

**Kathleen McGrath**

Senior Research Analyst

212.308.7433

kmm@thejdca.org

**Organizations of  
Focus:**

American Diabetes  
Association (ADA)

Diabetes Research  
Institute Foundation  
(DRIF)

JDRF

Joslin Diabetes  
Center (Joslin)

# Juvenile Diabetes Cure Alliance

March 16, 2012

## Improved Corporate Governance Begins with Frequency, Timeliness, and Notification

### *Conclusions:*

- Not-for-Profit (NFP) filings differ tremendously from Public Company (PC) filings in terms of frequency, time allowed for publication, and notification processes.
- In an effort to provide improved transparency at NFPs, we believe SEC reporting standards should serve as a baseline for the foundations' annual updates with a preference for the addition of quarterly updates.
- We believe improved standards would 1) serve as a self-reflection mechanism for NFP leaders to better align stated goals with actual progress; 2) provide improved transparency which we believe would result in an increased donor base; and 3) better align the use of contributions with donor intentions.

### **Our Mission:**

**To direct donor contributions to the charitable organizations that most effectively fund research with the goal of delivering a type I Practical Cure by 2025**

The JDCA and its employees seek to maintain independence from organizations covered in its research reports. The JDCA and its employees are free from conflicts of interest, receive no compensation from the organizations discussed in its reports, and seek to avoid any relationships with any organizations that could influence its objectivity and independence. Please see Analyst Certification and Other Disclosures at the end of this report

### Information on the Corporate Governance Series

We believe that a lack of transparency exists at not-for-profit (NFP) foundations and that the four diabetes NFPs that we actively follow would benefit from providing reports that follow SEC standards. Contributions serve as the main source of revenues at most of the major type 1 NFPs and the scope of fundraising dollars has reached levels commensurate with public companies (PCs) that seek and maintain capital influxes. Furthermore, NFPs require a recurring annual stream of donations to finance a large portion of their operations and research projects/grants. Given the size of NFPs' operations and their reliance on contributions as the primary source of revenues, **we believe the organizations need to provide more frequent, timely updates** to document progress and explain the allocation of funds relative to the course of action needed to achieve stated goals. We view contributors to the NFPs as stakeholders as they have a vested interest in how their dollars are utilized and look for a return on their donation (i.e. investment) in the form of progress. Therefore, we believe the NFPs should be held to an improved standard equivalent to a PC.

### Thesis

NFP and PC filings differ tremendously in terms of frequency, time allowed for publication, and notification processes. We believe that stakeholders in not-for-profit organizations should be provided with more frequent, timely updates and should receive notification upon publication. We believe donors would be better served by implementing the following standards for an annual filing with a preference for the addition of quarterly updates.

- 90-day filing time frame
- Publication alerts in the form of press releases or emails to subscribed contributors for all filings
- Ease of access on the NFP website
- Library of filings on the NFP website encompassing a five-year time frame at minimum

As stated in our Initiation Report on the topic of corporate governance, the JDCA feels that existing and potential NFP stakeholders would be better served by improved communication frequency, timeliness, and disclosure requirements that more closely mirror the SEC guidelines used by PCs. We believe these actions would 1) serve as a self-reflection mechanism for NFP leaders to better align stated goals with actual progress; 2) provide improved transparency, which we believe would result in an increased donor base; and 3) better align the use of contributions with donor intentions.

### What is the Purpose of Frequency, Timeliness, and Notification?

Publications serve as the primary source for information used to analyze a public company's past performance, current situation, and future outlook. These reports allow stakeholders to monitor their investment and serve as an additional means of oversight beyond that provided by the SEC. The SEC established reporting guidelines

for PCs in order to provide stakeholders with transparency into the organization and to remove the conflicts that can arise when management strays from stakeholder agendas. Frequency, timeliness, and notification standards serve the following purposes:

- Frequent updates allow stakeholders to assess operations and progress toward stated objectives. Additionally, compilation and review of the reports by management serves as a self-corrective tool to maintain focus on the corporate mission. Standardized annual and quarterly filings are supplemented by ad hoc updates for material events that impact the stakeholders' investment. PCs also file a Proxy Statement that includes thorough corporate governance details related to the executives and the board in charge of decision making.
- In addition to frequent reports, the SEC has guidelines in place for the time allowed between the end of the period and the subsequent report submission. These standards ensure that stakeholders receive sufficiently up-to-date information about what is taking place at the company.
- Lastly, notification serves to alert stakeholders about the availability of new publications so as to ensure that all interested parties are kept abreast of the most up-to-date information. Notification does away with the need to constantly monitor the company and SEC websites for new publications.

### NFP versus PC Filings

#### **Public Company Standards**

SEC rules require public companies to update stakeholders a minimum of four times a year through in-depth annual (10K) and quarterly (10Q) filings. The publication of an 8K occurs when a press release is published or any other material event occurs that requires disclosure on a more timely basis than through the 10K or 10Qs. Additionally, a Proxy Statement is filed once a year. Quarterly reports must be issued within 40-45 days of the end of the quarter, and annual reports must be filed within 60-90 days of the close of the fiscal year, with the exact timing dependent on the market capitalization of the public company. Additionally, notifications are sent by the company and/or the SEC upon publication of all of the aforementioned filings, allowing for immediate review by interested parties. The PC and SEC websites maintain a library of all filings that are easily accessible.

#### **Not-for-Profit Standards**

Form 990 filed with the IRS serves as the most comprehensive update provided by the NFP. IRS rules require the filing of Form 990 within 4½ months of the exempt organization's fiscal year end, but organizations may take up to 10½ months if an extension is authorized by the IRS. Besides that, a short annual report is published with general information related to business objectives, and an additional report containing financial information is issued and intended for stakeholders. However, the annual-only details are compiled in two separate reports (the financial statements and the Form 990) that lack timeliness and have no publication alert and no quarterly updates are provided by the NFPs.

## What are the 4 Major Diabetes Foundations Doing?

### American Diabetes Association (ADA):

#### → **Frequency**

- The ADA provides updates annually and lacks quarterly reports. The website supplies the most recent five years of available publications.

#### → **Timeliness**

- The most recent fiscal year ended December 31, 2011.
- Form 990 has not been posted for 2011. The ADA has filed with the IRS for an extension for submitting Form 990 for the last five years of available filings. For the last two years submission occurred in mid-November, the end of the 10.5 month extension period. Given the trend in utilizing extensions, we would not expect to see an annual filing for fiscal 2011 until the fall of 2012 which is in the fourth quarter of fiscal year 2012.
- The Annual Report has not been provided for 2011, but a 2012-2015 Strategic Plan is available on the website.
- Financial Statements have not been posted for 2011.

#### → **Notification**

- No notification is sent out to alert stakeholders about the release of annual financial publications. Available documents are posted on the website at [www.diabetes.org/about-us/annual-report-and-strategic-plan.html](http://www.diabetes.org/about-us/annual-report-and-strategic-plan.html)

### Diabetes Research Institute Foundation (DRIF):

#### → **Frequency**

- The DRIF provides updates annually and lacks quarterly reports. The website only supplies Form 990, Annual Report, and Financial Statements for the most recent fiscal year end.

#### → **Timeliness**

- The most recent fiscal year ended June 30, 2011.
- Form 990 has been posted for 2011. The DRIF signed the filing on November 16, 2011 which is in line with the 4.5 month filing requirement without the use of an extension.
- The Annual Report has not been provided for 2011. The 2010 report is available on the DRIF website.
- Financial Statements have been posted for 2011.

#### → **Notification**

- No notification is sent out to alert stakeholders to annual financial publications. Available documents are posted on the website at [www.diabetesresearch.org/page.aspx?pid=270](http://www.diabetesresearch.org/page.aspx?pid=270)

### Juvenile Diabetes Research Foundation (JDRF):

#### → **Frequency**

- The JDRF provides updates annually and lacks quarterly reports. The website supplies the most recent six years of Form 990s, the most recent five years of Financial Reports, and the most

recent three years of Annual Reports. However, the 2011 Annual Report has not been linked to the filing page on the website.

→ **Timeliness**

- The most recent fiscal year ended June 30, 2011.
- Form 990 has been posted for 2011. The JDRF has filed with the IRS for extension for submitting Form 990 for the last five years of available filings with filing occurring near February for an average date of submission roughly 7.5 months following the fiscal year end.
- The Annual Report has been provided for 2011.
- Financial Statements have been posted for 2011.

→ **Notification**

- No notification is sent out to alert stakeholders to annual financial publications. Available documents are posted on the website at [www.jdrf.org/index.cfm?page\\_id=100998](http://www.jdrf.org/index.cfm?page_id=100998)

Joslin:

→ **Frequency**

- Joslin provides updates annually and lacks quarterly reports. Joslin's Form 990 from fiscal year 2010 states the Form 990 is available upon request directly through the foundation. There is no archive of current or past reports on the company website. Stakeholders wishing to review current or past Form 990s can utilize the services of third-party websites to access Joslin's IRS filings.

→ **Timeliness**

- The most recent fiscal year ended September 30, 2011.
- Form 990 has not been posted for 2011. Joslin has filed with the IRS for an extension for submitting Form 990 for the last three years of available reports with submission to the IRS occurring in mid-August at the end of the 10.5 month extension period. Given this trend, we would not expect to see an annual filing for fiscal 2011 until the late summer of 2012 which is in the fourth quarter of fiscal year 2012.
- Only the 2009 Annual Report (fiscal year ended September 30, 2009) is available on the Joslin website. We note that the publication for 2010 has not yet been provided—Joslin is currently in their 2012 fiscal year.
- Financial Statements are available for fiscal 2011, but they must be acquired by contacting Joslin directly and have not been posted on the website.

→ **Notification**

- Notification is sent out to alert stakeholders for annual financial publications. Available documents are posted on the third-party websites such as [www.guidestar.com](http://www.guidestar.com) that provide file archive services for the public to access NFP filings.

### Summary and Conclusion

NFP publications are severely lacking frequency, timeliness, and notification for stakeholders relative to PC standards.

→ **Frequency**

- Reports are only filed on an annual basis for NFPs in the form of IRS Form 990, the Financial Statements, and the Annual Report without quarterly updates.
- The ADA and JDRF websites contain the most filings for prior years. The DRIF only supplies reports/filings for the most recent year. Joslin does not supply the filings on their website; finding them necessitates the use of a third-party charitable organization data provider.

→ **Timeliness**

- Filing for an extension has become the industry standard among the majority of dominant diabetes foundations.
- The DRIF is the most timely while both the ADA and Joslin commonly submit Form 990 at the end of the 10.5 month maximum time frame.

→ **Notification**

- No notifications for financial publications exist for any of the four NFPs covered. Navigation on company websites tends to be difficult and the website search engines do not return consistent results when looking for key words such as Form 990, Annual Report, and Financial Statement.

As stated in the introductory report, “Utilizing Corporate Governance to Align Agendas,” the JDCA feels that existing and potential NFP stakeholders would be better served by improved communication frequency, timeliness, and disclosure requirements that more closely mirror the SEC guidelines used by PCs. We believe these actions would 1) serve as a self-reflection mechanism for NFP leaders to better align stated goals with actual progress; 2) provide improved transparency, which we believe would result in an increased donor base; and 3) better align the use of contributions with donor intentions.

Please see the following exhibits for the components of annual and quarterly updates per the SEC, and Form 990 per the IRS. We will continue to address the variance in filing requirements in greater detail, including the procedures that the ADA, DRIF, JDRF, and Joslin follow on an individual basis, in the ongoing series of follow-on reports. For additional details on the corporate governance series, please refer to our introductory piece “Utilizing Corporate Governance to Align Agendas,” available at:

<http://www.thejdca.org/wp-content/uploads/2012/03/Utilizing-Corporate-Governance-to-Align-Agendas.pdf>

## Improved Corporate Governance Begins with Frequency, Timeliness, and Notification

### Exhibit 1: Form 10K SEC Requirements (Annual Filing)

<b>Part 1</b>	
Item 1	Business
Item 1A	Risk Factors
Item 1B	Unresolved Staff Comments
Item 2	Properties
Item 3	Legal Proceedings
Item 4	Mine Safety Disclosures
<b>Part 2</b>	
Item 5	Market for Registrant's Common Equity, Related Stockholder Matters and Issuer Purchases of Equity Securities
Item 6	Selected Financial Data
Item 7	Management's Discussion and Analysis of Financial Condition and Results of Operations
Item 7A	Quantitative and Qualitative Disclosures About Market Risk
Item 8	Financial Statements and Supplementary Data
Item 9	Changes in and Disagreements With Accountants on Accounting and Financial Disclosure
Item 9A	Controls and Procedures
Item 9A (T)	Controls and Procedures
Item 9B	Other Information
<b>Part 3</b>	
Item 10	Directors, Executive Officers and Corporate Governance
Item 11	Executive Compensation
Item 12	Security Ownership of Certain Beneficial Owners and Management and Related Stockholder Matters
Item 13	Certain Relationships and Related Transactions, and Director Independence
Item 14	Principal Accounting Fees and Services
<b>Part 4</b>	
Item 15	Exhibits, Financial Statement Schedules
<b>Signatures</b>	

Source: sec.gov

### Exhibit 2: Form 10Q SEC Requirements (Quarterly Filing)

<b>Part 1 - Financial Information</b>	
Item 1	Financial Statements
Item 2	Management's Discussion and Analysis of Financial Condition and Results of Operations
Item 3	Quantitative and Qualitative Disclosures About Market Risk
Item 4	Controls and Procedures
Item 4T	Controls and Procedures
<b>Part 2 - Other Information</b>	
Item 1	Legal Proceedings
Item 1A	Risk Factors
Item 2	Unregistered Sales of Equity Securities and Use of Proceeds
Item 3	Defaults Upon Senior Securities
Item 4	Mine Safety Disclosures
Item 5	Other Information
Item 6	Exhibits
<b>Signatures</b>	

Source: sec.gov

**Exhibit 3: Form 990 and List of Accompanying Schedules**

<b>Form 990 Return of Organization Exempt From Income Tax</b>	
Part 1	Summary including mission statement/number of voting members of the governing body/total employees/total volunteers/revenue/expenses/net assets and liabilities
Part 2	Signature block
Part 3	Statement of program service accomplishments
Part 4	Describe three largest program services by expenses
Part 5	Checklist of required schedules
Part 6	Governance, Management and Disclosures
Part 7	Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors
Part 8	Statement of Revenue
Part 9	Statement of Functional Expenses
Part 10	Balance Sheet
Part 11	Reconciliation of Net Assets
Part 12	Financial Statements and Reporting
<b>Schedules</b>	
A	Public Charity Status and Public Support
B	Schedule of Contributors
C	Political Campaign and Lobbying Activities
D	Supplemental Financial Statements
E	Schools
F	Statement of Activities Outside the United States
G	Supplemental Information Regarding Fundraising or Gaming Activities
H	Hospitals
I	Grants and Other Assistance to Organizations, Governments, and Individuals in the United States
J	Compensation Information
K	Supplemental Information on Tax Exempt Bonds
L	Transactions with Interested Persons
M	Noncash Contributions
N	Liquidation, Termination, Dissolution, or Significant Disposition of Assets
O	Supplemental Information to Form 990 (all the items that require further explanation)
R	Related Organizations and Unrelated Partnerships

Source:  
IRS.gov

# Juvenile Diabetes Cure Alliance

14 East 60th Street  
Suite 208  
New York, NY 10022

Phone: 212.308.7433  
E-mail: [info@thejdca.org](mailto:info@thejdca.org)  
[www.thejdca.org](http://www.thejdca.org)

## **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.

## **Other Disclosures**

All Rights Reserved. The JDCA and its employees will not be liable for any claims or lawsuits from any third parties arising from the use or distribution of this document. This report is for distribution only under such circumstances as may be permitted by applicable law.

All information expressed in this document was obtained from sources believed to be reliable and in good faith, but no representation or warranty, express or implied, is made as to its accuracy or completeness. All information and opinions are current only as of the date of this report and are subject to change without notice