

Juvenile Diabetes Cure Alliance

August 5, 2013

Peter Miselis, CFA

Director of Research Analysis

212.308.7433

pdm@thejdca.org

Foundational Data Report: The Size of the Population Impacted by Type 1 Diabetes

Conclusions:

- Surprisingly, there is no consensus within the type 1 research and charity community on the number of people who are living with the disease. Estimates range widely from 1 to 3 million people. Given that nearly everyone with type 1 receives insulin an accurate estimate should be achievable.
- The number of people directly impacted by type 1 includes immediate family. In addition to the people who have type 1, an additional 4 –12 million are in the immediate families, bringing the total of people living in the U.S. and directly impacted by type 1 up to as many as 15 million or 5% of the population.
- These 15 million people represent the majority of donations to the major diabetes non-profits. This group consistently prioritizes the pursuit of a Practical Cure that could be delivered in the next 15 years over a cure that is more likely to come in another lifetime.

Organizations of Focus:

American Diabetes Association (ADA)

Diabetes Research Institute Foundation (DRIF)

JDRF

Joslin Diabetes Center (Joslin)

TAKE ACTION NOW

Ensure it's for a Cure



✓ Specify for Practical Cure research.
Use our letter at www.thejdca.org/

✓ Call us for an advisory meeting at
212-308-7433

This report reveals the size of the population impacted by type 1 diabetes in the United States. While the majority of our reports focus on the type 1 diabetes non-profits, this one directly addresses the population affected by type 1, who are at the heart of and the reason for our efforts to bring about a Practical Cure.

The American Population Affected by Type 1 Diabetes

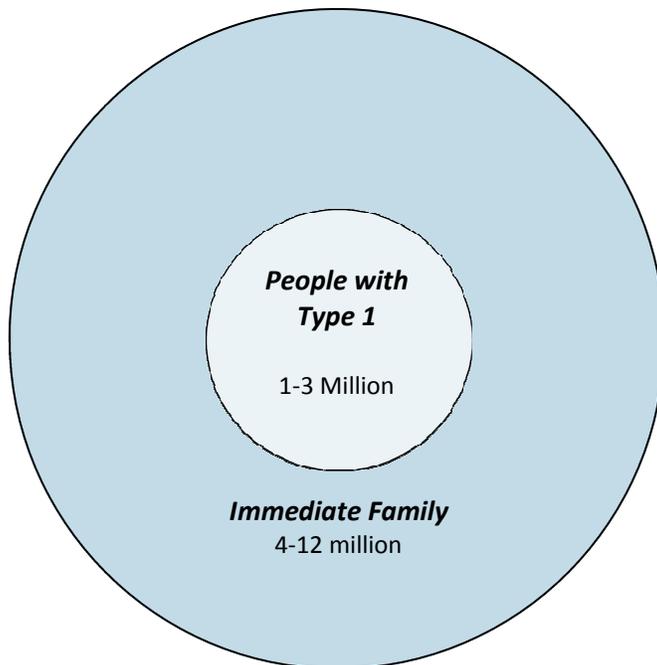
The total impacted population can be broken down into two main groups: those who have type 1 diabetes and their immediate family members. We estimate their numbers as follows:

- **Individuals with type 1:** There is no clear consensus on the number of people diagnosed with type 1 in the United States. Estimates range from 1 to 3 million. One of the most commonly referenced sources is The Centers for Disease Control and Prevention, which states that approximately one million people in the U.S. are living with type 1.¹ JDRF, on the other hand, puts the number as high as 3 million. Their estimate was derived from a survey-based research study conducted in 2010. Other studies place the number between 1.1 and 1.4 million people.²

Given that patients have been treated for type 1 diabetes for almost a century, and that nearly every individual in the United States who has type 1 requires medical treatment, it is hard to understand that the major non-profits or the National Institutes of Health do not yet have a strong estimate for the size of the population impacted by type 1.

- **The immediate family of individuals with type 1:** The estimated size of the impacted population grows by 4 to 12 million as we include the immediate family members of people with type 1. These are the parents, siblings, spouses, and children who also live with diabetes as they aid in managing the disease and share the medical expenses incurred by type 1.

The Population Affected by Type 1 Diabetes in the United States



Source: JDCA estimates

Altogether, as many as 15 million people in the United States are directly impacted by type 1 diabetes, as illustrated in the chart. These 15 million people represent 5% of the U.S. population.³ The number expands even further when considering extended family members including grandparents and close relatives.

These 15 million people represent the majority of donations to the major diabetes non-profits. The charities should seek to align with the wishes and desires of this group when setting objectives, goals, and work plans. There is no more important stakeholder group.

As previous JDCA research reports have noted, the number one priority expressed by the type 1 donor community is to fund cure research. Nine out of ten donors prefer to see their donations used for Practical Cure research over idealized cure research, i.e. they would prefer to fund initiatives which have a chance to come to fruition in the next 15 years over the initiatives who are unlikely to see results until another lifetime.⁴

The Far-reaching Cost of Type 1

In addition to the incalculable human cost of type 1, there is also a quantifiable economic reality associated with the disease. Incremental expenses attributable to type 1 are estimated at \$14.4 billion per year. This includes out-of-pocket costs plus third-party payments that total \$6.9 billion and cover hospital and doctor visits, insulin, prescription drugs, medical supplies, home health provider services, and vision and dental care. Another \$7.5 billion is attributable to lost income from missed work days and lower productivity.⁵

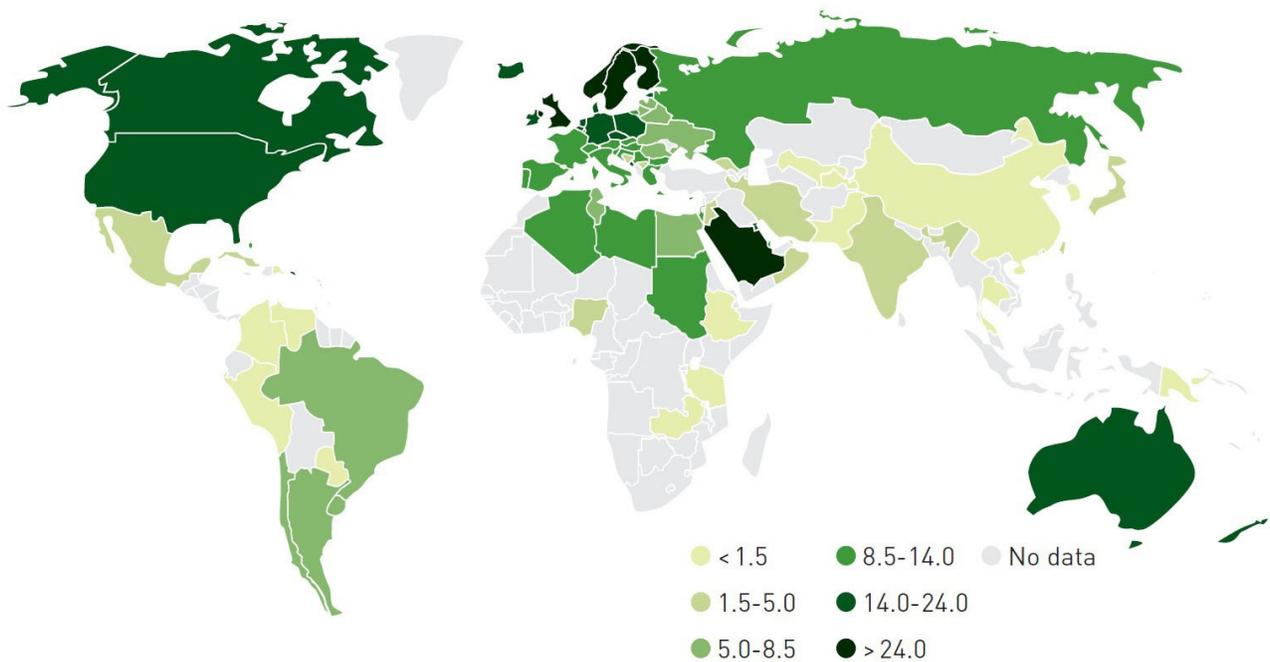
Americans with diabetes incur medical expenses significantly higher than those without diabetes. Annual medical costs for a person with type 1 average around \$9,900, or nearly three times the average of \$3,600 for people without type 1.⁶ In addition, managing type 1 becomes more costly later in life because the longer that one lives with the disease, the greater the chances of developing complications.

If a Practical Cure were to be developed, the potential economic savings over the course of a lifetime would be staggering. One study estimates that the present value of a cure, from avoided costs attributable to type 1, could be approximately \$423 billion just for an existing type 1 population of 1.1 million people in the U.S. These potential cost savings increase by an estimated \$11 billion each and every year just from people who would be newly diagnosed.⁷

Type 1 Growing Globally

Type 1 is a global challenge. The rate at which new cases of type 1 are diagnosed in youth has been increasing 3% annually in the U.S and abroad.⁸ The United States is among the countries with the highest rate of diagnosis in children 14 years of age and younger. It ranks sixth after Finland, Sweden, Saudi Arabia, Norway and the U.K.⁹ Exhibit B maps the incidence of new diagnoses around the world in 2011.¹⁰

Exhibit B: New Cases of Type 1 Diabetes (0-14 years per 100,000 children per year), 2011



Source: International Diabetes Federation Diabetes Atlas, 5th edition

The International Diabetes Federation estimates that 78,000 children around the world will develop type 1 diabetes in 2013.¹¹ There are no global estimates, as far as our research shows, for the number of adults who will be diagnosed with type 1 this year.

Counting the immediate family members of those 78,000 children adds over 300,000 more people to the directly impacted population this year. Adding the families of newly diagnosed adults, would make the number much larger.

Summary and Conclusion

Type 1 is a growing global health concern that directly impacts as many as 15 million people in the U.S. alone. Given the scale of type 1, it is incumbent upon government agencies and the major charities to compile more accurate population statistics in order to more effectively manage resources that address the needs of this community.

These 15 million account for the majority of donations to the major diabetes non-profits, and their number one priority is to see a cure for type 1 delivered in the near future. The JDCA shares that goal and works on behalf of the 15 million to deliver a Practical Cure for type 1 by 2025.

Juvenile Diabetes Cure Alliance

14 East 60th Street
Suite 208
New York, NY 10022

Phone: 212.308.7433
E-mail: info@thejdca.org
www.thejdca.org

1. The Centers for Disease Control and Prevention estimates that type 1 accounts for 5% of diagnosed cases of all diabetes in the U.S. have been diagnosed with diabetes. 18.8 million people have been diagnosed with diabetes in the U.S. as of 2011, which means a population of 0.94 million Americans with type 1. (Centers for Disease Control and Prevention. "National diabetes fact sheet: national estimates and general information on diabetes and prediabetes in the United States, 2011." Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, 2011).
http://www.cdc.gov/diabetes/pubs/pdf/ndfs_2011.pdf)
2. JDRF claims that "As many as three million Americans may have T1D." (<http://jdrf.org/about-jdrf/fact-sheets/type-1-diabetes-facts/>). The Prime group for JDRF arrived at this figure from data gathered in 2010 (*Type 1 Diabetes, 2010; Prime Group for JDRF, Mar. 2011*). The 1.1-1.4 million figure comes from Tao, Betty, et al. "Estimating the Cost of Type 1 Diabetes in the U.S.: A Propensity Score Matching Method." *PLoS One*, 5, 7 (July 9, 2010)
3. The U.S. population in 2011 was approximately 311 million.
<http://quickfacts.census.gov/qfd/states/00000.html>
4. JDCA report, "Do Donors Feel That Practical Cure Research Is Important?," January 31, 2013.
5. Tao, Betty, et al. "Estimating the Cost of Type 1 Diabetes in the U.S.: A Propensity Score Matching Method." *PLoS One*, 5, 7 (July 9, 2010).
6. Ibid.
7. Ibid. Figure given represents 2005 dollars.
8. ADA 2012. *Diabetes Rates Increase Significantly Among American Youth*. [press release] June 9, 2012. <http://www.diabetes.org/for-media/2012/sci-sessions-SEARCH.html>
9. International Diabetes Federation, cited by Diabetes UK.
http://www.diabetes.org.uk/About_us/News_Landing_Page/UK-has-worlds-5th-highest-rate-of-Type-1-diabetes-in-children/List-of-countries-by-incidence-of-Type-1-diabetes-ages-0-to-14/
10. International Diabetes Federation. "Diabetes in the Young." *IDF Diabetes Atlas*, 5th edition.
<http://www.idf.org/diabetesatlas/5e/diabetes-in-the-young>
11. Ibid.

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.

Other Disclosures

All Rights Reserved. The JDCA and its employees will not be liable for any claims or lawsuits from any third parties arising from the use or distribution of this document. This report is for distribution only under such circumstances as may be permitted by applicable law.

All information expressed in this document was obtained from sources believed to be reliable and in good faith, but no representation or warranty, express or implied, is made as to its accuracy or completeness. All