

# Juvenile Diabetes Cure Alliance

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**Peter Miselis, CFA**

Director of Research Analysis

212.308.7433

pdm@thejdca.org

## What Do Donors Expect from the Major Type 1 Non-Profits?

### *Conclusions:*

- Donors have very high performance expectations from the major type 1 non-profits that they support. Donors expect the main charities to pursue cure research with focus and urgency.
- Donor expectations related to cure research involve three main areas: prioritization of cure work; speed to results; and transparency of communication.
- The non-profits meet some key donor expectations, but significant gaps exist between what donors expect from the organizations in their cure development efforts and what the non-profits deliver
- Implementing a Practical Cure research initiative would more closely align the non-profits' cure development efforts with many fundamental expectations of donors

### **Organizations of Focus:**

American Diabetes Association (ADA)

Diabetes Research Institute Foundation (DRIF)

JDRF

Joslin Diabetes Center (Joslin)

### TAKE ACTION NOW

Ensure it's for a Cure



✓ Specify for Practical Cure research.  
Use our letter at [www.thejdca.org/](http://www.thejdca.org/)

✓ Call us for an advisory meeting at  
212-308-7433

The JDCA recently sponsored a survey to better understand donors’ expectations of the diabetes non-profits. This report examines what donors expect of the non-profits’ type 1 cure development efforts, particularly the non-profits’ cure research funding and communications with donors.

A key finding is that donors have very high performance expectations of the type 1 organizations that they support. In particular donors expect the non-profits to apply focus and urgency to curing type 1, a goal set forth by each of the non-profits’ missions.

The report also compares donor expectations to what is being delivered by the organizations. We point out the places where expectations are met and provide suggestions to improve areas where donor expectations are not met.

The survey utilized an independent, third-party company to poll a statistically valid number of adults who either have type 1 themselves or have a family member or close friend with type 1. Respondents were geographically dispersed across the United States and concentrated within the age range of 22-55. All respondents have directly donated to a diabetes non-profit or participated in a fundraising event, eighty-five percent within the past two years.

### **Three Key Areas of Donor Expectations Involving Cure Research**

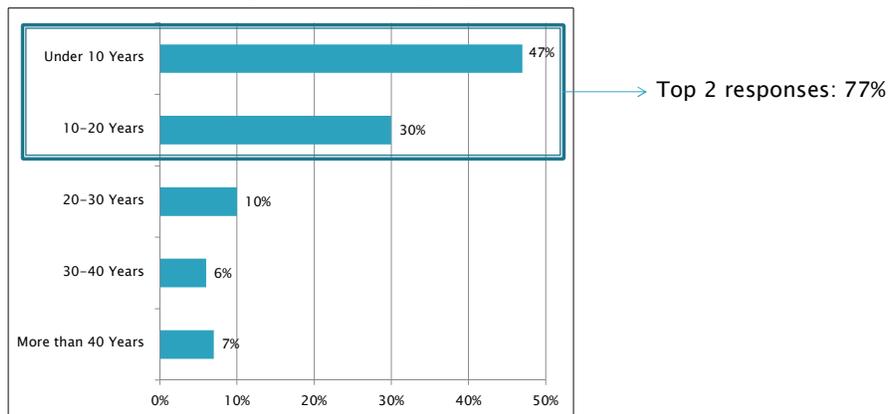
#### ***I. Cure Research Allocations***

Research is the largest area of spending for the four non-profits combined, and cure research receives more funding than any other research category.<sup>1</sup> This spending focus is aligned with donors’ preferences as eighty percent of donors rank cure research as their highest priority.<sup>2</sup> Among those donors who prioritize cure research, 9 out of 10 want their donations used for projects that have the best chances of delivering a cure in the foreseeable future. However, as indicated in our most recent report, only an extremely small 2% of donor contributions to the four major non-profits combined are directed to Practical Cure research, the type of cure research that could most expeditiously deliver a cure for type 1.<sup>3</sup>

#### ***II. Speed to a Cure***

It is no surprise that donors want a cure as soon as possible and expect that the organizations who receive their gifts are working with focus, clarity of purpose, and urgency. Survey results show that donors expect that the cure for type 1 will be delivered within the next twenty years and that a specific goal is in place to deliver this objective. Specifically, survey data indicates that 77% of donors “realistically expect” a cure within the next twenty years, as shown in Exhibit A:

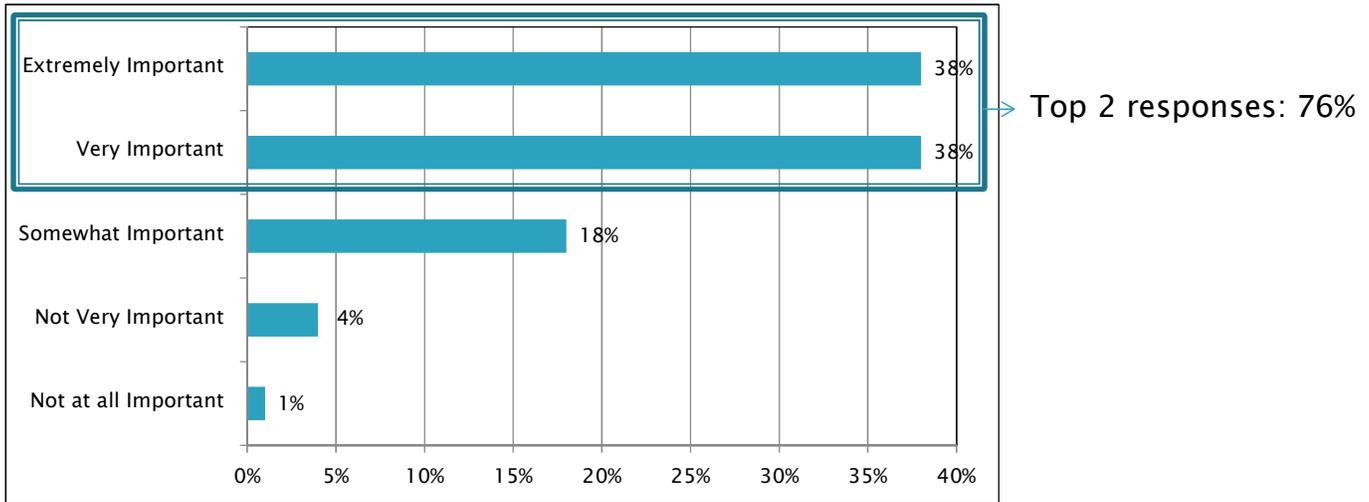
**Exhibit A: When do you realistically expect to have a cure for type 1 diabetes?**



Source: JDCA Research

The donor community also believes that having a clear time goal for developing a cure is important. Seventy-six percent of respondents feel that it is either extremely important or very important to have a clear time goal for developing a cure. Please see Exhibit B for the survey data.

**Exhibit B: How important to you is it that your primary type 1 diabetes charity/research center has a clear time goal for developing a cure?**



Source: JDCA Research

**Despite the importance that the donor community places on a time goal, none of the four major type 1 non-profits has established one.** Creating a time goal would focus research efforts, direct funding to the projects that are designed to deliver a cure within the desired timeframe, and probably speed the pace of cure development up to donor expectations. Embracing a time goal does not guarantee that a cure will be delivered by a specified date. However, the absence of a time goal results in scattered cure development efforts and justifies the funding of research that has no real potential to cure individuals who are now living with type 1.

**Although the majority of the donor community expects to have a cure within the next twenty years, the cure funding strategies of most non-profits do not align with this expectation.** Practical Cure research targets a cure within this twenty year timeframe (please see the Appendix on page 5 for a definition of a Practical Cure). Therefore, **if all the major type 1 charities adopted a Practical Cure research initiative and directed significant funding to this type of research it would better align cure efforts with donors' expectations.**

**III. Transparent and Timely Information Sharing**

Donors have high expectations for how they would like the non-profits to communicate with them. Survey results reveal several insights which are depicted in Exhibit C.

**Exhibit C: How important to you is it that your primary type 1 diabetes charity/research center:**

	(% Respondents) Extremely or Very Important
Provides a clear definition of a cure	90%
Shares successes toward cure progress	90%
Shares setbacks to cure progress	79%
Shares key research results in a timely manner	89%
Clearly and thoroughly communicates how it uses donor contributions	92%
Clearly communicates its annual budget-revenue, donations, expenses, etc.	83%
Clearly communicates strategies and goals	89%

Source: JDCA Research

When comparing what is important to donors with what the non-profits are delivering, the results are mixed in terms of the information that the non-profits share about their cure development efforts. Nine out of ten of those surveyed say that clearly defining the targeted cure outcome is either extremely important or very important to them. **Despite the importance that the donor community assigns to defining the cure outcome, only one of the four major non-profits, the DRIF, has defined the cure that it seeks.**

**Donors also feel that it is important for the non-profits to communicate both research successes and setbacks and to do so in a timely manner.** For the most part the charities effectively communicate research successes in a timely manner by posting favorable cure developments on their websites. In contrast, communications involving research setbacks and the implications for future research are less transparent. In addition, the non-profits periodically host seminars for donors that highlight research progress and cure development strategies, with far less emphasis on challenges and setbacks.

A third area where communications and transparency are important to donors involves reporting on issues of corporate governance, including the organization’s finances, how donor contributions are utilized, and the organizations’ research strategies and goals. Here too, the results are mixed. We believe that the non-profits effectively report only a portion of their financial performance. For a more detailed discussion of the non-profits’ corporate governance practices, please see our July 2012 report, “How Do the Major Type 1 Non-Profits Rate on Corporate Governance Issues?”. We will be updating these ratings in a forthcoming publication.

There are opportunities to meaningfully improve transparency into the non-profits’ operational performance and to more thoroughly communicate cure progress. We believe that **the non-profits could significantly enhance the thoroughness of their financial reporting and clarity into the use of donor contributions.** This would result in a more informed donor base and would more closely align with donors’ expectations.

**Summary and Conclusions**

The donor community has high performance expectations of the type 1 charities they support, particularly with respect to cure development efforts. Donor want a cure as soon as possible and expect that their donations will be used to fund research that has the potential to deliver this result in the foreseeable future.

Donors also have many other fundamental expectations regarding cure efforts and how they wish the non-profits to engage with them, including establishing a time goal for cure development and defining the cure outcome that the research seeks to develop. In addition, communications involving cure progress and providing transparency into the

operations and financial performance of the organization are meaningful to donors. Importantly, **implementing a Practical Cure research initiative would much more closely align the non-profit's cure development efforts with many key donor expectations.**

Cure-minded donors can ensure that some of their expectations will be met by requiring the charity to use their donations to only fund Practical Cure research. The JDCA has developed tools to assist cure donors with this endeavor. A sample Stipulation Letter can be found at <http://www.thejdca.org/wp-content/uploads/2012/11/Donor-Action-Letter.pdf>). Attaching this letter to your donation will ensure that it is used only for Practical Cure research.

## **Appendix A: JDCA Definition of a Practical Cure**

**A Practical Cure is outcome based and permits a 'like-normal' lifestyle**



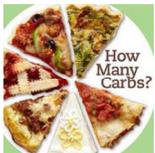
### ***Minimal Monitoring***

- ✓ Does not require blood glucose monitoring beyond once a week
- ✓ A1C levels 5-7%



### ***Sleep Worry Free***

- ✓ Allows patients to sleep care free



### ***Free Diet***

- ✓ Does not restrict a patient's diet
- ✓ Does not require carb counting



### ***Minimal Side Effects***

- ✓ Best case: Zero side effects
- ✓ Acceptable case: Insignificant side effects



### ***Reasonable Meds***

- ✓ If pharmacological, an easily managed regime



### ***Fast Recovery***

- ✓ If surgical, less than 72 hours recovery

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)

### **Endnotes**

1. JDCA report, "Review of Expense Categories of the Major Type 1 Non-Profits," March 8, 2013.
2. JDCA report, "Do Donors Feel That Practical Cure Research Is Important?" January 31, 2013.
3. JDCA report, "How Much Practical Cure Research Do the Major Type 1 Non-Profits Fund?" May 20, 2013.

### **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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