenues have changed or remained consistent over the period. Major changes in revenue composition could indicate a shift in the nonprofit’s business model.

- **Composition**: NFF shows major revenue sources common to most nonprofits. Though revenue diversification is often touted as a goal for nonprofits, developing expertise in generating a select few types of revenue may be a more viable long-term approach for most organizations. Cultivating new revenue sources may require more staff, time, and specific skills, which can make upfront investment necessary to generate new revenue.

- **Reliability**: Most organizations operate best with steady, predictable revenue to cover operating expenses. Revenue fluctuation may reflect programmatic changes or cycles. Significant or unusual swings in revenue need to be assessed for cause, with appropriate action taken to identify replacement revenue or reduce expenses.

QUESTIONS TO CONSIDER

- Has the mix of revenue remained steady over time?
- What internal and external factors may drive revenue results in the future?
- Is leadership investing in future revenue-generating capacity (staff, skills, time, etc.) with potential payoff?

DATA LIMITATIONS

Because the IRS Form 990 does not distinguish between restricted and unrestricted revenue, the total revenue indicated here may include some revenue that has donor-imposed restrictions on future use.
Expense Composition

One measure of a nonprofit's size is its total expenses. NFF uses natural classification of expenses which demonstrates how money is spent to support mission and programs through staff, occupancy, professional, and other expenses. The widely used breakdown of program vs. administrative vs. fundraising expenses is a poor measure of effectiveness or efficiency, and it too often encourages nonprofits to undercount administration and fundraising costs, thus misrepresenting their true infrastructure needs.

### Questions to Consider

- Has the organization grown steadily or become smaller?
- Which expenses have been the most significant drivers of overall costs?
- Which expense categories have grown or contracted significantly and why?
- Have expenses been managed in accordance with revenue realities?
- Does the organization's size reflect the demand for its programs?

### What to Look For:

- **Change over time**: multi-year trends show how operations have grown, contracted, or held stable.

- **Composition**: expenses provide insight into how an organization accomplishes its mission. Compared with revenue, expenses are typically more directly within nonprofit management's control. Understanding which expenses are key to mission success can help drive decisions about when expenses may need to be increased or cut in light of new goals or revenue realities. For most nonprofits, personnel costs are the largest expense and drive overall growth or contraction. People are how the work of most organizations gets done. Major changes in expense composition could indicate a shift in the nonprofit's business model.

- **Expense planning and growth considerations**: while some organizations experience incremental growth, others run periodic campaigns to scale their operations or go through planned cycles of increased and decreased activity. Growth can be destabilizing because hiring new personnel, building more complex infrastructure, and starting new programs often precede the expansion of revenue to pay for those activities. Additionally, growing organizations may often see infrastructure costs rise as they build their new capacity ahead of new program delivery.
Moving Toward Full Cost Coverage

Each nonprofit has a host of costs beyond its daily operating expenses that are equally crucial to its immediate and future financial needs – costs like working capital, reserves (or savings), and funds to pay down debt, add property and equipment, and innovate or adapt. Nonprofits must generate consistent surpluses to move toward covering their full costs, and should regularly identify which items beyond operational expenses they can build into their budget and fundraising planning. Covering all full costs every year with surpluses is aspirational for most nonprofits when breaking even can be difficult enough. Nonetheless, planning for and working toward full cost coverage is critical for short and longer term financial health and mission success.

WHAT TO LOOK FOR:

- **Full Cost Components:** This graph shows estimated unrestricted revenue compared to several major components of the organization's annual full cost of doing business, which is estimated as the sum of 1) expenses after depreciation 2) annual debt principal repayment (if any), 3) purchases of property and equipment (if any) and 4) one month of cash savings (based on the expense size in the given year). This graph is for illustrative purposes, as the size and components of a nonprofit's full costs will vary based on the organization's financial condition, strategy, revenue dynamics and capital structure.

- **Managing to Full Cost:** Organizations frequently budget only to meet expenses. However, the items reflected in this graph can be critical for maintaining and building a healthy enterprise supportive of mission and programs. Full cost components such as operating expenses, working capital and reserves (approximated here as an additional month of cash savings) are “must haves” for all organizations. Other full cost components such as funding for debt principal repayment, fixed asset additions and change to the business model are periodically needed and only by some organizations.

QUESTIONS TO CONSIDER

- Does the organization tend to generate enough unrestricted revenue to:
  - Generate surplus cash to set aside as working capital or a reserve?
  - Cover balance sheet investments like future repairs and replacements of fixed assets?
- Has leadership considered establishing and fundraising for one or more unrestricted board-designated reserves with policies governing use and replenishment?
Months of Liquidity

This financial safety net comprises the resources available to respond to risks and opportunities. While months of cash and investments indicate ability to pay the bills, months of liquid unrestricted net assets (LUNA) gives a more comprehensive view of free and available net worth. A nonprofit's ideal liquidity varies according to factors like business model, local market, debt, risk tolerance, and facility ownership.

**What to look for:**

- **Change over time:** multi-year trends show whether the organization's financial safety net has grown, contracted, or remained stable over the period. Here it is presented in terms of how many months of expense coverage cash and LUNA provide at fiscal year-end. Surpluses are typically the fuel for growing liquidity, while deficits diminish it.

- **Months of Cash:** the best measure of a nonprofit's solvency and its ability to meet day-to-day expenses and short-term obligations with cash on hand.

- **Months of Cash and Investments:** adds investments to the Months of Cash metric above for a fuller picture of cash and near-cash assets. While cash and investments may be readily accessible, not all may be available for the organization to spend. Cash and investments are often restricted by donors, creating the impression that a nonprofit is flush, when it may be dealing with a cash crunch. Additionally, some investments may represent a permanently restricted endowment, where the corpus cannot be spent.

- **Liquid Unrestricted Net Assets:** a measure of free and available net worth, indicating a nonprofit's adaptability to respond to changes, support innovation, and/or mitigate risk.

- **Vital signs:** A nonprofit's liquidity needs vary according to factors like business model, local market, debt, risk tolerance, and facility ownership. That said, access to at least three months of cash and/or LUNA generally indicates some breathing room. If you're assessing an organization's financial health, zero or negative months of liquidity may indicate significant financial vulnerability and warrants further conversation with the nonprofit's leadership.

**Questions to consider**

- What liquidity is available to manage cash flow cycles, handle the unexpected, and respond to future opportunities?
- If cash has been tight, how does leadership plan to address this in the future?
Asset Composition

A nonprofit's balance sheet shows what it owns (assets) and owes (liabilities), and its net worth (net assets) and changes daily. Form 990 balance sheet composition reflects the status on the last day of the nonprofit's fiscal year. Asset composition shows what is available to a nonprofit to help advance its mission and can include resources such as cash, investments, funds receivable, property and equipment, and other types of assets.

WHAT TO LOOK FOR:

- **Reflection of the business model**: The balance sheet can indicate what resources support the organization's mission and business model, and what obligations it needs to fulfill. For instance, the balance sheet can reveal whether a nonprofit owns property and equipment to deliver programs, if levels of receivables are high while waiting for cash from grants or contracts to be paid, or the extent to which assets have been financed with debt. The balance sheet is directly affected by annual surpluses or deficits generated from operations. Each year that ends with an operating surplus will increase net assets, while each deficit year will deplete net assets.

- **Driving assets**: Assets often influence business decisions and liquidity needs. For instance, organizations with significant property and equipment or receivables may need more cash on hand to appropriately manage these assets than organizations with simpler asset composition.

- **Asset availability**: As organizations grow, their balance sheets often become more complex. It is important to understand the terms of any donor-imposed restrictions on cash, receivables and investments, as they can limit the availability of funds.

QUESTIONS TO CONSIDER

- What assets does the organization require to support its mission, and do they meet its needs?
- If receivables are significant, how readily do they convert into cash? Can they be collected faster?
- Does the organization have adequate cash and/or liquid investments to manage the seasonality of cash flow and save for a rainy day? If not, what is its strategy to address liquidity constraints?
Liability Composition

Liabilities represent obligations an organization must fulfill, and commonly include short and/or longterm debt, accounts payable, and deferred revenue. Some nonprofits don't need or avoid taking on liabilities. However, liabilities can be necessary and effective options for managing day to day operations – like cash flow – or financing capital needs – such as property and equipment acquisitions or improvements. When nonprofits have liabilities, it is critical that they also have a plan for repayment.

Total Liabilities

WHAT TO LOOK FOR:

• **Composition and use:**

  **Debt:** debt (e.g. a line of credit, mortgage, note payable) can be an effective tool used as a temporary source of capital to manage operations and cash flow or to finance fixed assets or growth. Organizations that borrow need to understand the size of annual surpluses required each year to repay borrowed funds over the life of the loan. Dialogue with the organization's leadership can help provide context on the use of debt.

  **Accounts payable:** refers to monies owed to others due to receipt of a good or service. Accounts payable can occur due to a lag in payroll, bills due to vendors, etc. Organizations that delay payments to vendors and/or spend cash in advance of service delivery (deferred revenue) on an unrelated purpose may be jeopardizing relationships with important suppliers or constituents.

  **Deferred revenue:** refers to advance payments for services that are to be delivered at some point in the future. Care should be taken when a deferred revenue balance is close to the entire cash balance - that would show that the organization's cash is not free for operations (and is really intended for these already promised activities).

• **Amount and leverage:** If an organization owes more than it owns (e.g. 50% or more of total assets), or liabilities are trending significantly upward over time, the organization may be in a challenging financial position. For organizations showing significant or growing liabilities, it is important to understand why these liabilities exist and how the organization intends to deal with them. Some of this may be revealed through other trends (e.g., years of deficits that may have been funded by debt), but conversation with the nonprofit's leadership will be essential to better understand this trend.

QUESTIONS TO CONSIDER

• Has the organization delayed payables, incurred unplanned debt or inappropriately spent deferred revenue as a way of accessing cash to fund operations?

• If the organization has a line of credit, has it been used properly as a tool to manage cash flow, as opposed to a source of cash to cover deficits?

• If payables are increasing, what might be the cause? (Are expenses rising at a similar clip or is the organization accessing cash by delaying payments to vendors?)

• What is the nonprofit's strategy to reduce payables or accrued expenses if present?
Net Asset Composition

A nonprofit’s net worth – or net assets – can come in three forms: unrestricted, temporarily restricted and permanently restricted according to donor-imposed restrictions. Unrestricted net assets are owned free and clear by the organization but may not be liquid and readily available for operations. Temporarily restricted net assets are restricted to specific uses and/or for a particular period; they become unrestricted when the designated purpose is satisfied or period is over. Permanently restricted net assets are often referred to as endowments but may also be historic buildings or land trusts.

WHAT TO LOOK FOR:

- **Composition**: Net asset composition is best evaluated within the context of the amount unrestricted net assets available to support operations. Temporarily restricted net assets indicate secured funding, but can only be accessed in the future. Permanently restricted net assets can be a useful source of investment income, but cannot be spent for any reason. Both forms of restricted funding can limit the flexibility of the organization’s net worth. Understanding what portion of net assets is unrestricted and available to support operations provides insight into the resources that the organization has available to respond to changes, support innovation and mitigate risk.

- **Flexibility of Unrestricted Net Assets**: Understanding how much unrestricted net assets are truly liquid rather than invested in property and equipment depicts a more comprehensive view of an organization’s financial safety net and available net worth (See Liquid Unrestricted Net Assets or LUNA on Page 8.) This can reflect the organization’s ability to take advantage of opportunities, absorb deficits, or manage financial setbacks.

QUESTIONS TO CONSIDER

- What portion of unrestricted net assets has been liquid and available for operations, as opposed to invested in property and equipment?
- What portion of temporarily restricted net assets is not available within the year for program delivery and operations?
- Can the organization negotiate the terms of restricted funds?
- Does the organization have a permanently restricted endowment? If so, what percent of the annual operating budget is typically covered by interest income?