

Juvenile Diabetes Cure Alliance

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How Do the Diabetes Non-Profits Measure Cure Progress?

Conclusions:

- Many of the metrics that the non-profits use to monitor cure progress are broad and intangible
- It is difficult to objectively measure cure progress unless cure outcomes, time-lines, and interim benchmarks are defined
- Practical Cure research, which targets specific goals, lends itself well to objective and effective measurement of tangible progress

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 report investigates how the major diabetes non-profits measure progress towards a cure for type 1 diabetes. The JDCA interviewed mid- to senior-level representatives in research and marketing at the four major diabetes non-profits about the organizations' goals for cure development and their metrics for cure progress. We supplemented our research with information from the organizations' publications and websites.

The key learning in this report is that the non-profits measure cure progress against broad criteria rather than specific research milestones. To most readers of this report, the paradigms that the non-profits use to measure cure progress will appear abstract at best.

Measurements of Cure Progress

We identified three common paradigms used for measuring cure progress. The major non-profits utilize each approach to varying degrees. The three paradigms are: 1) Expanding knowledge of the disease, 2) Publishing scientific papers in peer-reviewed journals, and 3) Attracting young talent. The following paragraphs give an overview of each approach to evaluating progress toward a type 1 cure.

Expanding knowledge of the disease

One key metric the non-profits use is to determine how much new discovery and insight has been added to the overall body of type-1 knowledge. In this way of thinking, the first order of business is to fully understand type 1, and any new finding could potentially contribute to a cure. The more learning, the more progress made toward a cure. One often cited measure of this approach is the number of research projects currently underway. The non-profits often cite the total number of projects that are in motion to communicate performance toward adding to the overall type 1 knowledge base. Knowledge expansion may also be measured in a purely qualitative manner based on the judgment of managers and executives.

An obvious drawback to this measurement is that it does not address the research's potential to practically advance progress toward a cure. It can also be self-perpetuating, where the more that is known about type 1, the more avenues of investigation open up to scientists. **Learning everything there is to know about type 1 may eventually lead to a cure, but this approach is very unlikely to cure individuals who are now living with type 1.**

Publishing of scientific papers in peer-reviewed journals

A related way to measure cure progress is by the number of scientific papers published in peer-reviewed journals. There is a strong belief that the more papers published in well regarded journals, the more progress is being made toward a cure. Publications may demonstrate the organizations' contributions to the field of diabetes research and may serve to attract outside funding to further the research. The number of published papers may attest to increased knowledge of diabetes, but publications often do not translate to real, tangible cure progress.

That this approach tends to favor theoretical and exploratory research over practical application is the main challenge of using publications as a measure of cure progress. The problem is compounded by the fact that publications remain an important requirement for researchers who are seeking tenure at academic institutions. Thus, the researchers' primary goal in publishing may have more to do with securing personal career objectives than advancing cure development.

Attracting young talent

The non-profits also mark cure progress by their ability to attract new talent to type 1 research. Some non-profits make it a priority to channel scientists into careers in diabetes research. They fund scientists early in their careers to make the scientists more competitive candidates for government and other grants that will sustain their diabetes

research in the future. In this paradigm, the non-profits may measure progress according to the funding, publications, and prestigious appointments that researchers garner following their tenure with the non-profit. By supporting research careers that may span decades, the non-profits lay the groundwork for advancements in diabetes research far in the future, which is irrelevant to a cure in the near-term.

Implications

The current conventions used to measure cure progress are not focused on a clear end goal that is relevant to those now living with type 1. Cure research can go on expanding basic knowledge, producing publications, and launching scientific careers without making any material progress toward a cure for type 1 diabetes.

Without a cure definition and benchmarks to measure the path towards a cure, the meaning of the word “progress” gets lost. Quantifiable advancement toward a cure will require defining a cure outcome and setting goals for its delivery. Defining desired outcomes focuses efforts on expediently achieving the stated objective. Benchmarks facilitate an objective determination of cure progress by comparing research results against interim goals. Setting and communicating research goals creates greater transparency and establishes realistic donor expectations.

Summary and Conclusion

In conclusion, the measurements of cure progress commonly used by the non-profits do not directly relate to real, tangible progress that has the potential to impact the lives of established diabetics. The JDCA advocates defining a cure for type 1 diabetes as a Practical Cure, an outcome that would largely eliminate the worries and routines associated with managing type 1. (Please see Appendix A on page 4 for the JDCA’s definition of a Practical Cure.) The JDCA suggests this definition of a Practical Cure as a guide for the non-profits’ goals for cure progress and funding practices.

Current measurements of cure progress, which fail to address the goal of curing type 1 diabetes as quickly as possible, also fail to address the concerns of today’s cure donors. In response, donors who stipulate that their contribution be directed to Practical Cure research would ensure that progress toward this end would be measured against defined outcomes and an established timeline. As a result, donors would gain increased transparency into cure development, and cure research would become more focused.

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Appendix A: JDCA Definition of a Practical Cure



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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