The Voice of the Donor for a Cure

Juvenile Diabetes Cure Alliance

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Do Donors Feel That Practical Cure Research Is Important?

Conclusions:

- → The type 1 donor community believes that it is very important that the non-profits pursue cure research. Funding this activity is the donors' top priority.
- → Pursuing Practical Cure research is widely preferred by donors over pursuing an Idealized Cure
- → A cure-by date goal is highly valued within the donor community
- → A very high percentage of donors would likely contribute to Practical Cure research projects if that donating option was made easily available to them

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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Do Donors Feel That Practical Cure Research is Important?

This report will examine the type 1 community's views regarding the value of Practical Cure research. We base our analysis on data collected from a recent JDCA survey on donors' funding priorities.

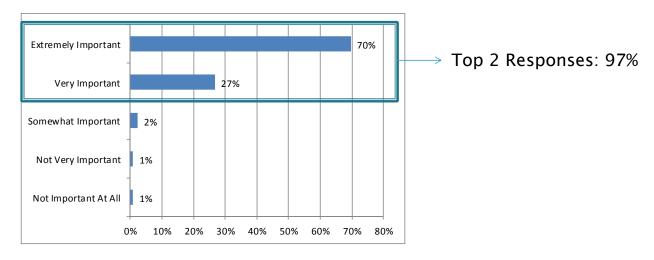
The JDCA contracted a third-party company to conduct a survey of 240 adults who either have type 1 themselves or have a family member or close friend with type 1. Respondents were geographically dispersed across the United States and concentrated between the age range of 22-65. Of the total respondents, 57% are active donors who have donated or raised money for type 1 within the past twelve months and/or plan to do so in the next twelve months. The remaining 43% of respondents are potential donors who have not donated or raised money in the past twelve months and have no plans to do so in the next year.

The survey data demonstrates that individuals affected by type 1 highly value cure research, and more specifically Practical Cure research. Additionally, it seems very likely that the donor community would financially support this type of cure research if the option was made easily available to them.

In the following sections we examine 1) general findings regarding the value that donors place on cure research, 2) donors' attitudes regarding a Practical Cure, and 3) their willingness to fund this type of research.

General Findings

The survey data indicates that **nearly all active donors consider cure research to be either extremely important or very important**, as depicted in Exhibit A:



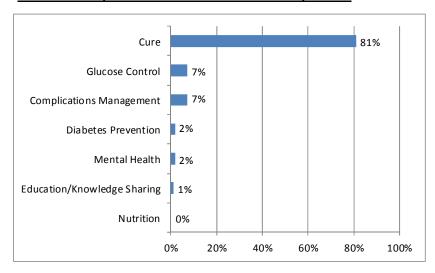
<u>Exhibit A</u>: How important is it to you that the scientific and medical research community is working to find a cure for type 1 diabetes?

Source: JDCA Research

This finding seems intuitive since those affected by type 1 would delight in the elimination of the disease. However, a follow-up question yielded exceptional insight into the significance that donors ascribe to cure research relative to other types of research. Active donors were asked to force-rank seven research areas in order from most important to least. Exhibit B illustrates that a very significant 8 out of 10 donors chose cure research as the number one area that they want funded.

<u>Exhibit B</u>: Please rank the following areas of type 1 diabetes research from 1: Most Important to 7: Least Important

Percent of respondents who selected "Most Important"

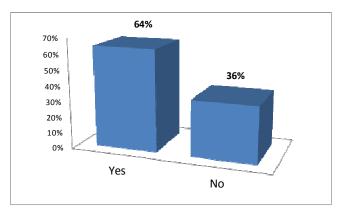


Source: JDCA Research

This data affirms that donors regard cure research as *the* top funding priority in diabetes research. The cure percentage overwhelms the other categories and is more than ten times the next most popular response.

In addition to the importance of cure research, active donors were also asked whether they view a time goal as relevant to the development of a type 1 cure. **Nearly two thirds of active donors feel that a time goal is a valuable component of cure research**, as can be seen in Exhibit C. Yet none of the major diabetes non-profits have implemented a time related objective for developing a cure.

<u>Exhibit C</u>: There is currently no timeline or target completion date for a cure. Do you feel that it would be valuable to introduce a target completion date as a goal?



Source: JDCA Research

The finding that a large majority of donors would support the introduction of a timeline for cure development is consistent with the fact that all survey respondents are currently impacted by type 1. The bottom line is that applying focus and urgency to attain the cure goal in this lifetime is highly valued by donors.

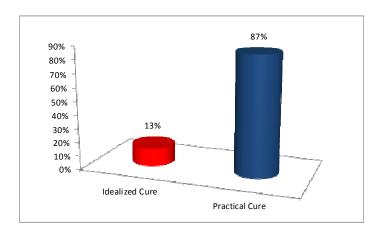
The Value of a Practical Cure

A targeted completion date is one of the primary features that distinguishes a Practical Cure for type 1 from an Idealized Cure. A Practical Cure seeks a specific set of outcomes that would provide patients with a cure-like lifestyle by 2025, although it does not return the patient to a state as if he or she did not have the disease. (Please refer to Appendix A on page 8 for a complete description of a Practical Cure.) In contrast, an Idealized Cure would render a diabetic completely free of the disease, which would be an attractive alternative if time were not a consideration. An Idealized Cure will likely require substantially more time to develop than a Practical Cure, and based upon our research is extremely unlikely to be developed in time to benefit individuals who are now living with type 1.

A key finding from survey questions, which we are about to present regarding the value of a Practical Cure, is that around 9 out of 10 survey respondents consistently indicated a strong preference for Practical Cure work and enthusiastic conviction in its worth.

When asked which type of research they prefer, almost 90% of total respondents prefer the pursuit of a Practical Cure over an Idealized Cure. This data can be seen in Exhibit D below. What this chart shows is that people prefer a Practical Cure in the near future over a perfect cure many generations from now.

Exhibit D: Please choose the outcome that you would prefer (choose one):



"Idealized Cure": A solution that entirely eliminates the disease and may take 75 years or more to achieve

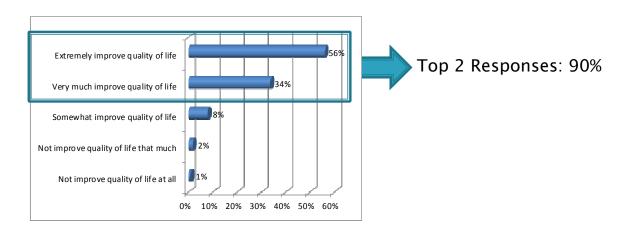


"Practical Cure": A solution that allows a type 1 diabetic to live a like-normal lifestyle free from daily insulin, daily glucose monitoring, and diet restrictions and may be achieved in the next 25 years.

Source: JDCA Research

A Practical Cure would relieve type 1 diabetics of the daily routines and psychological burdens of managing the disease. Consistent with these outcomes, nine out of ten respondents also believe that a Practical Cure would markedly improve the quality of life for type 1 diabetics. Exhibit E depicts this attitude.

<u>Exhibit E</u>: How much do you think a Practical Cure would improve the quality of life for people currently living with type 1 diabetes?



Source: JDCA Research

Continuing the trend of favorable views toward a Practical Cure, a compelling eighty-five percent of donors consider a Practical Cure to be either "Very valuable" or "Extremely valuable," as depicted in Exhibit F. Exhibits E and F also show that only a very small percentage of people feel that there is little value associated with a Practical Cure.

52% Extremely Valuable Top 2 Responses: 85% 33% Very Valuable 11% Somewhat Valuable **1**% Not Very Valuable Not Valuable at All 0% 10% 20% 30% 40% 50% 60%

<u>Exhibit F</u>: How valuable is a Practical Cure to you?

Source: JDCA Research

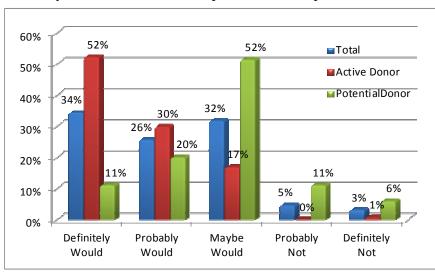
This portion of the survey clearly demonstrates that the donor community highly prizes Practical Cure research. In the next section we examine how this attitude translates into donors' willingness to fund this activity.

Practical Cure Funding

What our survey results indicate is that **Practical Cure research is a compelling reason to donate that appeals to active donors as well as those who do not give or have stopped giving**.

Exhibit G shows donors' willingness to give for a Practical Cure. For purposes of analyzing financial support for this type of research, the total pool of survey respondents are divided into two groups: active donors and potential donors. Recall that active donors have donated or raised money in the past twelve months and/or plan to do so in the next twelve. Potential donors are those who have not donated or raised money in the past twelve months and have no plans to do so in the next year. The chart depicts the likelihood that both active and potential donors would contribute to Practical Cure work.

<u>Exhibit G</u>: How likely would you be to donate to Practical Cure research projects if that option was made easily available to you?



| Definitely Would and Probably Would | |
|-------------------------------------|-----|
| Total | 60% |
| Active Donor | 82% |
| Potential Donor | 31% |

Source: JDCA Research

For active donors, 82% would either "Probably" or "Definitely" donate for a Practical Cure. This jumps to 99%, or virtually everyone, when including those in the "Maybe" category.

In the potential donor cohort that do not currently give, 3 out of 10 would "Probably" or "Definitely" donate to Practical Cure projects if that giving option was made easy. A significant 83% fall into the categories of "Maybe" or stronger. The fact that one third of potential donors express interest in giving to a Practical Cure is notable for the non-profits because this group of donors represents an untapped constituency that could substantially increase Practical Cure funding in the future.

The high percentage of active donors willing to fund Practical Cure research and the meaningful portion of potential non-donor converts is instructive. Donors value and are willing to contribute to outcome based cure research that has a reasonable timeframe associated with completion of the work.

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Summary and Conclusion

When comparing the pursuit of a Practical Cure versus an Idealized Cure, the donor community overwhelmingly (9 out of 10 people) selected Practical Cure as the preferred research approach. Moreover, it is clear that donors highly prize the targeted outcomes of a Practical Cure and believe that it would result in a significant improvement in the quality of life for type 1 diabetics.

Importantly, the donor community has a willingness to fund Practical Cure research. Over 80% of active donors surveyed indicated that they would likely fund this type of research if the option was made easily available to them. In addition, a meaningful portion of potential donors who are not currently giving also indicated a willingness to fund these projects. This finding suggests that pursuit of a Practical Cure research initiative by the non-profits may actually expand the total pool of type 1 givers.

The donor community's enthusiasm, however, does not correspond with the extremely small amount of donor funds that the major type 1 non-profits, in the aggregate, have directed to Practical Cure research. Only three cents out of every type 1 cure research dollar is allocated to Practical Cure research. If the major non-profits prioritized funding for a Practical Cure research initiative it would serve the dual purpose of better aligning the use of donor contributions with donor intentions, and very likely generate greater philanthropic support.

Juvenile Cure Alliance

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

Endnotes

1. JDCA Research

Analyst Certification
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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