

IFSO Congress: JDRF Australia presentation

Session 2.2.5 Power to the Patients – Lived Experience

The many millions dollar question – can lived experience advocacy improve equity and access to care?

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Conflict of Interest Disclosure

In accordance with the EACCME criteria for the Accreditation of Live Educational Events, please disclose whether or not you have any conflict of interest with the companies.

I have no potential conflict of interest to report.

What is T1D and who is JDRF?

- Type 1 diabetes is a chronic autoimmune condition that can develop at any age.
- The Juvenile Diabetes Research Foundation was founded by Mums in the 70s, who wanted not just better treatments for T1D, they wanted a cure.
- Today JDRF is the leading supporter of type 1 diabetes (T1D) research in the world.
- I'm here to talk to you today about how advocates, that's volunteers with lived experience, are fundamental to achieving this impact.

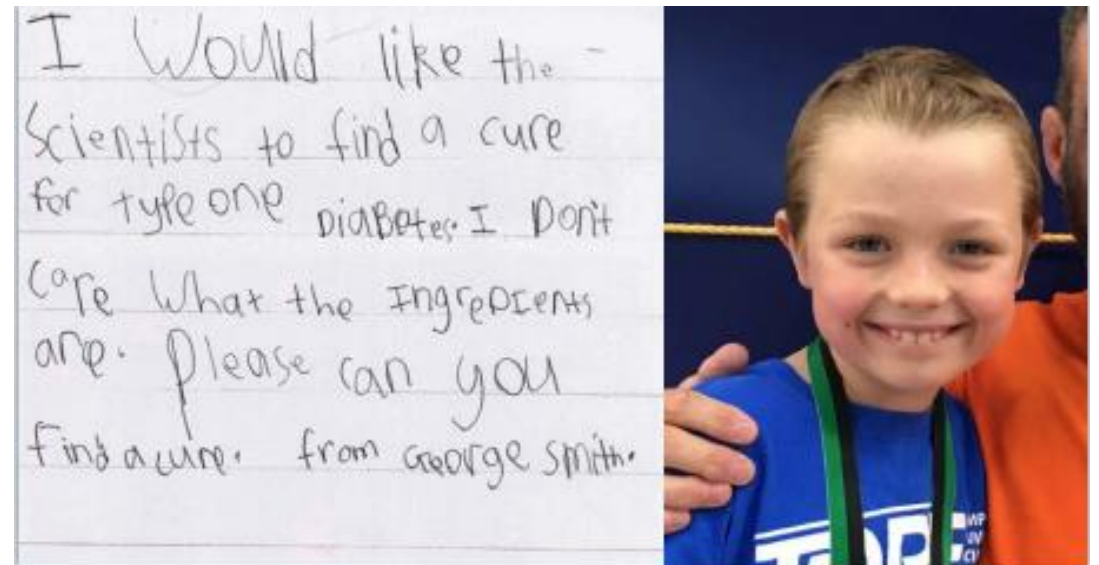


What do we want?

Everyone at JDRF wants the same thing – a cure.

Until we do, we want to make each day easier, and safer than the day before.

So how do we get it?

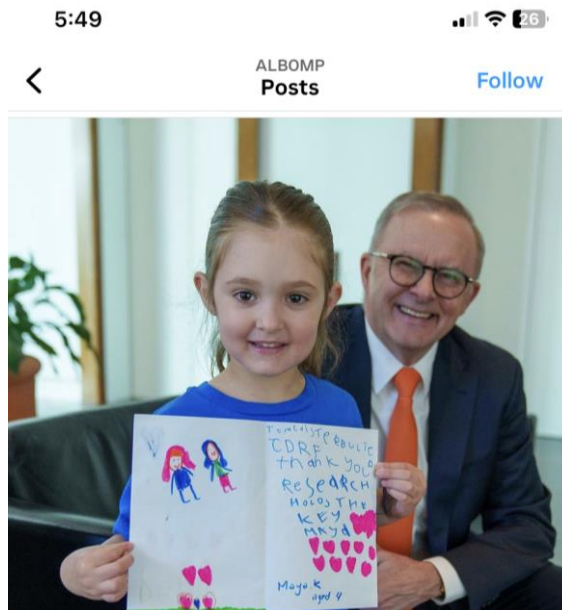


Advocacy

Our advocates are people with lived experience of type 1 diabetes.

Our advocates have achieved government investment into funded programs and policies worth millions of dollars.

So how do they do it?



JDRF's Advocacy framework – policy, politics, persuasion and project management



Policy

- Agree and be clear on your ask.
- And who you are asking.
- Cost it.
- Define the benefits and, in our case, health impacts and savings, of the ask.
- Get everyone singing from the same song sheet.

Our ask

JDRF Australia is seeking \$50m from the Australian Government for the next stage of research funding, CRN 4.

KEY MESSAGE

Over the past decade, funding for JDRF's CRN has achieved a lot. But there is more to do – and this funding will help us do it.

Politics

- Map your targets
- Find your natural supporters.
- Be bipartisan
- Target the decision makers for your ask
- Match the key politicians with a family from their electorate.



Persuasion

- Build your volunteer network of advocates
- Match your family to your target
- Lived experience rules – advocates are the experts
- Brief and debrief your advocates
- Be positive, respectful
- It takes time
- Say thank you



Takeouts

JDRF Australia started small, but JDRF advocates are at the centre of every Government funded T1D policy or program we've achieved.

Our advocacy starts with people with lived experience telling their stories to political decision makers, and the strength of our advocacy comes from relationships built over time.

Policy, politics and persuasion (and of course project management) can work.

- [Shanna](#), whose enduring relationship with her MP is paying off
- [Georgia](#), who at 12 swayed a group of researchers and clinicians in a group not unlike this one.
- [Zach](#), who at 7 was so on message with his politician, he still takes my breath away.



