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**Organizations of
Focus:**

American Diabetes
Association (ADA)

Diabetes Research
Institute Foundation
(DRIF)

JDRF

Joslin Diabetes Center
(Joslin)

Juvenile Diabetes Cure Alliance

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The Disconnect Between the Cure Message Used to Solicit Donations and the Allocation of Those Donations

Conclusions:

- The solicitation of donations by the four major non-profits overwhelmingly relies upon the message of a type 1 cure, according to JDCA's analysis
- Significant portions of donor contributions that some non-profits raise with the message of a type 1 cure are directed to activities completely unrelated to type 1 cure research
- We believe that donors have an expectation that donations solicited based on a cure message will fund cure research
- The large commitment to the areas of Education, Information, Awareness, and Advocacy by two of the four major non-profits relies on funds that we believe were raised based on cure messaging

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.

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The effective solicitation of donor contributions combined with the continual generosity of the type 1 diabetes (type 1) donor community generates the funding that drives the operations of the major diabetes charities, including their support of cure research. In this report we analyze the primary messages used to solicit donations and examine the relationship between those messages and the non-cure activities that donations fund.

The four major non-profits employ various fundraising tools and events to solicit donations. Among the most effective fundraisers are Special Events, which include walks, galas, cycling events, etc. Special Events, in the aggregate, are the single most important fundraising tool. For the four non-profits combined, Special Events raised an estimated \$180 million in 2011 and represented 49% of total donor contributions for the year.¹ In our opinion, these numbers demonstrate the very generous donor support for type 1 cure research. We believe that this level of fundraising success is only possible because of the tremendous number of volunteers that help to organize, operate and participate in the events.

The JDCA examined the four non-profits' key fundraising campaigns and we conclude that **the charities overwhelmingly rely upon a type 1 cure message to solicit contributions**, even when the organizations support both type 1 and type 2, as is the case for the ADA and Joslin. The message of a cure resonates deeply with donors and its use is intended to maximize contributions, in our view. The cure is either explicitly mentioned or clearly implicit in almost all major donor solicitations. The following briefly lists the most important Special Events and other fundraising methods for each of the four organizations:

JDRF

- Walk to Cure Diabetes
- Ride To Cure Diabetes
- Tee Off To Cure Diabetes
- Fund-A-Cure portion of galas
- Galas with a variety of names, the majority of which strongly or explicitly convey the idea of a cure, e.g. Hope For a Cure Gala, Promise Gala: A Cure Would Be a Classic , and Promise Ball Path To a Cure

ADA

- Tour de Cure
- Step Out: Walk to Stop Diabetes — the JDCA's view is that the only way to stop type 1 is to cure it
- Online general solicitations state that donations are funding cure efforts
- Children are depicted in fundraising literature, giving the impression that type 1 (juvenile) diabetics are primary beneficiaries of the contributions

DRIF

- Major galas with names that reference the cure explicitly (e.g. "Empire Ball: Unlock the Cure") or implicitly (e.g. "Love and Hope Ball")
- Galas, walks, and other fundraisers explicitly state that proceeds support the DRI's "cure-focused" work

Joslin

- High Hopes Gala
- A video on the website solicits donations to the High Hopes Fund with motivational cure messaging delivered by researchers, as well as a young Joslin patient living with Type 1²

The overt or clearly implicit message in virtually all signature fundraising campaigns is that donations are solicited based on the hope of a type 1 cure. We estimate that the vast majority of donor contributions generated by Special Event fundraisers in 2011 were solicited using the message of a cure.³ In addition, fundraiser events such as Walks tend to focus on teams that are raising funds to benefit a specific person. For example, JDRF guides family teams to write letters and make videos that encourage donations and participation on behalf of their diabetic child/children.⁴

The primary messages conveyed in the majority of the non-profits' major fundraising campaigns did not change from 2010 to 2011 and the central theme of a cure message has not materially changed over the past several years.

The JDCA believes that donors expect the charities to direct funding toward the cure activities that are implicit in the fundraising campaigns. However, our observation is that JDRF and the ADA solicit donations based on the cure message and then make significant allocations to activities unrelated to type 1 cure research. Activities that have no potential to deliver a cure received a great deal of funding from both organizations over the past several years including treatment and prevention research, and Education, Information, Awareness, and Advocacy (EIAA) in particular. The following table depicts the four charities' total donor contributions, donations raised through Special Events, the allocations made to EIAA, type 1 cure research, and other types of research:

Donor Contributions and Select Research/Non-Research Expenses

	<u>2011 (\$ mil.)</u>					<u>2010 (\$ mil.)</u>				
	<u>ADA</u> ¹	<u>DRIF</u>	<u>Joslin</u>	<u>JDRF</u>	<u>Total</u>	<u>ADA</u>	<u>DRIF</u>	<u>Joslin</u>	<u>JDRF</u>	<u>Total</u>
Total Donor Contributions	152	10	9	199	370	152	8	11	194	365
Donor Contributions to Special Events	46	4	2 ²	128	180	46	2	2 ²	124	174
E/I/A/A Activities	99	1	11	40	151	99	1	11	39	150
Type 1 Cure Research Grants	6	7	NA	60 ²	73	6	9	NA	67	82
Glucose Control Research	6	0	NA	33 ²	39	6	0	NA	23	29
Complications Research	5	0	NA	23 ²	28	5	0	NA	17	22

Source: Charity and Foundation data

1 The ADA's 2011 data not yet available. Assumes that 2011 figures are flat with 2010.

2 JDCA estimate

Summary Observations

- **The commitment to EIAA activities far exceeded allocations to Type 1 Cure Research Grants, especially for the ADA**
- JDRF's EIAA allocation of \$40 million was two-thirds of its \$60 million commitment to Cure Research Grants
- **JDRF increased its EIAA commitment in 2011 by \$1 million while its allocation to Type 1 Cure Research Grants decreased an estimated \$7 million, or 10%**
- The aggregate Type 1 Cure Research Grants for three of the four non-profits combined decreased from an estimated \$82 million in 2010 to an estimated \$73 million in 2011
- The decrease in type 1 cure research grants contrasts with an increase in the donations that the four non-profits gathered from Special Event fundraisers, from \$174 million in 2010 to \$180 million in 2011

Although the ADA has a revenue-generating offset to its \$99 million EIAA expense, the JDCA estimates that the majority of this \$99 million expenditure is funded from donor contributions. We estimate that Joslin fully offsets its EIAA expenditures from proprietary revenue-generating programs related to these activities.

Significant allocations are made to Glucose Control and to Complications research (sometimes referred to as Treatments), which have no potential to deliver a type 1 cure. These activities and the development of products designed to improve diabetes management are well addressed by the commercial sector, as we have discussed in prior reports.⁵

When reading the table, it should be noted that Prevention Research Grants are included under the umbrella of Type 1 Cure Research Grants for the ADA and JDRF. We estimate that Prevention Research Grants represent approximately 40% and 15% of the ADA and JDRF Type 1 Cure Research Grants, respectively.

The clear message of a type 1 cure is apparent in the charities' most important fundraising events and campaigns. We are not aware of any major Special Events designed to raise funds independent of invoking hope for a cure. The message of EIAA and the funding of other non-cure areas such as prevention or treatments is largely absent from Special Event advertising or subtly stated at best. Fundraisers with titles like "Walk to Educate Diabetics" or "Type 1 Diabetes Awareness Gala" would be less effective in attracting donations than the current campaigns emphasizing the theme of a cure, in our opinion. **We believe that there would be a substantial reduction in volunteer and donor participation if the fundraiser messaging matched how the contributions are actually allocated.**

The JDCA is not contending that Education, Information, Advocacy, and Awareness; prevention; and improved treatments do not have value or that these areas should go unfunded. In our view, it is reasonable for the charities to fund such programs if contributions are solicited based upon those messages, or for charities to direct a small amount of funding to those activities even if such funding is solicited based on cure messaging.

As it stands, **the commitment to non-cure activities results in an important disconnect between the cure message that is used to solicit donations and the activities that a meaningful portion of those donations ultimately fund.**

Summary and Conclusion

The message of a type 1 cure clearly shapes the fundraising efforts that garner the majority of contributions to the four major type 1 non-profits. This is evidenced by the names of signature fundraising events as well as the underlying online and print solicitations that bolster these campaigns. Although solicitations are based on a cure message, significant portions of total donations are subsequently directed to non-cure activities. **Allocations to non-cure activities far exceed the amounts directed to type 1 cure research grants.**

The misalignment of solicitation messaging with the allocation of contributions to non-cure related projects creates a disconnect. This disconnect is evidenced by the decrease in funding for type 1 cure research grants that took place from 2010 to 2011 at the same time that donor contributions to cure-driven Special Event fundraisers continued to grow. Cure research funding decreased as allocations to non-cure activities increased. Yet, neither EIAA, prevention nor treatments were elevated to the level of cure in the messaging for fundraising events.

We believe that donors expect the non-profits to direct funding to the activities that are implied in the messaging of fundraising campaigns. Donors and volunteers that support the type 1 cause display continual generosity and commitment and deserve to have their expectations met. If a fundraising event is a “Walk For A Cure,” then donors would anticipate that virtually all contributions will be directed to cure research. Instead, at some non-profits, the contributions are directed to other activities not associated with cure efforts. We believe that the meaningful divergence that exists between the messaging of fundraisers and the allocation of donor contributions represents a systemic disconnect at some, but not all, of the non-profits.

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1. Charity and foundation data for 2011 for the DRIF, JDRF, and Joslin; and 2010 for the ADA
2. See the video at http://www.joslin.org/giving/high_hopes_fund.html
3. See the JDCA report “Donor Messaging,” dated August 1, 2011
4. Find the sample family team letter link on the Walk to Cure Diabetes portion of the JDRF’s website: http://www.jdrf.org/index.cfm?page_id=102452, and the “Walk to Cure Diabetes Video Script,” pg.3 of the JDRF’s Fundraising Video Guide at: http://www.jdrf.org/files/General_Files/chapters_and_affiliates/new_york_chapter/2009_Walk_to_Cure_Diabetes/Fundraising_Video_Guide.pdf
5. See the JDCA report “Partnering with Commercial Enterprise,” dated November 3, 2011

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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