MAKING DIABETES RESEARCH PATIENT-CENTRIC

IMI-JDRF Diabetes Patient Meeting
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Brussels, Belgium

Patients' testimony

Kris Wood
Proinsulin Peptide Immunotherapy in New-Onset Type 1 Diabetes
Proinsulin Peptide Immunotherapy in New-Onset Type 1 Diabetes

- **Location:** Newcastle then transferred to London.
- **Project lead:** Professor Mark Peakman
- **Purpose:** Trialling a new vaccine which they hope will trigger an immune response to protect against T1D.
- **What’s involved:** 6 months of fortnightly visits followed by 6 months of monthly observation visits. The trial drug injection was given during the fortnightly visits, blood samples were taken at all visits and mixed meal tolerance tests were performed periodically.
Developing corneal confocal microscopy for human diabetic neuropathy
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- **Location:** Manchester
- **Project lead:** Professor Rayaz Malik
- **Purpose:** This project seeks to discover if a non-invasive eye test, looking at the nerves in the eye, could be used to diagnose diabetic neuropathy.
- **What’s involved:** Tests involved nerve conduction studies, the ability to sense pain/touch in my feet and eye tests to assess cornea sensitivity and health of the front and back of the eye.
Adaptive study of interleukin-2 dose on regulatory T cells in type 1 diabetes
Adaptive study of interleukin-2 dose on regulatory T cells in type 1 diabetes

• **Location:** Cambridge

• **Project lead:** Dr Frank Waldron-Lynch

• **Purpose:** Trialling a potential treatment (interleukin-2) to extend the honeymoon period using an existing molecule in the immune system that regulates T cells.

• **What’s involved:** One injection at the beginning, followed by 10 observation visits, seven being consecutive after the injection. Bloods taken at every visit.
My experience overall

- I had no problem attending clinic.
- Occasionally meet other patients on visits.
- The benefits out-weighed the risk every time.
- All research gets us a bit closer to the cure.
Benefits of taking part in research

- **Psychologically** – Seeing and meeting others with type 1 diabetes
- **Rewarding** – part of the ultimate goal
- **Superior care** – taken over by research team
- **Health checks** – blood tests, X-rays, ECGs etc
- **Educational** – learn from the process and professionals
- **Structure** – condition is closely watched and fine tuned
The benefits of my research

- **Vaccine research** *(Newcastle/London)*
  Possibility of extending my honeymoon period.
  Superior care in the early months.

- **Immunotherapy research** *(Cambridge)*
  Proved to put type 1 in to remission.
  Health checks.

- **Neuropathy research** *(Manchester)*
  The opportunity to have an annual neuropathy test.
Barriers of taking part in research

- Words like trial, research and clinical have **negative** perceptions.
- The **logistics** of getting to clinic and getting time off work.
- The **risk-benefit** assessment is individual and constantly changing.
- The **infrastructure** of letting people know research and how to get involved.
It’s all about communication

- Research needs to be communicated on a **wider scale**.
- Communicate progress whether it’s **good or bad**.
- Demonstrate how research is not **cheap, quick or easy**.
- **One central place** for all diabetes research.
- Open up communication between patients
- Using **patients as advocates** and recruiters following their participation on the trial.
- Communicate research through **new media** channels.
- Include patients in the **whole process** so they feel valued.
- **Encourage research** as a part of a patients clinical care plan or during clinical appointment.
Conclusion

- Overall I don’t believe risk is the biggest barrier.

- I think the frustration of living with type 1 reduces the perceived risk for most people.

- Focus needs to be on access to and education of research through improved communication.

77% of people with type 1 have never been given the opportunity to take part in research by their clinical team.

96% of those people are willing to take part in a clinical trial.

*Survey conducted by JDRF UK in 2013*
Research is expensive...

That’s why I am climbing Kilimanjaro for JDRF in four weeks!

Please help me raise as much money as possible for type 1 research

Thank you

www.justgiving.com/KrisonKili