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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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Donor Intentions and Cure Myths Revealed

Conclusions:

- Survey data reveals that myths surrounding a cure are widespread and contribute to donor disillusionment and frustration
- JDCA independent analysis of the diabetes landscape in conjunction with our survey data indicates that there are discrepancies between donor intentions and how their contributions are being used by some of the charities they support
- We believe that donors who contribute for a cure may not be aware that their contributions could be funding activities that are not aligned with their intentions
- We believe that informed donors can have a greater impact by specifying how they want their contributions to be used

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 Juvenile Diabetes Cure Alliance was founded to create an Alliance of donors who contribute for the reason of a type 1 cure and to unite their voices in order to accelerate the development of a Practical Cure for type 1. It is our belief that most donors are people with type 1 or parents/grandparents of a child with type 1 diabetes. We believe that they donate their time, energies, and financial resources in hopes of ridding themselves and their children of the burdens of living with type 1.

In addition to the JDCA's independent analysis on a variety of cure-related topics, we have also conducted four surveys to understand the intentions and perceptions of the type 1 diabetes community, reinforce our research, and work with donors to let their voices be heard. We compiled the most significant findings from each survey to convey the sentiments of the type 1 community.

Diabetes Myths

Our first survey investigated myths surrounding when a cure would be developed:

- 44% of respondents were told at diagnosis that there would be a cure¹
- Of these respondents, 61% were told that a cure would be delivered in the next 10 years¹

This myth perpetuates an unrealistic expectation within the diabetic community that a cure is “just around the corner.” If people are delivered this message and years go by with no cure in sight, they may lose hope and become frustrated with both the lack of cure progress and the lack of accountability within the research funding establishment.

- 28% of respondents said that in recent years their hope for the development of a cure has decreased¹
- 11% of respondents said that they do not think that a cure is achievable¹

When impractical expectations are set and then not completed, people can become discouraged and disillusioned. If donors are assured that a cure is imminent and then do not see tangible goals met, the result can be diminished levels of financial support for cure research.

Not only does this myth contribute to inflated hope, but it also contributes to a sense of complacency within the diabetes charitable and research community. If a cure is perceived to be within reach, perseverance and resolution dwindles because progress is assumed rather than demonstrated.

The JDCA is working to dispel this myth by urging the diabetes charities to adopt a cure definition and cure-by date. This strategy will increase transparency and help to set benchmarks that allow donors to monitor progress. These efforts will contribute to a more focused and effective cure research effort. Concentrating efforts on a Practical Cure will help to eliminate exploratory research and other activities that do not have the potential to deliver a cure for people now living with the disease. Without a cure-by date and clear plan, there

is no distinction made between projects with vague and attenuated initiatives and those that seek to deliver a tangible cure to fully established type 1 diabetics.

Donor Intentions

- **90% of donors indicate Practical Cure efforts as their primary reason for giving²**
- **Only 10% of donors do not mention a cure as a major intention in their giving²**

These data points suggest that most people who donate to a diabetes charity do so for the purpose of a cure. This is reinforced by the cure messaging that accompanies nearly all fundraising events. However, year after year, money that is raised with the intention of developing a cure is spent on projects for improved treatments, prevention, and other areas not directly related to the development of a cure. In 2010, only 21% of the combined total expenses for the four charities was allocated to type 1 cure research, although we note that this percentage can vary meaningfully from charity to charity.³

The JDCA believes that some of the major type 1 diabetes charities could better align their funding allocations to reflect why donors are giving their time and money.

Donor Action

The JDCA views donors as stakeholders in the diabetes charities because it is their contributions that drive these organizations. However, most donors do not seek accountability for their donations.

- 69% of people expect that the charity to which they donate will allocate their donations to accurately reflect their reason for giving, but do not specify how they want it to be used⁴

Some contributors direct their donations to reflect their particular intention for giving. Rather than simply hoping that it is used for a specific purpose, donors can add a stipulation to ensure that the contribution is effectively applied as intended. Informed donors who contribute for the reason of a cure can create a greater sense of urgency on the part of the diabetes charities to fund Practical Cure research.

Summary

Donors are the backbone and heart of the diabetes charitable community. We believe that they dedicate their time and passionately support charitable fundraising events to help themselves and their loved ones who are living with type 1 diabetes. JDCA surveys substantiate these beliefs and suggest that a pursuit of a cure is the highest priority for most donors.

The JDCA views donors as stakeholders in the diabetes charities. As such, they have the power to make their intentions heard and influence the funding of research projects. Informed donors can stipulate their intentions to ensure that their donations are used solely for their intended purpose. The JDCA believes that focusing resources toward a Practical Cure will accelerate its development and provide people who are now living with type 1 diabetes a cure-like lifestyle.

In order to sharpen the focus of research and accelerate the development of a cure, the JDCA believes that cure myths must be dispelled and that donor intentions should be reflected in funding allocations. We believe that this would reduce many of the frustrations felt by donors. Adopting a formal definition of a cure would also impart greater precision in research strategies and help to accelerate tangible progress toward a Practical Cure.

1. As of 3/15/22, 234 people were polled in an online survey conducted by the JDCA, entitled Cure Perceptions Survey
2. As of 3/15/22, 214 people were polled in an online survey conducted by the JDCA, entitled Prevention Survey
3. DCA "Industry Expense Models" report dated August 29, 2011
4. As of 3/15/22, 178 people were polled in an online survey conducted by the JDCA, entitled Donor Intentions

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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