The Voice of the Donor for a Cure

Juvenile Diabetes Cure Alliance

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How Much Practical Cure Research Do the Major Type 1 Non-Profits Fund?

Conclusions:

→ The Practical Cure research that the four major non-profits funded on a combined basis in 2012 amounted to just 2% of total donor contributions, with the remaining 98% of contributions used for other types of research and non-research activities.

→ JDRF and the DRIF were the largest funders of Practical Cure research in 2012, at $6 million and $3 million, respectively. The ADA and Joslin funded no Practical Cure research.

→ Nine out of ten donors prefer to fund Practical Cure research over Idealized Cure research, yet the overall allocation to Practical Cure research does not reflect this wish.

→ The non-profits and the donor community both have the ability to meaningfully increase Practical Cure funding. The non-profits can establish a Practical Cure initiative, and donors can stipulate that their contribution be used only for Practical Cure research.

Organizations of Focus:

American Diabetes Association (ADA)

Diabetes Research Institute Foundation (DRIF)

JDRF

Joslin Diabetes Center (Joslin)

This report quantifies the major type 1 non-profits' funding for Practical Cure research. Our key finding is that **the four major non-profits combined allocated just two cents of every donor dollar to Practical Cure research in 2012**. The remaining ninety-eight cents of every donor dollar were used to fund other types of research and non-research activities. This allocation is inconsistent with donors' wish to have Practical Cure research well-funded.

We will break down the ninety-eight cents of every donor dollar that is not directed to Practical Cure research to evaluate how donor contributions are being used at each of the four non-profits. We also offer suggestions to better align donor interests with how their contributions are spent.

In assembling the data, the JDCA examined the abstracts for over 550 individual research project that were funded in 2012. The JDRF and ADA make abstracts for nearly all of their type 1 projects publicly available on their websites. The DRIF and Joslin do not make abstracts for individual research projects publicly available. In the case of the DRIF, we obtained and reviewed information on their 2012 projects from management and the Diabetes Research Institute. Joslin declined to provide any such information.

How much was donated to the four non-profits and how much was allocated to type 1 research?

This section examines donors' generous contributions to the major diabetes non-profits and the non-profits' allocations to type 1 research. The table in Exhibit A illustrates select funding data for the non-profits in 2012.

Exhibit A: Donor Contribution and Type 1 Research Funding Data for 2012 ($ in Millions)

Organization	Donor Contribution $	Practical Cure Research $	All Other Type 1 Research $	Practical Cure Research as % Donor Contributions
ADA	$160	$0	$13	0%
DRIF	11	3	4	27%
JDRF	196	6	104	3%
Joslin	13	0	13	0%
Total	$380	$9	$134	2%

Source: Charity and Foundation data. JDCA Research. The ADA's financial statements for 2012 have not yet been published; ADA *Donor Contributions* and *All Other Type 1 Research* are JDCA estimates based on 2012 data being flat with 2011. DRIF's actual *Donor Contributions* for 2012 were $7 million. However, this figure is adjusted upward to $11 million because DRIF funded $4 million of its 2012 operating budget from a reduction in its net asset position. This $4 million originated with donor contributions. Therefore, the $11 million figure is a more accurate representation of donor contributions used to fund research. Joslin's *All Other Type 1 Research* is a JDCA estimate arrived at by assuming that 40% of its Total Research budget is directed to type 1 and 60% to type 2, similar percentages that Joslin provided for 2010, the most recent year for which the JDCA has data.

As seen in Table A, **allocations to Practical Cure research in 2012 totaled $9 million, or just 2% of total donor contributions to the four major non-profits combined**. The funding and prioritization of Practical Cure research varied significantly by organization, and our analysis indicates that only two of the four organizations, the DRIF and JDRF, funded Practical Cure work last year.

Ninety-eight percent of donor contributions were directed to funding other categories of type 1 research in addition to activities other than type 1 research. Funding for research in all other major categories significantly exceeded the support for Practical Cure research. Please see Appendix A on page 6 for a more detailed breakdown of type 1 research funding broken down into key categories for each non-profit .

Practical Cure vs. Idealized Cure funding represents a disconnect

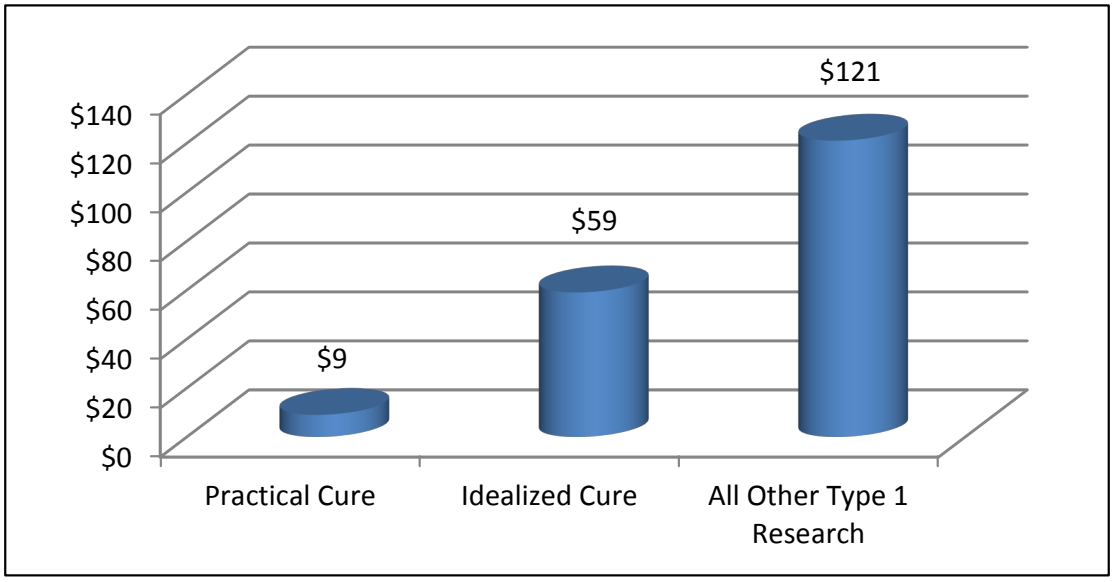
It is important to make the distinction between the two primary types of cure research, Practical and Idealized. A primary difference between Idealized Cure and Practical Cure research is whether the research is designed to deliver a cure for type 1 in the foreseeable future.

- **Practical Cure research** is defined by outcomes that would provide a "like normal" lifestyle to individuals who are currently living with type 1. Importantly, Practical Cure projects have the potential to deliver the targeted outcomes by a time goal in the foreseeable future. Please see Appendix B on page 6 for a more detailed explanation.

- **Idealized Cure research** encompasses many areas and types of research that on their own are unlikely to deliver a cure within the foreseeable future. Please see Appendix C on page 7 for a more complete description of the different types of Idealized Cure research.

The chart in Exhibit B compares the combined allocations that three of the four non-profits (ADA, DRIF, and JDRF) made to Practical Cure research, Idealized Cure research and all other categories of type 1 research in 2012.

Exhibit B: 2012 Type 1 Research Funding for Three Non-Profits Combined (Millions)



Source: Charity and Foundation data for ADA, DRIF, JDRF; JDCA Research

The fact that funding for Practical Cure research was dwarfed by the allocations to Idealized Cure research and to all other types of type 1 research for the three non-profits combined last year represents a gross disconnect with donor preferences. JDCA research indicates that 9 out of 10 donors strongly prefer Practical Cure research over Idealized Cure research.[1] Yet the funding for these two categories in 2012 was heavily weighted in the opposite direction, as Idealized Cure research received $59 million in funding compared with $9 million for Practical Cure.

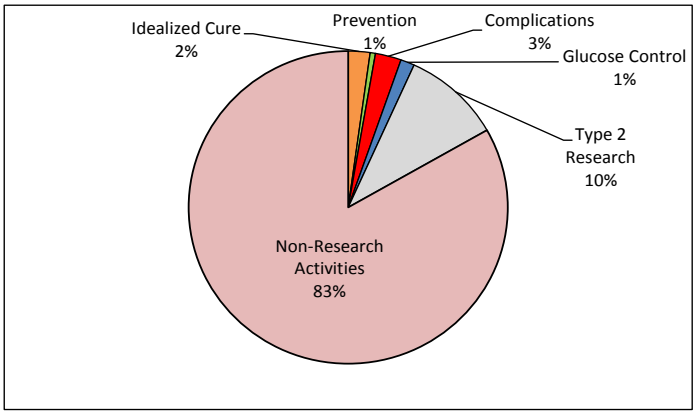
Comparing the $9 million in funding for Practical Cure research to the $121 million allocated to all other type 1 research is even more striking. This proportionately low level of support for Practical Cure research is inconsistent with donor priorities as an overwhelming 85% of donors believe that Practical Cure research is either very valuable or extremely valuable.[2]

The allocation of funds for research and non-research purposes

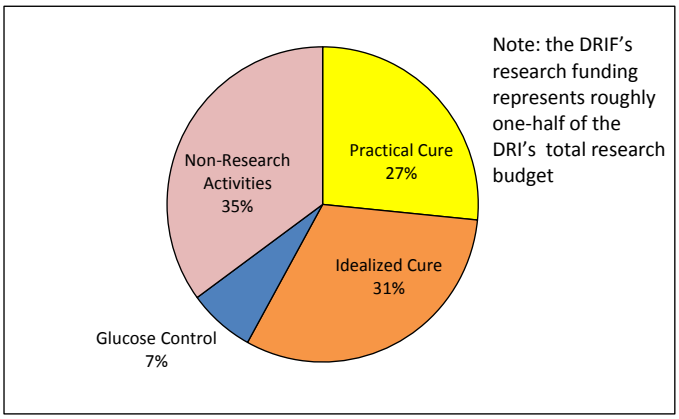
The charts in Exhibit C depict the organizations' funding for research and non-research activities, with research activities divided into the following categories: Prevention, Complications, Glucose Control, Idealized Cure, Practical Cure, and Type 2 Diabetes.

Exhibit C: 2012 Allocation of Total Operating Expenses

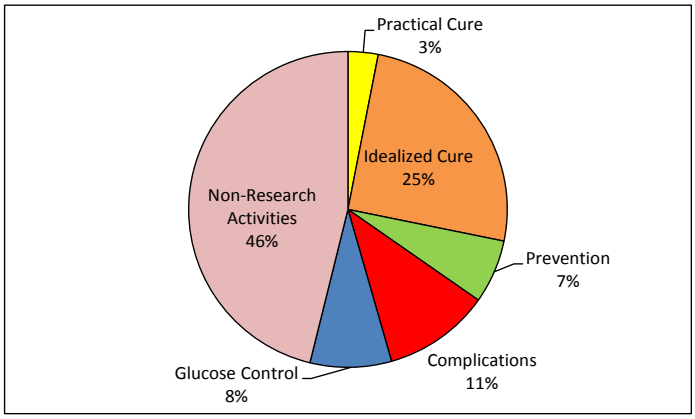
ADA ($200 Mil.)



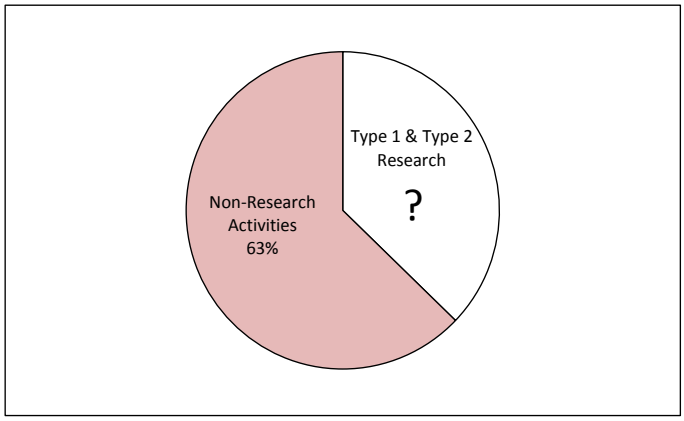
DRIF ($11 Mil.)



JDRF ($205 Mil.)



Joslin ($86 Mil.)



Source: Charity and Foundation data; JDCA Research

Exhibit C Summary Observations

- → JDRF's allocation of $6 million to Practical Cure research made it the largest funder in dollars, exceeding the DRIF's $3 million allocation. The ADA and Joslin funded no Practical Cure research in 2012.
- → The vast majority of cure research is Idealized, which is highly unlikely to deliver a cure by 2025.
- → Funding for non-research activities (which may include overhead, fundraising, education, awareness, and clinical care) is the single largest category for every non-profit. It is important that the commitment to these activities does not divert resources away from Practical Cure research.
- → Additional details of the research budgets for the ADA and JDRF can be seen in Appendix D on page 8, which breaks down research spending into sub-categories.

The JDCA believes that an equitable allocation of donor contributions would represent the intentions of donors as well as the messaging that is used to solicit donations. There is a moral imperative for the non-profits to recognize the interest of all stakeholders and fund the activities that are important to them.

The key point in the current funding situation is that most of the major non-profits do not prioritize Practical Cure research despite the facts that donors highly value it and the type 1 cure promise is heavily relied upon in fundraising messaging.[3] Donors who favor Practical Cure research are underrepresented in the allocation of donor contributions for most of the non-profits. Practical Cure research receives the least funding of all major spending areas and is dwarfed by Idealized Cure funding. Yet donors have an overwhelming preference for Practical Cure research, which results in a **gross inconsistency between what donors want and how their contributions are actually used**.

What can be done?

Solutions can be easily implemented to directly address inconsistencies in the use of donations by making a greater commitment to Practical Cure work. The non-profits can implement specific steps to establish a Practical Cure research initiative which would involve:

- → **Defining** specific Practical Cure outcomes and setting a time goal to focus research efforts and create urgency
- → **Determining** which projects have the potential to deliver the targeted outcomes and implementing objectives to tangibly measure progress along the way
- → **Developing** the prioritized projects by fully funding them and communicating progress with stakeholders
- → **Delivering** results by ensuring that the best projects are fast-tracked to human trials

Donors also play a crucial role in funding Practical Cure research. The easiest, most direct way to make an impact is to stipulate that your donation be used only for Practical Cure research. The JDCA provides tools to guide donors' giving decision, ranging from a Stipulation Letter that can be attached to your donation to a Donor Giving Guide that can be used to structure a more complex philanthropic relationship with your preferred charity or foundation. These tools can be accessed on the JDCA website at: http://www.thejdca.org/donor-page/.

Summary and Conclusions

After an extensive examination of research projects that were funded by the major non-profits in 2012, we have concluded that Practical Cure research is clearly not a priority for most of the non-profits. Our research indicates that Practical Cure research received very limited funding in 2012, an extremely small 2% of total donor contributions for the four major charities combined. Only the DRIF and JDRF funded Practical Cure projects last year, according to our analysis. Funding for Practical Cure research as a percentage of donor contributions was significantly greater for the DRIF than JDRF. The ADA and Joslin provided no Practical Cure funding.

An important disconnect exists between the non-profits' use of contributions and what donors view as important. Although donors overwhelmingly prefer Practical Cure research over Idealized Cure research, the non-profits' allocations to other types of research and non-research activities far outweigh the amounts directed to Practical Cure projects.

Both the non-profits and donors can initiate action steps to meaningfully close this gap. Every non-profit could implement a Practical Cure research initiative that would prioritize this type of work and direct more resources to it. Alternatively, donors themselves can be instrumental in increasing funding for Practical Cure research by stipulating that their donation only be used for this purpose.

Appendix A: Type 1 Research Funding for 2012 ($ Mil.)

	Practical Cure	Idealized Cure	Prevention	Glucose Control	Complications	Total Type 1 Research	Non-Research
ADA	0	4	1	3	5	13	187
DRIF	3	3	0	1	0	7	4
JDRF	6	52	13	17	22	110	95
Joslin	0	NA	NA	NA	NA	13	73
Total	9	59	14	21	27	143	359

Source: Charity and Foundation data. JDCA Research. The ADA's financial statements for 2012 have not yet been published. The total type 1 research figure assumes that 2012 spending was flat with 2011. The ADA's individual research category figures are percentages based on the $13 million of total type 1 spending. Joslin's $13 million for total type 1 research is arrived at by assuming that 40% of its Total Research budget of $32 million is directed to type 1 and 60% to type 2, similar percentages that Joslin provided for 2010 which is the most recent year for which the JDCA has data.

Appendix B: Practical Cure Outcomes

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

Appendix C: Idealized Cure Research

The following is a more detailed description of the Idealized Cure sub-categories. Joshua Levy, is an independent observer of the type 1 landscape. His contributions helped to determine the composition of these subcategories.

At a basic level, a cure for type 1 diabetes would provide a source of insulin that responds to changes in blood glucose in real time, and protect that source from attack by the immune system. Developing components of a cure in isolation significantly increases the amount of time required to put the pieces together. Therefore, any research project that did not ultimately endeavor to deliver all components of a Practical Cure by 2025 was classified as Idealized rather than Practical Cure research.

The first three sub-categories have to do with restoring insulin production in the body:

1) **Cell supply**:
   - beta cell reprogramming: changing one type of fully developed cell into an insulin-producing beta cell
   - beta cell programming: making an undifferentiated stem cell become an insulin-producing beta cell
   - donor cells: obtaining insulin-producing beta cells from an exogenous source

2) **Beta cell growth**: expanding the mass or insulin-producing ability of beta cells

The next two sub-categories have to do with keeping the insulin-producing cells safe from immune system attack in one of two ways:

3) **Immune modification**: altering the immune system by halting the immune response that kills beta cells, or by teaching the immune system not to attack in the first place

4) **Immune protection**: hiding the beta cells from the immune system attack

Additional subcategories of Idealized Cure research include:

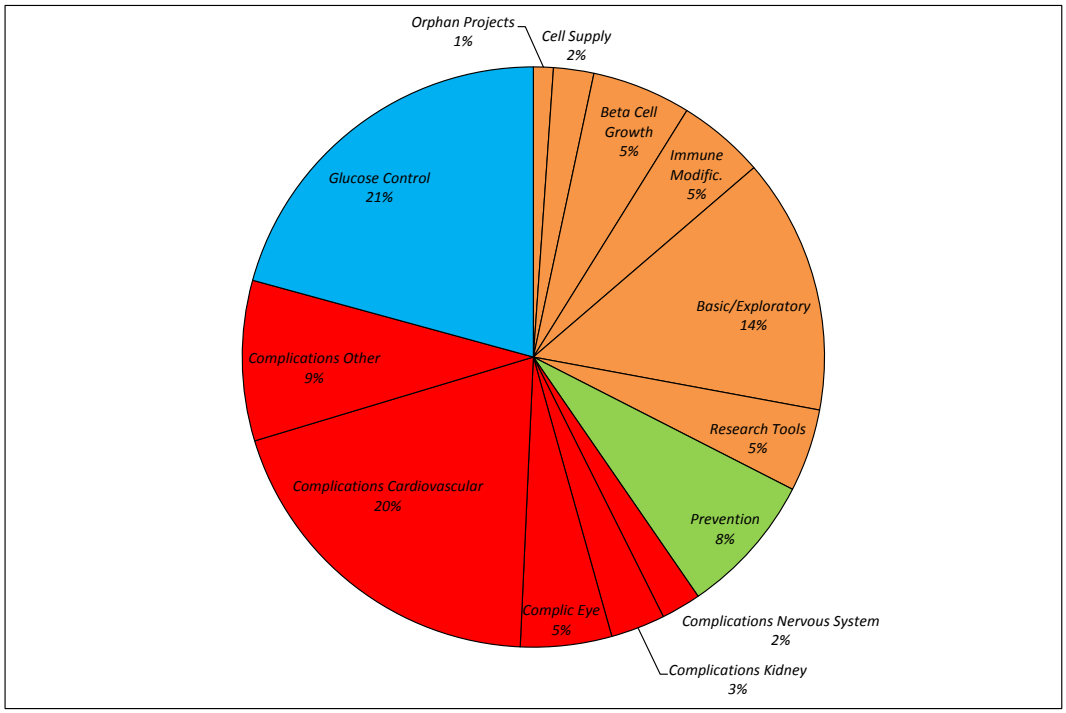
5) **Basic and Exploratory**: investigating essential aspects of how diabetes works, its causes and progression

6) **Research Tools and Techniques**: developing material to be used in experiments (e.g. genetically modified mice) or equipment with which to conduct experiments (e.g. imaging systems to measure beta cell mass)

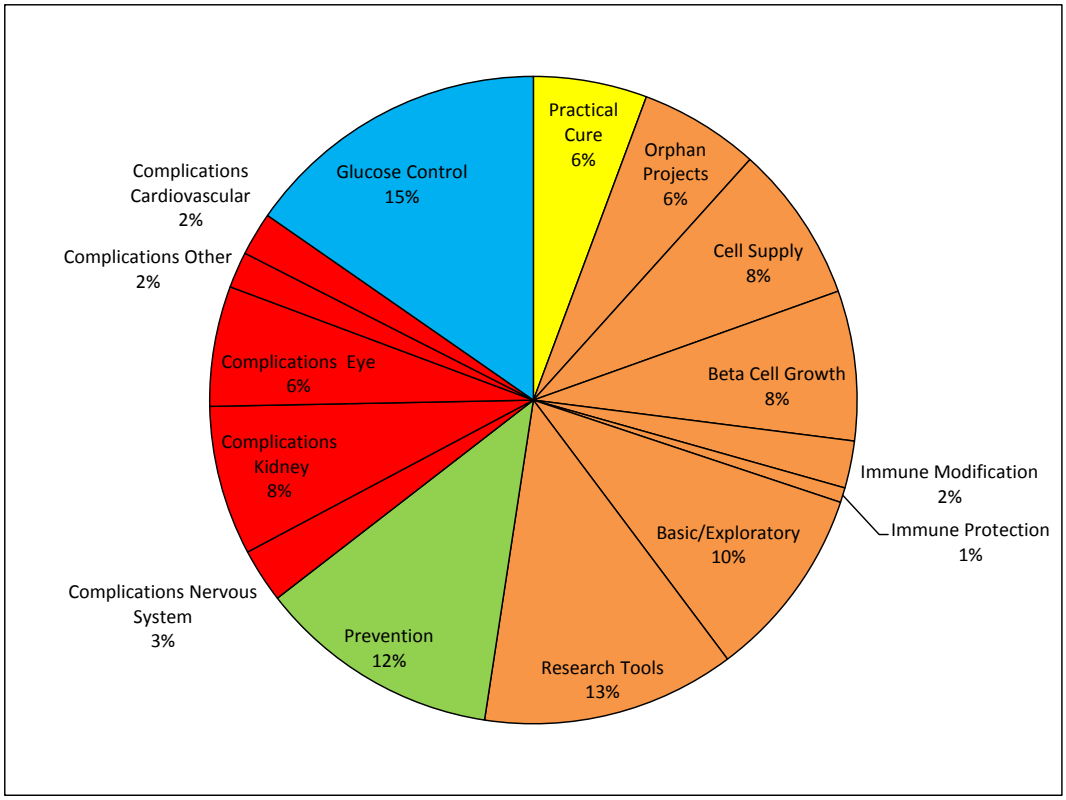
7) **Orphaned** projects are not Practical Cure projects by themselves. If they were combined with other potential Practical Cure projects then together that research could be categorized as Practical Cure research. Islet transplantation is the area of research that most often contains these “orphaned” projects.

Appendix D: Breakdown of Type 1 Research

ADA



JDRF



Source: Charity and Foundation data; JDCA Research

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Endnotes

1. JDCA report, "Do Donors Feel That Practical Cure Research Is Important?" Jan 31, 2013

2. JDCA report, "Do Donors Feel That Practical Cure Research Is Important?" Jan 31, 2013

3. JDCA reports, "Do Donors Feel That Practical Cure Research Is Important?" Jan 31, 2013; and "Are Fundraising Event Proceeds Used for the Purpose for Which the Money Was Solicited?," October 25, 2012; and "The Disconnect Between the Cure Message Used to Solicit Donations and the Allocation of Those Donations," March 22, 2012.

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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