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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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Review of Expense Categories of the Major Type 1 Non-Profits

Conclusions:

- We estimate that 20% of aggregate donor contributions to three of the four major type 1 non-profits was directed to type 1 cure research grants in 2011, although this percentage varied considerably from charity to charity
- The JDCA believes that an even smaller amount of donor contributions are directed to research that has the potential to meet our definition of a Practical Cure
- Our analysis indicates that allocations to type 1 cure research grants by the four major charities decreased in 2011 in both absolute dollars and as a percentage of donor contributions
- Activities with no potential to result in a type 1 cure account for a significant portion of the combined total expenses of the four major charities

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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In August 2011 the JDCA analyzed the major expense categories of the four major type 1 charitable organizations for the year 2010. Financial information for the year 2011 is now public for three of the four charities (DRIF, JDRF, Joslin), and financial statements for the ADA for 2011 are expected to be issued in May 2012. This report updates and analyzes the charities' spending in the major expense categories based on their most recent financial statements.

When reading this report, readers should bear in mind some key differences in the missions of these charities. For example, JDRF and the DRIF are committed only to type 1, whereas Joslin and the ADA have a dual focus on types 1 and 2. Other differentiating features include the ADA's large awareness and advocacy programs, Joslin's operation of a renowned clinic and the DRIF's nearly exclusive focus on cure research. Appendix A on page 7 lists the mission statements of the individual charities in order to provide a more complete context for how each one allocates its spending.

The four major type 1 charitable organizations combined fund a range of activities in addition to type 1 cure research. Their expenses are broadly categorized as either Program Services or Supporting Services. Program Services directly fund the primary activities and programs of the organization. Supporting Services includes management and general expenses as well as fundraising costs. In the following discussion and analysis, expenses categorized as education, information, public awareness and advocacy are combined into one category, though the individual organizations may separate them for reporting purposes.

The following is a brief description of the major expense categories:

→ **Program Services**

- Research Grants
 - * Funds distributed to scientists to conduct research projects
- Non-Grant Research
 - * Costs for scientific meetings, conferences, printing, publications and other expenses that support research
- Patient Care
 - * Clinical care for diabetes patients
- Education/Information/Public Awareness/Advocacy
 - * Various programs designed to improve health through better understanding and management of diabetes
 - * Diabetes publications for consumers and healthcare professionals
 - * Awareness programs concerning the seriousness of diabetes among diabetics and individuals at risk of developing the disease
 - * Advocating for legislation and policy changes to benefit diabetics

Review of Expense Categories of the Major Type 1 Non-Profits

→ Supporting Services

- Management and General
 - * Management compensation, general overhead and related costs
- Fundraising
 - * Personnel costs and other expenses directly related to fundraising efforts

Exhibit A: 2011 Charitable Organization Expenses (millions of dollars)¹

	ADA ^A		DRIF		Joslin		JDRF		Total	
	\$	%	\$	%	\$	%	\$	%	\$	%
Program Services										
Research Grants	33	17	7	64	31	37	116 ^B	57	187	38
Non-Grant Research Expenses	10	5	0	0	0	0	12	6	22	4
Patient Care---Clinic	0	0	0	0	20	24	0	0	20	4
Education/Information/Awareness/ Advocacy	99	51	1	9	11	13	40	19	151	31
Total Non-Research Grant Program Services	109	56	1	9	31	37	52	25	193	39
Supporting Services										
Management and General	10	5	1	9	18	22	14	7	43	9
Fundraising	43	22	2	18	3	4	22	11	70	14
Total Expenses	\$195	100%	\$11	100%	\$83	100%	\$204	100%	\$493	100%

^A ADA data is for the year 2010

^B JDRF Research Grants include \$14 million in non-recurring funding from the Canadian government

For donors that are seeking a cure for type 1, a higher percentage of Research Grants than Non-Research Grant Program Services is desirable. This is because Research Grants might include type 1 cure research. However, bear in mind that figures posted for Joslin and the ADA in the Research Grants category include allocations for both type 1 *and* type 2. Other than Research Grants, all expense categories depicted in Exhibit A involve non-cure-related activities.

Review of Expense Categories of the Major Type 1 Non-Profits

Exhibit A Summary Observations

- Total Research Grants for both type 1 and 2 combined were \$187 million in 2011, versus \$185 million in 2010, a 1% increase
- In 2011, Research Grants represented 38% of combined Total Expenses for the four organizations, meaning that 38 cents of every dollar spent by the four charities funded either type 1 or 2 research projects. This percentage varied significantly by organization.
- Without the Canadian government's \$14 million non-recurring funding program through JDRF, combined total Research Grants for the four charities would have decreased in 2011 in both absolute dollars and as a percentage of Total Expenses
- At \$193 million, Total Non-Research Grant Program Services for the four charities is the largest expense category, slightly exceeding the combined allocations to type 1 and 2 Research Grants
- The category of Education/Information/Awareness/Advocacy represented 31% of Total Expenses and is the primary reason why Non-Research Grant Program Services spending exceeds allocations to Research Grants

The Research Grant figures depicted in Exhibit A include research on both types 1 and 2. These are completely different diseases, and type 2 research will not deliver a cure to individuals with type 1. In addition, Research Grants listed in Exhibit A include type 1 projects that target glucose control and prevention of complications, i.e. research that will not deliver a cure.

The data in Exhibit B separates Type 1 from Type 2 Research Grants and highlights Type 1 Cure Research Grants, which may have the potential to develop a cure for type 1. Also, Type 1 Research Grants are separated into three components: cure, glucose control, and complications.

Exhibit B: 2011 Charitable Organization Research Grant Breakdown (millions of dollars)²

	ADA ^A	DRIF	Joslin ^B	JDRF	Total
Type 1 Research Grants ^C	\$17	\$7	\$12	\$116	\$152
Type 2 Research Grants	16	0	19	0	35
Components of Type 1 Research Grants					
Cure ^C	6	7	NA	60 ^D	73 ^E
Glucose Control	6	0	NA	33 ^D	39 ^E
Complications	5	0	NA	23 ^D	28 ^E
Total Type 1 Research Grants	17	7	12	116	152
T1 Cure Research as % Total Expenses	3%	64%	NA	29%	18% ^E
Donor Contributions & Special Event Fundraising	152	10	9	199 ^F	370
T1 Cure Research Grants as % Donor Contributions & Special Event Fundraising	4%	70%	NA	30%	20% ^E

^A ADA data is for the year 2010

^B Type 1 and 2 Research Grants for Joslin are JDCA estimates. Estimates are based on applying the same percentage breakdown between types 1 and 2 as in 2010 as provided by Joslin. NA = Data Not Available

^C Data as provided by the organizations. The JDCA has not independently verified the accuracy of these figures, but will continue to research and monitor allocations made to general Type 1 Research Grants and Type 1 Cure Research Grants.

^D This is a JDCA estimate. JDRF does not provide a precise breakdown of its research expenditures based on the \$116 million of Research Grants.

^E Figures include data for only three organizations: ADA, DRIF and JDRF. Joslin is excluded because its data is unavailable.

^F Figure includes Affiliate Contributions of \$23 million

Donors who contribute for a type 1 cure would see their intentions met if their donations supported type 1 Cure Research Grants instead of funding type 2 research and non-cure projects for type 1. Research that specifically targets a type 1 cure may have the potential to deliver that outcome, whereas other types of activities do not. When looking at Exhibit B, cure-minded donors would also prefer a higher overall number for Type 1 Cure Research as a percentage of both Total Expenses and Donor Contributions.

Exhibit B Summary Observations

- Estimated Type 1 Cure Research Grants for the ADA, DRIF, and JDRF combined were \$73 million in 2011 compared with \$83 million in 2010 and were only 18% of their combined Total Expenses
- Estimated Type 1 Cure Research Grants as a percentage of Total Expenses ranged from a low of 3% for the ADA to a high of 64% for the DRIF
- Estimated Type 1 Cure Research Grants for the ADA, DRIF, and JDRF combined were 20% of Donor Contributions, a decrease from 24% in 2010. This percentage ranged from a low of 4% for the ADA to a high of 70% for the DRIF.
- Funding for all the different categories of Type 1 Research Grants was an estimated \$152 million in 2011, an increase of 3% from 2010
- JDRF was the only organization to increase funding of overall Type 1 Research Grants in 2011. However, this increase was solely due the Canadian government's \$14 million non-recurring contribution. Even though JDRF's overall Type 1 Research Grants increased, we estimate that the amount it directed to Cure Research Grants decreased.

Organization Specific Comments

(ADA comments apply to 2010 results. All other organization specific comments apply to 2011.)

ADA

- Only 3% of Total Expenses was allocated to Type 1 Cure Research Grants
- **Type 1 Cure Research Grants represent just 4% of Donor Contributions**
- 51% of Total Expenses are directed to efforts in the Education, Information, Awareness, Advocacy category

JDRF

- Type 1 Research Grants of all types increased by \$8 million to \$116 million in 2011 due to the inclusion of a non-recurring \$14 million program funded by the Canadian government. We estimate that the entire Research Grant increase was due to greater funding of Treatments/Device research.
- **Including the Canadian government's contribution, our estimate of JDRF's allocation to Type 1 Cure and Prevent Research Grants (\$60 million) as a percentage of total Research Grants (\$116 million) decreased to 52% in 2011, JDRF's lowest percentage in at least the past six years.** Our analysis of the data and the method of reporting it differs from the presentation by JDRF in its 2011 Research Funding Fact Sheet, which indicates that Cure and Prevent research funding was 62% of the total. The difference between JDRF's 62% and our 52% estimate is that JDRF's reporting excludes all funding associated with the Canadian government's program, whereas the JDCA includes it.
- Cure and Prevent Research Grants decreased in 2011 to an estimated \$60 million. Even with this decrease, JDRF is, by far, the largest funder of Type 1 Cure Research Grants among the four charities that we cover

DRIF

- 64% of Total Expenses was allocated to type 1 Cure Research Grants, the highest percentage of any of the four non-profits we cover. Also, 70% of donor contributions were allocated to type 1 cure research
- 9% of Total Expenses was allocated to Education
- All research funding is directed to the Diabetes Research Institute (DRI) at the University of Miami. Therefore, DRIF-funded research is limited to the scope of DRI's projects.

Joslin

- Joslin maintains a commitment to both type 1 and type 2 diabetes
- \$31 million, or 37%, of Total Expenses were allocated to Research Grants
- We estimate that the 2011 allocation to type 2 research exceeded that for type 1, as was the case in 2010 when Joslin stated that the split between type 2 and type 1 was 60/40
- Costs associated with providing diabetes patient care through its clinic account for 24% of Total Expenses

We note that none of the four organizations have adopted a formal definition of a type 1 cure. Without a definition, the pursuit of a cure is less structured and lacks clear goals. From the data presented in the exhibits above, it is clear that funding for type 1 cure research grants in 2011 represented only a small percentage of both the combined total expenses of and aggregate donor contributions to the four major type 1 non-profits. The JDCA estimates that an extremely small allocation is made to research with the potential to meet the JDCA's definition of a Practical Cure (please see Appendix B on page 7 for the definition).

Summary/Conclusion

Combined annual revenues and expenses of the four major type 1 non-profits were approximately \$500 million in 2011, a considerable sum.³ Annual expenses of the two largest organizations, the ADA and JDRF, totaled around \$200 million each. Their business models are based on a stream of recurring contributions from donors.

The JDCA's review of expenses in this report does not include an evaluation of the charities' operating efficiency. Nonetheless, our clear conclusion is that only a small percentage of aggregate donor contributions are directed to type 1 cure research.

Donor contributions to the four organizations totaled \$370 million in 2011.⁴ The JDCA estimates that only around one-fifth of these generous donor contributions actually fund type 1 cure research grants. Donors should be aware that each of the four type 1 charities has a different mission and each prioritizes type 1 cure research differently. As a result, large percentages of donor contributions to some of the four major type 1 charitable organizations are directed to activities that have no potential to deliver a cure for individuals living with established type 1.

In prior reports analyzing type 1 clinical trials, the JDCA examined how much emphasis is given to type 1 cure research that has the potential to meet our definition of a Practical Cure.⁵ Although we cannot accurately quantify funding of research that potentially meets the JDCA's definition of a Practical Cure, the JDCA believes it is an extremely small amount of the total expenses of these charities. Donors who are contributing for a type 1 cure, or more specifically, for a type 1 Practical Cure, should be aware that unless stipulations are attached to their contribution stating that the donation is to be directed to this specific type of research, then their contribution may be utilized for an entirely different reason than the donor intended.

Appendix A: Diabetes Charities' Mission Statements

ADA

To prevent and cure diabetes and to improve the lives of all people affected by diabetes.⁶

DRIF

To provide the Diabetes Research Institute with the funding necessary to cure diabetes now.⁷

Joslin

To improve the lives of people with diabetes and its complications through innovative care, education, and research that will lead to prevention and cure of the disease.⁸

JDRF

To find a cure for type 1 diabetes and its complications through the support of research.⁹

Appendix B: JDCA Definition of a Practical Cure

- For at least 1 year, a cure must:
 - Not require blood glucose monitoring beyond once a week
 - Not require carb counting
 - Not restrict a patient's diet
 - Allow patients to sleep care free
 - Maintain A1c levels between 6-7

- A cure must be delivered through a treatment that:
 - If it is surgical, requires a full recovery time of less than 72 hours.
 - If it is pharmacological, requires no more than a reasonable pill and/or injection Regimen

- A cure, which may include a drug regimen, must not have side effects, or pose longer term risks, greater than current complications of Type 1

Juvenile Diabetes Cure Alliance

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1. Charity and foundation data for 2011 for the DRIF, JDRF and Joslin; and 2010 for the ADA
2. Ibid.
3. Ibid.
4. Ibid.
5. JDCA "Type 1 Human Clinical Trials" report dated December 14, 2011, JDCA "Type 1 Clinical Trials That Target a Practical Cure" report dated January 11, 2012 and JDCA "Type 1 Human Clinical Trial Landscape" report dated January 19, 2012.
6. See the ADA's 2010 Annual Report, p. 4: <http://main.diabetes.org/dorg/PDFs/Financial/ADA-2010-Annual-Report.pdf>
7. See the DRIF's 2010 Annual Report, p. 3: <http://www.diabetesresearch.org/document.doc?id=483>
8. See Joslin's 2009 Annual Report, p. 2: <http://www.pageturnpro.com/Joslin-Diabetes-Center/14320-2009-Joslin-Diabetes-Center-Annual-Report/index.html#/4>
9. See JDRF's 2011 Annual Report, p. 12: <http://www.jdrfapps.com/eReport/index.htm#?page=14>

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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