

Volunteer Role Description JDRF UK Patient Insight Group

We are seeking to form a virtual group of people with type 1 diabetes and parents and carers of young people who live with type 1 diabetes to help with a one year study. The goal of the study is to identify the most effective way to keep beta cells working and making insulin in people newly diagnosed with type 1 diabetes. The study will compare and analyse the results of previous research publications in this area. We need the group of volunteers to help in giving their views on the studies that we find.

We would like to involve 10 - 15 young people or parents of recently diagnosed young people. More specifically we would like the JDRF UK Patient Insight Group to include:

- 5 – 8 people who live with type 1 diabetes aged 8 – 25 years old
- 5 – 8 parents of young people who live with type 1 diabetes.

What will I be doing?

The role of the JDRF UK Patient Insight Group will be

- to share their views and expectations of interventions that could help people keep making their own insulin for longer after been diagnosed with type 1 diabetes,
- to look at, and give their views on studies that are identified by the research team,
- to help the study team engage with people with type 1 diabetes and seek their views,
- the one representative from the group (aged 16 or over), must be comfortable representing the group and contributing at the study's meetings. We envisage there will be 3 meetings over the year.

How will this benefit me?

You will engage with other people with type 1 diabetes and develop your skills and networks. You will also work closely with JDRF staff, and type 1 diabetes researchers – gaining a better understanding of research and clinical trial design.

When do you need me?

You will be expected to contribute to the Patient Insight Group for the duration of the project, beginning in January 2019 until September 2019. The members of this virtual group will discuss and share their views via email. The group representative will be required to attend 3 meetings in person (Birmingham) or via teleconference. These meeting are likely to take place during working hours. Preparation related to these activities may amount to 1-2 hours reading per month throughout the year though it is unlikely to be on consecutive months.

How will this benefit JDRF?

This role will help JDRF support a type 1 diabetes research team funded by the National Institute for Health Research (NIHR), ensuring good patient representation so that the voices of people with type 1 diabetes can influence medical research. This group will also be the

first of its kind for JDRF and help us develop a new model for helping people from around the UK actively participate in developing and informing the medical research agenda.

Where is this role based?

This group is a virtual group and no travel is required, except for the group representative.

What training will I receive?

The lead researchers will introduce the study, provide guidelines and training about how to understand scientific studies. JDRF staff team will provide support to ensure good communication within the group and with the research team.

What skills and attributes do I need?

- Aged 8 – 25 year old diagnosed with type 1 diabetes or
- Parents/carers of young people who live with type 1 diabetes,
- An interest in research (but we don't expect you to be research expert in any shape or form),
- Familiar with email,
- Confidence in sharing your opinions,
- A willingness to listen to different views with respect.

What support is available to me?

You will be able to contact the Research Partnership team for any questions.

Sounds great! How do I get involved?

If you're interested in applying, send us a short letter explaining how your experience and knowledge is relevant to this role and why you would like to join the JDRF UK Patient Insight Group (500 words max). In your letter, please let us know about your connection with type 1 diabetes and if you would be interested in holding the role of representative. Email your application letter to the Volunteering team at volunteering@jdrf.org.uk. Once we receive this, those shortlisted for the role will be invited for a phone chat, which will give you the opportunity to ask us questions and give us the chance to find out more about you too. We want to make sure that this is the right role for you and that you'll be happy providing this support to the research team. For the representative, the first meeting is likely to take place in January/February 2019.

If you have any questions, or would like to discuss the role in more detail, please send an email to us at the address above.

The deadline is Wednesday 19 December 2018.