

# typenone

## MAKING DIABETES RESEARCH PATIENT-CENTRIC

IMI-JDRF Diabetes Patient Meeting  
20 May 2014  
Brussels, Belgium

Patients' testimony

Kris Wood



Innovative Medicines Initiative

# Proinsulin Peptide Immunotherapy in New-Onset Type 1 Diabetes

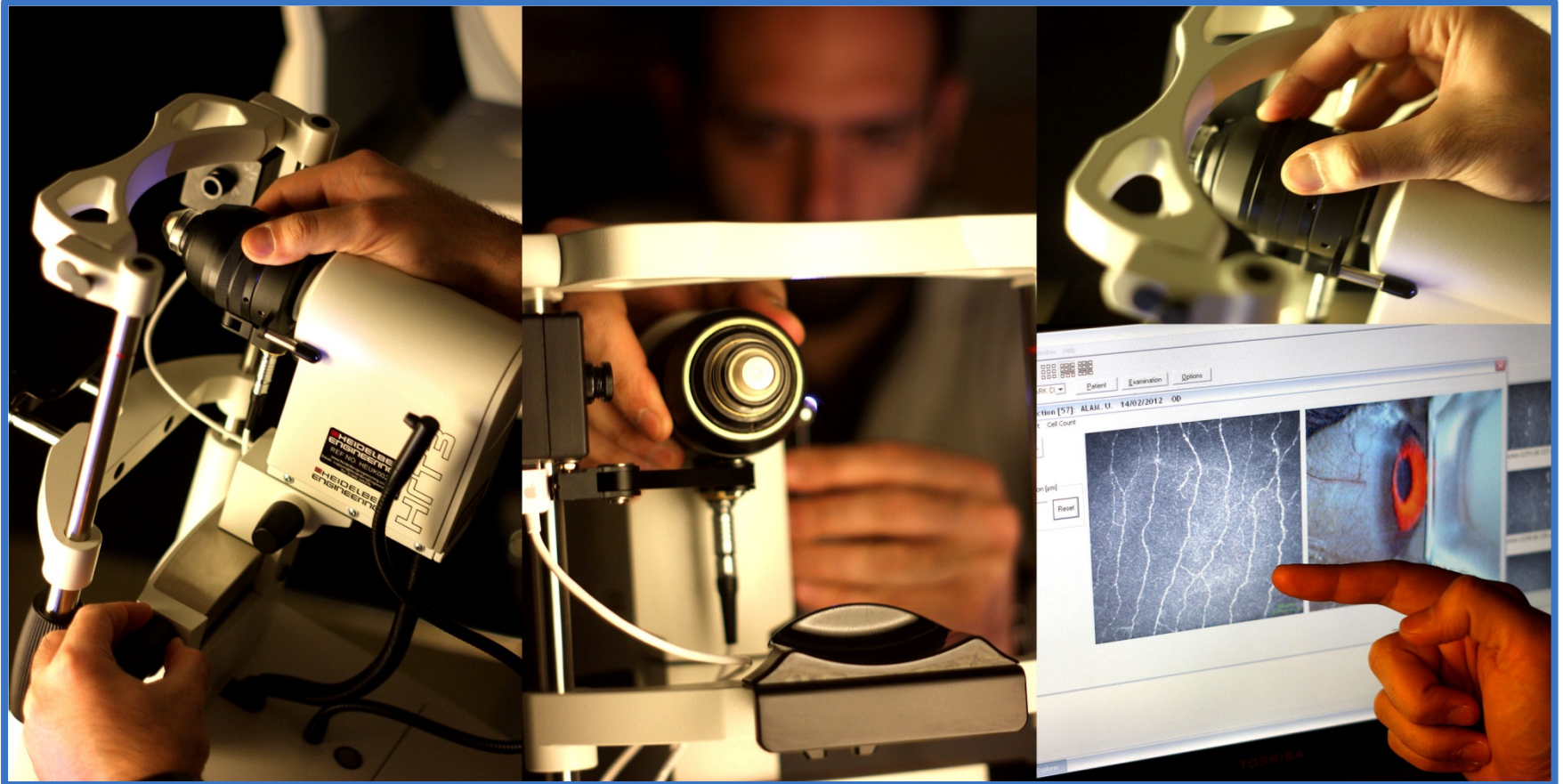


# Proinsulin Peptide Immunotherapy in New-Onset Type 1 Diabetes

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- **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

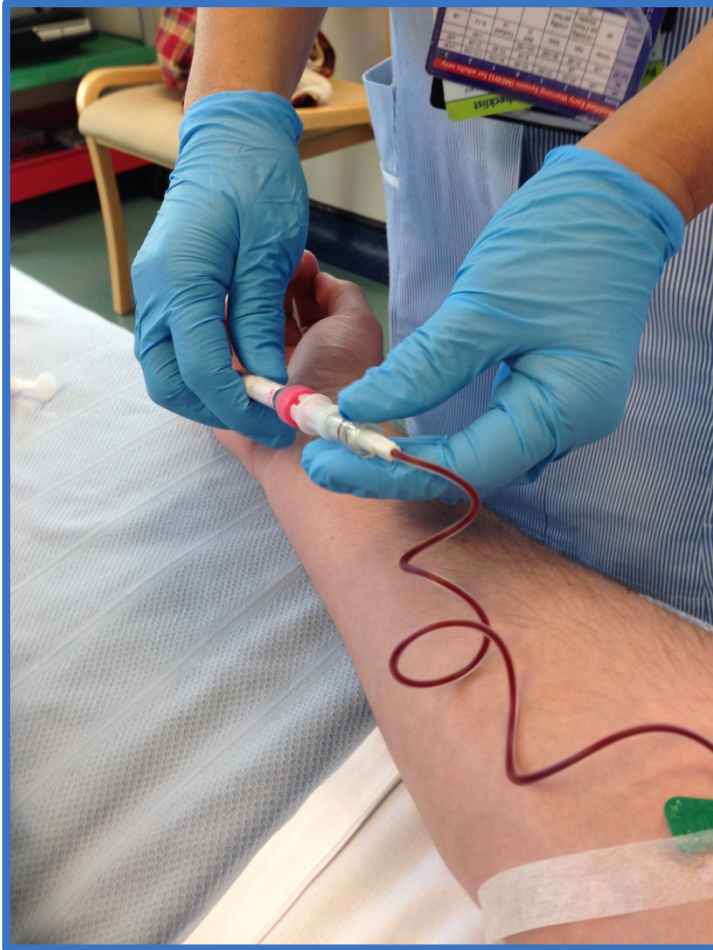


# Developing corneal confocal microscopy for human diabetic neuropathy

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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

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- **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

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- 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

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- **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

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- **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

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- 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

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- 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

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- 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](http://www.justgiving.com/KrisonKili)**

**Diabetic**  **Banana** type 1 diabetes blog

[www.diabeticbanana.org](http://www.diabeticbanana.org)