

ADDRESS & ADDRESS-2 NEWSLETTER

Issue 2 - January 2018



Working together to understand type 1 diabetes – it's an all-age thing

It is 9 years since we started ADDRESS and 6 since the beginning of ADDRESS-2. More than 6,000 of you have joined, including over 5,000 with type 1 diabetes and roughly 1,000 siblings. Together, you make up a huge group of people who have given up time to participate in diabetes research. Volunteering for something that is more likely to benefit others than yourself is an amazing thing to do at any age, but we have been really impressed by how many children and teenagers have chosen to take part.

Over half of you who have joined were children when diagnosed (aged 5-16 years), but nearly as many of you were diagnosed in adulthood. It is known that type 1 diabetes can be diagnosed at any age, but it is still often thought of as affecting mostly children and young adults. Twenty percent of you were over the age of 30 when diagnosed. You can see the breakdown by age at diagnosis in Figure 1. Like other researchers with similar findings, we are working to raise awareness that people of all ages develop type 1 diabetes.

We are using the information we have collected from you and the blood samples that you have donated, to learn more about type 1 diabetes, soon after diagnosis, in modern and diverse Britain. We would like to thank you all for helping with this research.

Other content in this issue:

- Spreading the word about type 1 diabetes research
- Stories of ADDRESS-2 participants: Sam and Kelvin
- ADDRESS-2 Patient Advocate Group: looking for volunteers
- Increasing the presence of the 'immune system police' to protect insulin-making beta cells

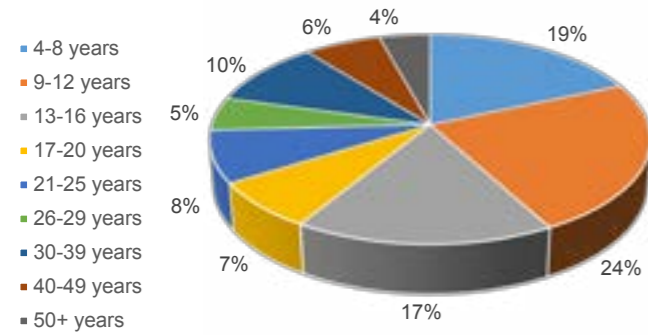


Figure1: Age of ADDRESS-2 participants when diagnosed with type 1 diabetes

At the time of joining ADDRESS-2 people must be aged 5 years or older and have been diagnosed for less than 6 months.

Spreading the word about type 1 diabetes research!

An important part of ADDRESS/ADDRESS-2 involves us letting you know about other type 1 diabetes research studies for which you might be eligible. It is up to you to decide whether or not you want to find out more about any study, and whatever you decide is absolutely fine.

Since 2011 there have been 22 studies to which we have matched people. These studies have almost all been looking for adults with type 1 diabetes. There are studies involving children with type 1 diabetes that started this year, and others that will start this year. We are in the process of contacting some siblings too.

When we match someone to a study, we send them some information about the study. If that person wants to find out more about the study, we help to put them in touch with the research team running the study.

We have sent information about at least one study to over 2,000 participants in ADDRESS/ADDRESS-2 and 17% of you have asked to be put in touch with individual study teams to find out more. Many of you have also let us know why you did not wish to hear more, which is valuable information to help us and other researchers understand how to design and run studies better.

You can read in this newsletter about the experiences of two of our participants who opted to take part in a recent trial of a new treatment (see: Stories of ADDRESS-2 participants: Sam and Kelvin). You can also read about one of the studies that has published some of their findings. The study was looking at a way to help people with type 1 diabetes keep making some of their own insulin (see: Increasing the presence of the 'immune system police' to protect insulin-making beta cells).

You can read more about other type 1 diabetes research studies on our website:

www.address2.org/type1-diabetes-studies



Stories of ADDRESS-2 participants: Sam & Kelvin

Sam and Kelvin joined ADDRESS-2 in the last year. We gave each of them information about another type 1 diabetes research study. They chose to find out more, and then volunteered to take part. Here are their experiences in his own words.

Sam:

"When I was diagnosed with type 1 diabetes it completely caught me off-guard; I had no family history; it was a complete surprise to find out that I had developed type 1 diabetes. Within the first month of being diagnosed, I was offered the opportunity to take part in a clinical trial and I thought it would be a good way to find out more information about type 1 diabetes and be able to contribute something back to the research and hopefully be able to develop new techniques and drugs in the future".

"I've found it really useful to have close contact with the research nurses here at the clinical research centre. I thought it might be a bit daunting at first having so many visits for the trial, but it's completely flexible.

I've been moving house in the meantime, changing cities, changing jobs and taking holidays and things like that. It has been incredibly flexible to arrange the appointments around my personal life."

Kelvin:

"When I was first diagnosed with diabetes I was keen to take part in research, so I was put in touch with a research nurse. She told me about ADDRESS-2 and that there was a study that needed people as soon as possible, so I was all for it at first."



Kelvin on his bike!

"Then I took a bit of time to think about it, as I was confused about my sudden diagnosis and had to get my head around it. But when I received more information and spoke to my mum, who had worked in cancer care, I knew it was the right thing to do. Because if no-one takes part, we won't make the progress we need.

It wasn't a decision I will benefit from, but it wasn't about that, I want to make a bit of difference for others early on with diabetes."

Kelvin, travels from Oxford to London every six weeks for treatment and check ups.

"It is quite intensive, but now I'm taking part I'm quite enjoying it. I also get to quiz the top diabetes experts about my condition and get all of the information I need. It means I can live my life how I want and keep cycling. If I have any problems, I'm in close contact with the lead consultant, so I can email or call him. And the research team contact me on a weekly basis."

ADDRESS-2 Patient Advocate Group: looking for volunteers

Do you want to help us improve the way we run ADDRESS-2?

We have a group of people with type 1 diabetes and parents of children with type 1 diabetes who give advice and input into the way we run ADDRESS-2. The group has a particular focus on communication and engagement with people living with type 1 diabetes and with healthcare professionals. We are looking for more volunteers to join the group. Business is conducted mainly via email with occasional face-to-face meetings. We understand that individual members of the group do not always have time to respond to requests for feedback or input, and rely on people contributing when they can. If you would like to find out more, please email me: (Helen Walkey, Study Coordinator; h.walkey@imperial.ac.uk).

Dr Helen Walkey
Study Coordinator for ADDRESS & ADDRESS-2



Professor Desmond Johnston
Chief Investigator for ADDRESS & ADDRESS-2



Increasing the presence of the 'immune system police' to protect insulin-making beta cells

DILT1D: Adaptive Study of IL-2 Dose on Regulatory T Cells in Type 1 Diabetes

The 'DILT1D' study was run at Addenbrooke's Hospital in Cambridge. A number of people in ADDRESS-2 were matched to this study and chose to take part. The research team, led by Professor John Todd and Dr Frank Waldron-Lynch, looked at a therapy called aldesleukin (also known as interleukin-2 or IL-2). Aldesleukin is used in high doses to treat specific types of cancer by changing the way body's immune system works. The research team wanted to know if ultra-low doses of aldesleukin would affect the immune system in people with type 1 diabetes in a way that might help prevent the body from attacking itself: When the body attacks itself, the insulin-making beta cells get damaged and eventually the body cannot make enough insulin.

How aldesleukin was investigated

The aim was to look at the effect of aldesleukin on cells in the immune system. It involved adults who had been diagnosed with type 1 diabetes for less than 2 years. Aldesleukin was given by injection. Participants were monitored and gave blood samples at intervals over a period of 2 months.

To find out more reference for the research article in which the findings were reported is:

Todd JA, Evangelou M, Cutler AJ, Pekalski ML, Walker NM, et al. (2016) Regulatory T Cell Responses in Participants with Type 1 Diabetes after a Single Dose of Interleukin-2: A Non-Randomised, Open Label, Adaptive Dose-Finding Trial. *PLoS Med* 13(10): e1002139

<http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1002139>

What was found?

The results of the study showed that a single ultra-low dose of aldesleukin increased the presence of cells in the immune system called regulatory T cells (Tregs). Tregs help to prevent the body from attacking itself, and are sometimes described as the 'immune system police'. The researchers worked out the best doses of aldesleukin to get an increase in Tregs and be safe for people to take.

What does this mean?

This study was an early step towards finding out whether treatment with aldesleukin might help people with type 1 diabetes to keep making some of their own insulin. The next step has already been completed in the follow-on study, 'DILfrequency', but the results have not been made public yet. Professor John Todd, now at the University of Oxford is currently setting up a study to look at aldesleukin in children with type 1 diabetes.

To find out more about ADDRESS-2:

www.address2.org

www.diabetes.org.uk

www.jdrf.org.uk

www.type1diabetesresearch.org.uk

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