The Voice of the Donor for a Cure

Juvenile Diabetes Cure Alliance

August 29, 2013

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Corporate Governance STAR Review

Conclusions:

→ We evaluate the non-profits' corporate governance practices using the STAR rating system criteria: **S**trategic direction, **T**imeliness and **T**ransparency of reporting, **A**ccountability, and **R**esource utilization

→ Compared to the best practices of public companies and SEC standards, all of the major diabetes non-profits have significant room for improvement

→ Implementing good corporate governance practices would improve organizational performance and increase donor contributions

→ The table below provides a summary of our STAR ratings:

	ADA	DRIF	JDRF	Joslin
Strategic Direction	★★	★★	★★	★
Timeliness & Transparency	★	★	★★	★
Accountability	★★	★	★	★
Resource Utilization	★	★★	★★	★
Overall STAR Rating	★+	★+	★★	★

★★★★★: Meets or exceeds all the Best Practices of Public Companies' Corporate Governance
★★★★: Meets all the Best Practices of Public Companies' Corporate Governance
★★★: Meets most of the Best Practices of Public Companies' Corporate Governance
★★: Meets some of the Best Practices of Public Companies' Corporate Governance
★: Meets a few of the Best Practices of Public Companies' Corporate Governance

Organizations of Focus:

American Diabetes Association (ADA)

Diabetes Research Institute Foundation (DRIF)

JDRF

Joslin Diabetes Center (Joslin)

This is our second annual review of the corporate governance practices of the four major type 1 diabetes charities.

We define corporate governance as the leadership policies and reporting practices that an organization follows. Strong corporate governance ensures that the organization is acting in the best interests of its stakeholders.

Public for-profit companies are held to high standards of corporate governance because they are regulated by the Securities and Exchange Commission (SEC) and are closely monitored by their shareholders. Donors should be viewed as a non-profit's "shareholders" because donor contributions fund the charity's pursuit of its mission. The major diabetes charities have an obligation to their donors to practice sound corporate governance and would benefit from adopting a number of the best practices of public companies.

While the non-profits' corporate governance in 2012 included some areas of strength, their governance practices are well below the best practices of public companies. There are many opportunities for the major diabetes charities to improve governance in all areas of STAR.

STAR Review Methodology

This year we inaugurate our "**STAR**" rating of the non-profits' governance. A detailed rubric for the STAR review ratings can be found in Appendix A on page 10. The key elements of the JDCA's STAR review are:

S: **Strategic direction**, i.e. the organization's clarity of purpose and priorities
T: **Transparency and Timeliness** of information reporting and Board processes
A: **Accountability** of leadership for setting and achieving goals
R: **Resource utilization**, i.e. allocation of resources consistent with the mission and donor intentions

The JDCA sought to avoid conflicts of interest and maintain objectivity in conducting this evaluation. Our analysis incorporates publicly available information, including each organization's annual report, Form 990, audited financial statements, by-laws, official website, and other publications.

STAR Review Highlights

We begin with a composite STAR review of the non-profits' corporate governance practices. Individual evaluations of each organization follow.

Strategic Direction

Strategic direction for each organization is disclosed in the mission statement and other communications between management and its stakeholders. Similar to last year, communicating the mission is a strength common to all four non-profits. The mission statements are clearly and consistently communicated and accessible on the websites and the Form 990s.

Strategic changes tend to be infrequent, however, when change does occur the underlying rationale should be clearly articulated, widely communicated, and continually evaluated in order to minimize any misunderstanding about an organization's new priorities. JDRF announced an important change in strategic direction in 2011 which was not well communicated. We comment on this in the JDRF section.

Transparency and Timeliness

The timely and thorough dissemination of financial data is necessary for donors to asses an organization's performance. The SEC mandates that public companies issue financial statements within 90 days after the close of the fiscal year. Three of the four non-profits issued their year-end financial statements well beyond the SEC guideline. Joslin, an exception, issued its financials within three months of year-end.

The tardy publication of the annual report is a glaring weakness for all four non-profits. An annual report is one of the best communication and marketing tools available to convey important messages and developments. The non-profits typically publish their annual report many months after year end. Joslin's annual report is years out of date. Issuing an annual report 10-12 months after year-end severely limits its usefulness.

Reporting on results, strategies, and near-term expectations lacks depth across the board. None of the charities' annual reports or financial statements provide a Management's Discussion and Analysis (MD&A). An MD&A is a comprehensive evaluation of the year's operating performance and financial results. It discusses the organization's greatest challenges and its future outlook. Publishing annual raw financial data in conjunction with sporadic press releases does not adequately assess performance or research progress.

The non-profits could vastly improve reporting on their cure research programs by including a thorough discussion of strategies, goals, and tangible progress. None of the organizations engages in a frequent and thorough review of the research portfolio. A forthright assessment of progress or setbacks in pre-clinical and clinical trials would improve transparency and avoid confusion about progress.

Transparency into several Board-level processes is also inadequate. There is often little or no insight into the processes that determine executive compensation packages, appointments to the Board, or the composition of Board Committees. This topic will be covered in an upcoming report.

Accountability

The Board of Directors and senior management are accountable for setting and articulating major goals, delivering results toward those goals, and for the organization's overall performance.

Accountability is an area rife with deficiencies for all four organizations. There is a distinct lack of transparency in communicating short- and long-term goals and no metrics to measure progress. The ADA is the most transparent of the four charities in goal setting. Its 2012-15 Strategic Plan outlines four-year goals.

Management accountability can be enhanced by linking financial incentives to short- and long-term goals. It is not clear if, or to what extent, executives' compensation is tied to specific performance metrics, particularly metrics related to tangible cure progress. We will cover this topic in an upcoming report.

Resource Utilization

Donor contributions should be applied toward stated goals in keeping with the organization's mission, donors' intentions, and the message used to solicit donations. Donor contributions are generally aligned with the mission, with some exceptions, such as the DRIF's funding of education, an activity not mentioned in its mission statement.

The non-profits' spending does not align with donor intentions or the cure message used to solicit donations. Eight out of ten donors expect to have a cure for type 1 within twenty years and name cure research as their top funding priority. So it is no wonder that the non-profits use the cure message at over 90% of total fundraising events.[1] However, most of the non-profits direct a small percentage of funds, if any, to research that targets a type 1 cure in the near future. Management's use of donor contributions should be far better aligned with donor interests.[2]

Organization-Specific Highlights

ADA

Overall STAR Rating: ★+

Strategic Direction ★★

This is an area of relative strength, but there are opportunities for improvement. The mission statement is clear and communicated widely and consistently. The 2012-2015 Strategic Plan outlines a vision through 2015, but the commentary related to research is general and not linked to type 1 cure progress.

Timeliness and Transparency ★

The timeliness of reporting is a shortcoming. The annual report, financial statements, and Form 990 are published after the SEC's guidelines for public companies.

Financial statements present the raw financial data well, but without an MD&A. An abbreviated financial review in the annual report discusses different revenue components and fundraising results. While this summary falls short of being a complete review, the ADA provides more insight into its financials than the other three non-profits.

The annual report does not thoroughly review research strategy and results. The ADA analyzes research results by the number of publications that result from its research grants or by the financial support that ADA-funded researchers subsequently receive. The evaluation does not focus on cure progress.

The breakdown of research grant allocations between type 1 and type 2 is not published, nor are the allocations to various research areas. This lack of transparency into research grants is somewhat offset by the fact that the ADA makes abstracts describing its funded projects accessible on the website.

Accountability ★★

The Strategic Plan for 2012-2015 outlines several areas of focus. **Most relate to type 2 and involve information, advocacy, and awareness of diabetes**. Each area has specific goals which serve as metrics to measure success in 2015. The goals for research are vague and not directly tied to type 1 cure research or tangible cure progress.

Management's accountability for achieving the stated goals is unclear. There do not appear to be meaningful financial incentives for senior management to achieve the stated goals, nor are there interim milestones to gauge progress along the way. In addition, management did not communicate any self-evaluation following the 2008-11 Strategic Plan, so donors cannot assess management's performance against the previous strategic goals.

Resource Utilization ★

Spending of donor dollars is heavily skewed toward type 2 activities and aligns less with the priorities of a type 1 donor. Although most donors place cure research as their highest priority, funding for information, awareness, and advocacy (primarily type 2 activities) represented 58% of donor contributions.[3] This compares with allocations to type 1 cure research that represented 2% of donor contributions. The ADA funded no Practical Cure research last year.[4]

There are also transparency issues with the ADA's resource utilization. Their allocations of donor contributions are inconsistent with the cure message that is prevalent in the ADA's fundraising activities. In addition, no insight is given into the process for determining resource allocations.

DRIF

Overall STAR Rating: ★+

Strategic Direction ★★

Strategic direction is a strength. A simple mission statement that is consistently presented makes it clear that DRIF's priority is to fund cure research. DRIF clarified its research focus in 2012 when it adopted a formal definition of a cure. This definition is accessible in the annual report and on the website.

Timeliness and Transparency ★

Timeliness of information reporting was problematic as the 2012 annual report was published nearly 14 months after year-end. This is far too late to be of value to donors who wish to evaluate 2012 on a timely basis. In addition, its tax Form 990 and annual financial statements were published after the SEC guidelines for public company filings.

Transparency was mixed in 2012. Communications related to research improved. The introduction of the Diabetes Research Institute's (DRI) BioHub research initiative provides insight into the types of projects that DRIF may fund. Now that the BioHub has been formally launched, we hope to see in-depth quarterly reviews of its progress .

An important weakness of the DRIF continues to be limited transparency into its research funding because it does not publish a list of the specific projects that it funds. By way of comparison, JDRF and the ADA publish the abstracts of the projects they fund on their websites. The DRIF's annual report provides little insight into which specific projects it funds.

Regarding management of the organization, there is little transparency into Board processes involving the appointments of executive officers and Board members, committee composition, and other Board-level matters.

Accountability ★

There appears to be little accountability of management to donors. Management does not publicly disclose short- or long-term goals for either fundraising or tangible cure progress, nor do they disseminate metrics to measure progress in either area. Bonuses were paid to select executives in 2012, but it is unclear what performance metrics were used as the basis for these awards.

Resource Utilization ★★

Spending is largely consistent with the mission of funding cure research. A relatively high proportion (64%) of donor contributions was allocated to type 1 cure research and a smaller 27% to Practical Cure research.[5] We note, however, that an increasing percentage of the budget was allocated to overhead and fundraising efforts versus recent years and that education spending, which is not part of the mission, represented around 5% of donor contributions.[6]

JDRF

Overall STAR Rating: ★★

Strategic Direction ★★

The strategic direction has been shifting away from cure research for the past several years. JDRF has not thoroughly articulated its rationale for the shift in the annual report or other publications, nor has it uniformly represented the change in other forms of communication, including the primary fundraising message, which remains for a cure.

Timeliness and Transparency ★★

Timely reporting is another opportunity for improvement. JDRF's annual report, financial statements, and Form 990 were published later than the SEC's 3-month guidelines for public companies.

Transparency into key issues could be meaningfully enhanced. The annual report and financial statements lack a thorough discussion of financial information that would be useful to donors. A complete MD&A of the financials would include, among other things, a discussion of why investment income swung from a profit of $21 million in 2011 to a loss of $3 million in 2012. No explanation was provided even though this shift directly impacted funding for many mission-related activities.

An in-depth review of the progress of the entire research portfolio would also benefit donors. JDRF funds many hundreds of research projects every year. Detailed reporting on a select few projects or on projects that relate to only one key initiative does not represent a comprehensive analysis of the entire portfolio.

JDRF requires some of the scientists it funds to submit quarterly progress reports. **Stakeholders would benefit from JDRF being held to the same standard by providing a thorough review of its research portfolio every three months**.

JDRF has numerous relationships with commercial enterprises for the development of products across its research spectrum. It discloses very few details about these relationships. Good corporate governance dictates that full disclosure of key details be made available to donors, particularly for the largest corporate relationships.

Accountability ★

Discussion of goals lacks specificity which makes it difficult to assess performance. The annual report outlines a vision of the future that includes several broad objectives. However, there are no time goals associated with this vision nor does the JDRF articulate the strategy by which it intends to make this vision a reality.

JDRF's periodic research updates present near-, intermediate-, and long-term objectives in general terms with few specifics relating to time goals or interim milestones. If specific goals, including timelines, were widely disseminated, it would facilitate the assessment of management's performance and inform donor expectations.

Resource Utilization ★★

From a corporate governance perspective there are significant deficiencies in JDRF's allocation of resources. Spending could be much better aligned with donors' priorities. JDRF directs just 3% of donor contributions to Practical Cure research, yet donors value this type of research above any other.[7] Furthermore, JDRF has directed more dollars to public education in recent years, reaching 22% of donor contributions in 2012.[8] Despite the large sums, there is very little discussion of the rationale for this level of support or disclosure of what specific educational purposes this money is being used for.

Joslin

Overall STAR Rating: ★

Strategic Direction ★

Strategic direction is clear in the mission statement which is consistently stated across its publications and the website. However, no clear strategic focus for its research program has been communicated. Strategies involving the main activities within the mission are typically discussed in general terms.

Timeliness and Transparency ★

There are select major issues with the timely dissemination of information. The publication of documents ranges from very timely in the case of the financial statements (published within three months of year end) to a long overdue annual report. **The most recent annual report is from the year 2009, almost four years ago**. Publication of the Form 990 was nearly eleven months after fiscal year end, well beyond the SEC's public company guidelines.

Transparency is another area where there is significant opportunity for improvement. Patient care activities are widely communicated, but there is a lack of transparency into type 1 and type 2 research strategies, spending on the type 1 and type 2 research programs, and the type 1 cure research effort. Moreover, there is no comprehensive research portfolio review. The fact that the financial statements and Form 990 are not accessible from the website compounds the transparency issue.

The reporting of Functional Expenses (a detailed breakdown of the major expense categories) is far less detailed for Joslin than for the other three diabetes non-profits. Similar to the other three organizations, Joslin does not provide a thorough evaluation of its performance by way of an MD&A commentary.

There is no transparency involving the Board of Trustees appointments, committee composition, or the process to determine executives' compensation.

Accountability ★

Accountability is a considerable weakness. Joslin has not publicly disseminated goals for research and other mission activities or any metrics with which to measure progress toward such goals. Also, there is no self-evaluation by management regarding performance. **With no annual report or other publication to candidly assess performance, no goals, and no metrics to gauge success, management would appear to be unaccountable to donors.**

Resource Utilization ★

Important deficiencies may also exist in the alignment of spending with donor priorities. No rationale or guidance is provided on precisely where donor contributions are directed. The clinic incurred a meaningful operating loss in 2012 which required utilizing funds from donations or other revenue sources to offset the operating loss.

Summary and Conclusion

Management is accountable to stakeholders, particularly donors, to implement sound governance because the non-profits depend upon donations to pursue their mission. Good corporate governance leads the organization to use resources in a more effective and focused pursuit of goals. Critical to achieving sound governance is the timely reporting of information that is vital to understand and evaluate the organization. A more transparent and communicative organization better informs donors thereby allowing them to make more educated giving decisions.

The overall ratings for the four non-profits indicate that there is substantial room for improvement. The average rating for each indicates that there are systemic deficiencies in corporate governance. Although there are pockets of strength for each organization, these are overshadowed by weaknesses in each of the STAR elements. Fundamental improvements in many areas would benefit stakeholders.

The following enhancements to governance practices would yield material benefits for donors and other stakeholders:

- publish annual financial statements, the annual report, and Form 990 within 3 months of year-end
- incorporate a thorough Management's Discussion & Analysis (MD&A) of operations
- increase the frequency of research updates to at least quarterly and improve their comprehensiveness
- communicate short- and long-term goals including those for cure development
- hold the organizational leadership accountable to achieving these goals
- align spending with the message used to solicit donations
- increase the transparency into Board-level processes such as determining executives' compensation

Improved corporate governance would better align the allocation of resources with the priorities of donors. Greater transparency into goals, research strategies, and progress reports for all mission-related activities would also result in a more informed donor base. This, in turn, would result in increased donations and provide greater resources with which to fund research and other mission related activities.

Appendix A

STAR Review Guidelines

★★★★★: Meets all of, and goes beyond, the Best Practices of Public Companies' Corporate Governance

★★★★: Meets all of the Best Practices of Public Companies' Corporate Governance

★★★: Meets most of the Best Practices of Public Companies' Corporate Governance

★★: Meets some of the Best Practices of Public Companies' Corporate Governance

★: Meets a few of the Best Practices of Public Companies' Corporate Governance

Best Practices of Public Companies' Corporate Governance:

Strategic Direction

→ mission and strategic direction clearly and consistently communicated
→ priorities clearly identified
→ changes in strategic priorities fully communicated

Timeliness and Transparency

Timeliness (following the SEC guidelines for public companies)

→ annual report, financial statements, and Form 990 published within 3 months of year end

Transparency

→ Management's Discussion and Analysis of operating results and financial statements thoroughly communicated
→ research strategy and results clearly defined and comprehensively communicated
→ processes by which the Board performs essential tasks (e.g. determining Board membership, committee composition, executive compensation, etc.) publicly disclosed

Accountability

→ short- and long-term goals clearly articulated
→ performance metrics identified and defined
→ performance against goals candidly assessed

Resource Utilization

→ spending consistent with the mission
→ spending aligned with donor priorities and the messaging used to solicit donations
→ rationale for spending thoroughly communicated

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Endnotes

1. JDCA reports, "Do Donors Feel That Practical Cure Research Is Important?," January 31, 2013; and "Are Fundraising Event Proceeds Used for the Purpose for Which the Money Was Solicited?" October 25, 2013.

2. JDCA report, "How Much Practical Cure Research Do the Major Type 1 Non-Profits Fund?," May 20, 2013.

3. JDCA report, "Do Donors Feel That Practical Cure Research Is Important?," January 31, 2013.

4. JDCA reports, "How Much Practical Cure Research Do the Major Type 1 Non-Profits Fund?," May 20, 2013; and "Non-Profit Revenue and Spending Review for Fiscal Year 2012," June28, 2013.

5. JDCA report, "How Much Practical Cure Research Do the Major Type 1 Non-Profits Fund?," May 20, 2013.

6. DRIF data

7. JDCA report, "How Much Practical Cure Research Do the Major Type 1 Non-Profits Fund?," May 20, 2013.

8. JDRF data

Analyst Certification

The JDCA analyst responsible for the content of this report certifies that with respect to each organization covered in this report: 1) the views expressed accurately reflect his own personal views about the organizations; and 2) no part of his compensation was, is, or will be, directly or indirectly, related to the specific views expressed in this research report.

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