The Voice of the Donor for a Cure

# **Juvenile Diabetes Cure Alliance**

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# **Shrinking Funding Of Type 1 Cure Research By the Four Major Non-Profits**

#### **Conclusions:**

- ightarrow Combined annual funding of type 1 cure research grants by the four major non-profits decreased by 44% from 2008-11
- → Concurrently, allocations to type 1 cure research grants as a percentage of total research grants declined from 56% to 41%, a decrease of 15 percentage points
- → The primary fundraising messages, which focus almost solely on a cure, are inconsistent with actual research grant allocations and recent funding trends

## Organizations of Focus:

American Diabetes Association (ADA)

Diabetes Research Institute Foundation (DRIF)

**JDRF** 

Joslin Diabetes Center (Joslin)

#### **Our Mission:**

To direct donor contributions to the charitable organizations that most effectively fund research with the goal of delivering a type 1 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

#### Shrinking Funding Of Type I Cure Research By the Four Major Non-Profits

Recent JDCA reports examined the level of type 1 cure research funding by the four major non-profits in the past year and compared it with allocations to non-cure activities over the same time period. That data indicated that type 1 cure research represented a small percentage of the non-profits total expenses. We now take a slightly longer term view and analyze the trend in funding for type 1 cure research in comparison to the organizations' funding of other research activities over the past four years .

We estimate that contributions to the four major type 1 non-profits combined were \$370 million in 2011, which testifies to the donor community's passionate support for type 1 cure research.<sup>2</sup> The diabetes charitable organizations benefit from this robust degree of financial support which makes large type 1 cure development efforts possible.

The JDCA compiled information related to type 1 cure research using data supplied by the non-profits, which we have supplemented with JDCA estimates in select instances where an organization did not provide the information. The data presented in the following graphs is striking, in our view, and leads to very disappointing conclusions for donors that contribute for the reason of a type 1 cure.

Exhibit A depicts the four charities' allocations to type 1 cure research for the period 2008-11. Since the non-profits have not defined a cure for type 1, we believe that their reported cure research allocations fall short of the JDCA's definition of Practical Cure research. The JDCA does not consider prevention research to be cure research, however, the charities do not segregate prevention allocations from cure allocations in their public reporting. Therefore, for the purposes of our analysis in this report, we have utilized cure/prevent research allocations as reported by the non-profits.

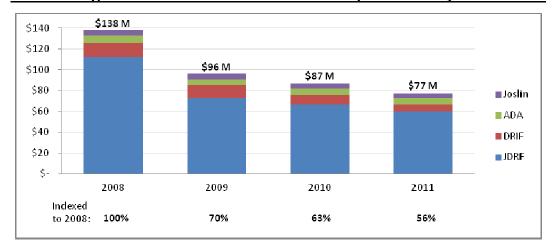


Exhibit A: Type 1 Cure Research Grant Allocations By the Four Major Non-Profits

Source: Charity and Foundation data and JDCA estimates. Please see endnote 3 for a more complete description.

#### **Exhibit A Summary Observations**

- → Total combined type 1 cure research grants for the four non-profits decreased dramatically from 2008-11, from \$138 million to \$77 million, a decline of 44% according to JDCA estimates
- ightarrow Combined type 1 cure research grants for the four non-profits declined in every year from 2008-11
- → Funding of type 1 cure research was lower in 2011 than in 2008 for each of the four organizations

→ The percentage decrease in type 1 cure research grant allocations varied by individual organization and ranged from an estimated decline of 14% to a decline of 50% for the period

External forces have exerted negative influences on the level of absolute dollars directed to type 1 cure research. The financial crisis that began in 2008 adversely affected philanthropy in general, including donations to the diabetes charities.<sup>4</sup> The graph in Exhibit B attempts to eliminate the effect of external economic influences by focusing on type 1 cure research expenditures as a percentage of total research grants instead of the absolute dollar expenditures. As a reminder, Total Research Grant figures include cure, glucose control, and complications research.

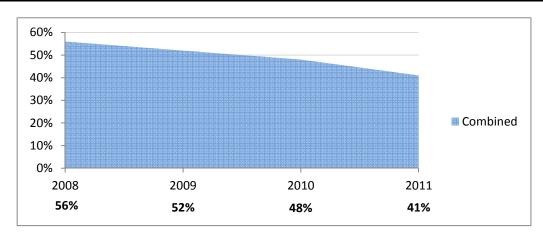


Exhibit B: Four Non-Profits' Combined Type 1 Cure Research Grants as a % of Total Research Grants

Source: Charity and Foundation data and JDCA estimates. Please see endnote 5.

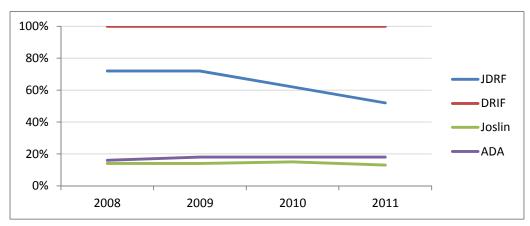
### **Exhibit B Summary Observations**

- → Type 1 cure research spending as a percentage of the combined research grants decreased from an estimated 56% in 2008 to an estimated 41% in 2011——effectively, this means that in 2008 nearly six out of every ten research dollars were spent on a type 1 cure, whereas in 2011 that number decreased to only four out of ten
- → The 41% of research spending that is allocated to type 1 cure research grants is overshadowed by the remaining 59% that is directed to either treatments (glucose control and complications) or, in the case of Joslin and the ADA, type 2 research
- → It is our observation that cure research has become a lower funding priority for at least one of the four major charities

#### Why Has Type 1 Cure Research Spending Declined?

Changes in research priorities may have occurred within the individual organizations and may help to explain some of the decrease in type 1 cure research funding. Exhibit C graphs the individual charities' allocations to type 1 cure research grants as a percentage of their total grants and helps to identify the relative importance of type 1 cure research within each organizations' funding priorities.

Exhibit C: Type 1 Cure Research Grants as a % of Total Research Grants



Source: Charity and Foundation data and JDCA estimates. Please see endnote 6.

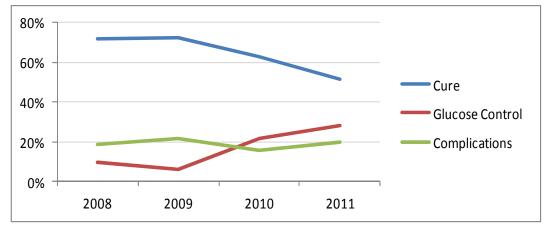
## **Exhibit C Summary Observations**

- → JDRF experienced a dramatic decrease in its allocation to cure research grants from 72% to 52% from 2008-11
- → DRIF has the highest and steadiest allocation at 100%, as it states that all of its research funding is directed to cure research.
- → Both the ADA and Joslin have remained relatively steady, however, their percentages are low when compared with the DRIF or JDRF

JDRF is easily the largest funder of type 1 cure research among the four non-profits we cover. Given its disproportionate weighting among the four, JDRF's decrease in cure research funding is the primary reason why the total combined type 1 cure research grants decreased from 2008 to 2011.

Examining JDRF's allocations may reveal clues about the decrease in total type 1 cure research grants. Exhibit D graphs JDRF's division of total research grants among cure, glucose control, and complications research for the period 2008-11.

**Exhibit D: JDRF Research Grant Allocations (%)** 



Source: JDRF Research Funding Fact Sheets for 2008-2011 including JDCA estimates for 2011.

Please see footnote 7 for a description of the JDCA estimates.

#### Shrinking Funding Of Type I Cure Research By the Four Major Non-Profits

#### **Exhibit D Summary Observations**

- → Cure research grants decreased 20 percentage points from 72% to 52%
- → Combined allocations to Glucose Control and Complications (Treatments) correspondingly gained 20 percentage points from 28% to 48%
- → Glucose Control alone increased from 10% to 28%

We note that JDRF's growing commitment to Treatments is not supported by the heavily cure-oriented message that is used to solicit donations. In addition, Treatments is an area that is adequately funded by the commercial sector due to abundant consumer demand for innovative products. 9

#### **Summary and Conclusion**

At the heart of the efforts to develop a cure for people living with type 1 is a passionate and committed community of supporters. Although the total support they provide seems immeasurable, one tangible metric is the level of donations to the four major type 1 charities. In 2011 donors gave an estimated \$370 million to the four organizations and an estimated \$77 million was allocated to type 1 cure research grants. We believe this level of donor support is capable of funding a significantly larger type 1 cure research program.

We have illustrated that funding for type 1 cure research grants declined in both absolute dollar terms and as a percentage of total research grants for the period 2008-11. In addition, spending on type 1 cure research in 2011 was overshadowed by allocations to other types of research which include research for Treatments and for type 2. Therefore, we conclude that funding type 1 cure research is either a low priority or a declining priority relative to other research alternatives at most of the four major diabetes charities.

For this report, the JDCA utilized each non-profit's self-defined cure/prevent research allocations for purposes of analytical uniformity. As a result, the cure figures in this report represent a broad definition of what constitutes cure research. For example, the JDCA does not consider prevention research to be cure research, yet prevention allocations are included in the data provided by the non-profits. We have also not verified that the individual projects that the organizations classify as cure research are, in fact, exactly that. In any event, it is clear that overall type 1 cure research levels are declining which is a significant trend in the wrong direction that is very disappointing for cure donors.

Cure minded donors that seek to reverse this trend may wish to attach a stipulation with their donation stating their wish to fund Practical Cure research, as defined by the JDCA, i.e. research that has the potential to cure individuals living with type 1 by 2025. 10

- 1 JDCA "Review of Expense Categories of the Major Type 1 Non-Profits" report dated March 8, 2012, see Exhibit B on page 4.
- JDRF, DRIF, Joslin data for 2011. Also assumes that the total contributions to the ADA in 2011 are unchanged from those received in 2010.
- Information sources for the graphs include the following: JDRF: Foundation data for 2008-11 supplemented by JDCA estimate for 2011. DRIF: Foundation data for 2008-11. ADA: Charity data for 2010 and JDCA estimates for the other three years that assume an identical division between type 1 and 2 research; and within type 1, the same division between cure/glucose control/complications that was experienced in 2010. Joslin: JDCA estimates for all years 2008-11. Assumes that the Joslin-supplied division between type 1 and type 2 of 40/60 for 2010 is applied to the other years 2008, 2009, and 2011. Also assumes that the division of type 1 research for all years between cure/glucose control/complications is 1/3 for each.
- JDCA "Impact of Financial Crisis on the Major Type 1 Organizations" report dated September 29, 2011.
- 5 Same sources as listed in endnote 3 above.
- 6 Ibid.
- JDCA estimates that cure research grants were \$60 million in 2011. This is based on total research expenditures of \$116 million, which includes \$22.8 million of funding associated with the Canadian government program.
- JDCA "The Disconnect Between the Cure Message Used to Solicit Donations and the Allocation of Those Donations" report dated March 22, 2012.
- JDCA "Partnering with Commercial Enterprise" report dated November 3, 2011.
- 10 JDCA "Type 1 Clinical Trials That Target a Practical Cure" report dated January 11, 2012, see page 2 for the JDCA's definition of a Practical Cure.

<u>Analyst Certification</u>
The JDCA analyst responsible for the content of this report certifies that with respect to each organization covered in this report: I) 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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