

Juvenile Diabetes Cure Alliance

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Are Fundraising Event Proceeds Used for the Purpose for Which the Money Was Solicited?

Conclusions:

- The vast majority of non-profit-organized fundraising event donations are solicited with a clear message of a cure
- There is a large disconnect between what the charities promise in their primary solicitation message and how they actually use donations
- Donors who contribute for type 1 cure research may not be getting what they want
- Cure donors can ensure that they get what they want by stipulating that their donations be used only for type 1 cure research, or more specifically, Practical Cure research with a target date of 2025.

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.

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This is the time of year when the major type 1 diabetes charities and foundations host some of their biggest fundraising events. These popular fundraisers include walks and galas, as well as cycling, golf, and other events. Some have attained widespread name recognition, like “Walk To Cure Diabetes,” “Ride to Cure Diabetes,” and “Tour de Cure.” As these event titles indicate, there has been a proliferation of fundraisers in recent years that solicit donations based on the message of a cure.

This report is an update of our August 2011 “Donor Messaging” report in which we analyzed the cure message that the non-profits use to solicit contributions at fundraising events. The JDCA reviewed over 400 fundraising events that the four non-profits organized in the United States in 2012. Our analysis excludes the hundreds of generally smaller events that are organized and developed by third parties who are not affiliated with the charities. Although third-party-organized events are important to the total fundraising effort, we exclude them from our analysis because the charity does not originate the third party’s solicitation message.

The 400+ fundraisers that we examined represent the majority of the total number of non-profit-organized events and include the largest campaigns such as walks, galas, and cycling and golf events. Therefore, the data reflects the full complement of charity-organized fundraisers, in our view. We analyzed the marketing messages of these 400+ events to derive the percentage of donations that each organization will solicit with a cure message at fundraising events in 2012. We then applied this calculation to reported 2011 fundraising event revenues to project the amount of money that the non-profits will generate from cure messaging at fundraising events in 2012. Table A depicts our findings.

Table A: Donations To Charity-Organized Fundraisers in the United States

	JDCA Estimated Percentage of 2012 Fundraising Event Donations Solicited With a Cure Message	Actual Total 2011 Fundraising Event Donations (\$MM)	Projected 2012 Fundraising Event Donations Solicited With a Cure Message (\$MM)
ADA	89%	49	44
DRIF	53%	4	2
JDRF	95%	128	122
Joslin	50%	2	1
Total	92%	183	168

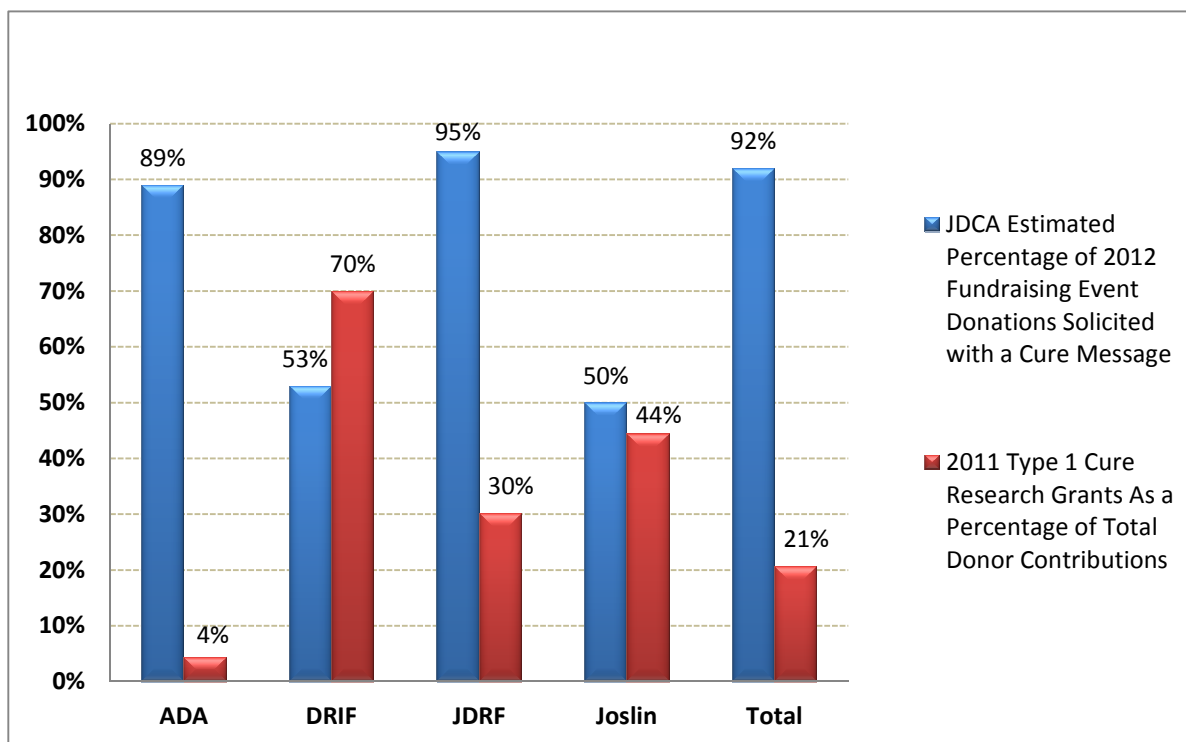
Source: Charity and Foundation data; JDCA research. Total figure in last column does not equal sum of the four components due to rounding.

Table A Summary Observations:

- **The overwhelming percentage of donations to charity-organized fundraising events in 2012 will be solicited using the promise of a cure.**
- Our analysis concludes that 92% of 2012 total fundraising event donations will be generated using a cure message. This percentage is virtually unchanged from a year ago.
- Of the four organizations, JDRF and the ADA most heavily rely on the cure message. Their cure messaging results in the highest dollar level of giving to fundraising events.

Management has an obligation to donors to use their contributions in a manner consistent with the solicitation message. Since the cure message is the central theme in the vast majority of type 1 fundraising events, donors would logically expect that the majority of their donations be allocated to type 1 cure research, but this is not the case. Chart A compares the primary message used in fundraising events with how the funds are actually used.

Chart A: Fundraising Promise vs. Actual Use



Source: Charity and Foundation data; JDCA research

Chart A Summary Observations:

- **There is a strong disconnect between how donations are solicited through fundraising events and how they are actually used.**
- 92% of charity-organized fundraising event donations to the four organizations combined this year will be solicited using a cure message, according to our analysis. However, type 1 cure research grants represented a far lower 21% of total donor contributions in 2011.
- The red bars depicting type 1 cure research grants as a percentage of total donor contributions reflect the non-profits' allocations to their self-defined cure research, which includes prevention and idealized cure research. If the red bars instead measured Practical Cure research spending as a percent of total donor contributions, the percentages shown would be either far lower or zero.
- Allocations to type 1 cure research grants as a percentage of donor contributions vary considerably by organization due to differences in their missions and priorities. The ADA directs the smallest percentage (4%) of total donor contributions to type 1 cure research while the DRIF directs the highest (70%).
- The DRIF has not disclosed how it defines cure research. Therefore, although the 70% figure appears high, it may include projects that donors would not consider to be cure work.
- Unlike the other three organizations, only a small portion of Joslin's total revenues derive from donor contributions. Therefore, the 44% figure indicated by the red bar differs significantly from the percentage of total revenues allocated to type 1 cure research.
- **If the allocation of donor contributions was consistent with the primary solicitation message in fundraising events, the result would be a much more robust type 1 cure research program.**

It is likely that many contributors to fundraising events are not getting what they expect from the charities. The charities solicit donations to fundraising events with the cure theme, but only direct a minority of event proceeds to type 1 cure research grants. Furthermore, the vast majority of the type 1 cure research that the non-profits fund is idealized

cure research or prevention research, which we believe is very unlikely to deliver a cure to people living with type 1 in our lifetime.

Practical Cure research with the potential to deliver a cure for people who are now living with type 1 by 2025 is not being prioritized by the non-profits and receives extremely little, if any, funding. The four non-profits combined direct only three cents of every type 1 cure research dollar to Practical Cure research, according to JDCA analysis. (For the JDCA's definition of a Practical Cure please see Appendix A on page 5.)

Donors can alleviate this mismatch between the fundraising message and the use of their donations. Donors who wish to fund research that targets a cure for established type 1 diabetics can ensure they get what they want by specifying how their donations are used. For example, if donors wish to fund type 1 cure research, they can require the charity to utilize their donation only for this purpose. **More specifically, donors who wish to fund research that targets a Practical Cure for type 1 by 2025 can attach a JDCA stipulation letter to their donation which obligates the charity to use the donation only for Practical Cure research. A link to the JDCA's stipulation letter can be found at:** <http://www.thejdca.org/wp-content/uploads/2012/10/Donor-Action-Letter.pdf>

Summary and Conclusion

The non-profits rely on the message of a cure to solicit donations to their many fundraising events. Although the main solicitation theme is a cure, the four major non-profits direct only a small portion of their combined total donor contributions to type 1 cure research grants. Moreover, a significant majority of the type 1 cure research that the non-profits fund is idealized or prevention research, and none of the funded research targets a specific cure deadline. Only three cents of every type 1 cure research dollar funds projects with the potential to deliver a Practical Cure by 2025, according to our analysis.

The disconnect between the fundraising event message and the application of donor contributions implies that most donors are getting something other than what they have been led to expect. Donors who wish to support research with the potential to deliver a Practical Cure by 2025, a timeframe that most donors would consider meaningful, can increase the chances of success by stipulating that their donation be used specifically to fund Practical Cure research.

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Appendix A: Practical Cure Definition



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

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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