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Greetings!

Hoping that not too many of our readers have been struck down by swine flu! Keep well, and keep calm!

This month in Yada Yada we bring you a special issue all about research. Starting with the most pondered question: 'Will we ever see the cure?'. We also share with you a range of research more relevant to us while we wait for the cure - stuff that's unlikely to hit the headlines anywhere but here! Enjoy!

***** SPONSORED ANNOUNCEMENT *****

New Clinical Study for People with Type 1 Diabetes

Hospitals in Australia are inviting volunteers to participate in a research study looking at a new type of treatment for Type 1 Diabetes.

Are you:

- Between 18 to 45 years of age
- Diagnosed with Type 1 diabetes within last 5 years

The study will be performed over the course of 24 to 36 months and will require 20 to 38 visits.

For more information please visit www.clinicaltrials.gov/ct2/show/NCT00453375 and contact your nearest participating hospital in **Melbourne** (City), **East Ringwood** (Melbourne), **Fremantle** (Perth) or **Kippa-Ring** (QLD).

[Click here for more information](#)

Will we ever see The Cure?? Experts tell all.

In a quick poll, more than half of people on the Reality Check website said they'd been promised when they were diagnosed that 'the cure' would be here within 5 years! Others of us were told 'by the year 2000', 'in 10 years', 'in my lifetime'. But sitting here in 2009, don't you sometimes wonder if will we ever see it?

The Type 1 Diabetes Network took this question to some experts.

Mr Mike Wilson. CEO of the Juvenile Diabetes Research

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Foundation in Australia, whose *mission* it is to find a cure, told us that one of the most difficult questions they are asked at JDRF is 'How long until we find a cure?'

"While we need to be cautious of overhyping recent developments, there is an incredible amount of research to be excited about," says Mr Wilson.

Some of the advances that JDRF is excited about include:

- understanding how insulin-producing cells develop and grow
- vaccines that might retrain the immune system
- drugs that can help regenerate beta cells
- therapies to prevent and reverse complications, and
- progress towards an artificial pancreas.

It is promising that 40 JDRF-funded clinical trials of such things are currently underway worldwide - there were only five in 2000.

Mr Wilson raised another important issue - the work that is needed outside of the laboratory. "A cure won't truly be a cure unless it is achieved (scientifically), available (commercially), and accessible (financially) to those who may benefit. So, JDRF are working on removing regulatory impediments, and ensuring appropriate reimbursement as well," he adds.

So, things are moving along and we can be hopeful. But how hopeful? Do we hedge our bets, live life hard and get ready to be first in line for the cure? Is it possible to be too optimistic? How do we get our heads around all of this? We turned to an expert in coping with all that diabetes throws us.

Helen Edwards, long-term Type 1 herself, counsellor and diabetes educator, meets many people through her work with [Diabetes Counselling Online](#) who would dearly love to see a cure, yesterday. Her message is simple: "A lot of people are doing a lot of good work," says Helen, "but don't hold out for the cure and put your life on hold."

It's important to keep abreast of new technologies and things that are available now to help, Helen told us. "Better to embrace new technologies and work out how to live the best life you can and then IF they come up with a cure we will all line up!"

Helen adds a word of caution that we must watch out that any purported cures don't involve "horrible drugs with side effects or something implanted in me that I have no control over!". Wise words from a Type 1 veteran.

NEXT MONTH in Yada, a veteran of Type 1 research and passionate advocate for people with Type 1 diabetes, [Professor Len Harrison](#), from Melbourne's esteemed Walter and Eliza Hall Institute of Medical Research (WEHI) will speak with us.

I remember hearing Len speak very passionately quite a number of years ago, assuring a roomful of people with Type 1 that research was progressing rapidly, that more had been discovered in the previous couple of decades than the centuries before. We will check in with Professor Harrison next month to get his thoughts on where we are up to today.

Diabetes Research - The Latest direct to You

The Diabetes Research Institute (DRI) in Miami, USA has always been at the forefront of using technology and clever ways of explaining the latest in research to us mere mortals. Their animated images explaining islet cell isolation spread through the diabetes community like wildfire at the height of the islet transplantation excitement in the late 90s.

The DRI's **New York Research update** event was attended by more than 300 people late last year, and videos of the lecturers from international leaders in their fields are available for viewing.

Diabetes Research Institute Seminars Online

We especially recommend:

- [**The State of Diabetes Research - A Global View**](#)
by Dr Camillo Ricordi, DRI Scientific Director
- [**New Tools and Technologies for Diabetes Management**](#)
by Dr Bill Tamborlane

Make yourself a bucket of coffee, munch on a bagel and you'll feel like you're right there in New York too!

Where have all the Endos Gone?

The biggest diabetes conference of the year is about to kick off, with 13,000 top scientists, physicians and other health care professionals about to descend on New Orleans.

The Banting lecture for Type 1 research will this year be all about prevention. The Outstanding Educator in Diabetes lecture is about "making the connection between patient and provider". Ask your endo if s/he is going, and what they learnt. Or to check it out yourself, [click here](#).

The World Diabetes Congress is also on this year - October in Montreal. Your very own Type 1 Diabetes Network is delighted (and a little terrified) to have been invited to attend and present a session about 'Diabetes Online'. If it's anything like the last one a few years ago in CapeTown, where [Kate reported to you](#) on the millions of inspiring things to learn, it should be one to watch.

We are considering a Twitter feed, or something like that, to send home all the news pronto - thoughts anyone?

Which led me to see if the Americans are onto this -
and of course they are! You can follow the New Orleans conference from 5th June on Twitter, here: <http://twitter.com/AmDiabetesAssn>

And before we start on about 'junkets' and free overseas holidays, the current issue of DiabetEzine, an e-newsletter for doctors and endos that I subscribe to, talked about the benefits for doctors - and their patients, us! - of being involved with research, including:

- Be on the forefront of what's going on in our field.
- Provide a service to your patients.
- Keep your mind active.
- Give your patients extra time. [More...](#)

Sounds like the kind of thing I want all my doctors doing!

Research about Life and Living with Type 1

Diabetes Research isn't just about a cure. A lot of research goes on to understand what impact it has on our lives, what health professionals should be doing to help us, what impact different models of health care have on getting us to achieve all those magical numbers. Slowly this trickles down to the conversations we have with our doctors and others.

One researcher who has been committed to growing the understanding of what it is really like to live with Type 1 Diabetes (while we wait for the cure researchers to strike gold) is Dr Bodil Rasmussen. Bodil is a nurse and her day job includes managing the diabetes education course for Deakin University, training the next generation of diabetes educators.

For her PhD thesis a few years ago, Bodil undertook in-depth interviews with women with Type 1 diabetes about what strategies they use to manage all sorts of life 'transitions' - critical times in our lives, made all the more complex by diabetes, **when things can all fall apart or they can miraculously stay on track - what makes the difference?** One of the things she found was that women used the [Reality Check online community](#) as a source of support and it played an important role for many of them! *We didn't pay her, I promise!* She has also written about 'the mother-daughter guilt dynamic' that she uncovered.

□ This research of Bodil's was published in some **very prestigious journals** ([click here for some articles](#)) and presented at some important conferences, which shows how high quality the research was and how seriously it is being taken by other researchers around the world. **We are very fortunate to have Bodil and her colleagues in our corner!**

GET INVOLVED: Bodil is launching Stage Two of this project. She is running a focus group on 10 June in Melbourne. If you are interested in helping, [click here for more information.](#)

***** Sponsored Announcement *****

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QUICK SHOTS

Hot topics on Reality Check online discussion this week:

- [The return of Steel Magnolias...noooooo....](#)
- [Dave Hughes on Nova - offensive to Ds or funny?](#)
- [Type 1 landscapers / labourers / physical work](#)
- [Breastfeeding problems](#)
- [Yoga teacher wants to 'help' my diabetes](#)
- [Federal budget for health consumers](#)

Jump over to www.realitycheck.org.au for much more.

There's 2,000 years of T1 Diabetes experience to tap into!

Your FAMILY can Help & be helped by Research Too

Intranasal Insulin Trial II (INIT II) Prevention Trials

A clinical trial of a nasal insulin

spray that may prevent or delay the onset of type 1 diabetes in people who have a higher

spray that may prevent or delay the onset of type 1 diabetes in people who have a higher risk of developing the condition is currently underway, and recruiting.

A simple, free test is available to any relatives aged 4 - 30 years of people with Type 1 diabetes to detect whether or not they are at high risk of developing diabetes.

Please tell your relatives about this trial. Call 1300 138 712 or visit www.stopdiabetes.com.au for more information.

Research about Type 1 BY real live People with Type 1

Here at your very own Type 1 Diabetes Network, we like to try our hand at research too. And we are pleased to have been pretty well received by most of the more traditional researchers as we stand up at conferences and tell *them* what you tell *us* about what Type 1 diabetes is really like.

If you have ever completed a survey, after we yelled out to you in this very newsletter, the results and the publications which have resulted are always published at the link below.

Some of the things that we have learnt from you, and shared with the doctors and researchers at recent conferences:

- Only **4% of young Type 1s receive recommended care** in transition from children's to adults' diabetes services
- **Diabetes Burnout might be masking Depression**, and might also be a significant psychological concern that should be picked up and supported
- **1 in 3 Adults with Type 1 diabetes were Misdiagnosed** (with a condition other than Type 1 when they first visited their healthcare professional with all the symptoms).
- **What health professionals think we need to know**, and what adults newly-diagnosed with Type 1 actually wanted to know at diagnosis are very different - but put it altogether and you get a great resource in our [Starter Kit](#).
- **Complication screening rates were only 60-70%** in 867 Australian adults surveyed.
- **Complication screening rates didn't improve** even if you had seen an endo, educator & dietitian in the last year.

For summaries and slide presentations of our research, visit
www.d1.org.au/resources.htm#abstracts

*******Sponsored Announcement*******

BREAKING NEWS: Type 1 on the US Supreme Court!

You may have heard that Barack Obama has just nominated a Latino woman to the highest court in the land over there. Did you know that if confirmed to the U.S. Supreme Court, Sonia Sotomayor, 54, would not only be the first Latino to sit on the high court, but also its **first member with Type 1 diabetes?**

also its first member with Type 1 diabetes:

There has been some controversy brewing in the US about whether her diabetes will affect her ability to do her job. Certainly, when Sotomayor was diagnosed at age 8 in the 1960s Type 1 was no fun at all. But Obama, again, said yes we can!!

This reminded us of a now retired Type 1 legal eagle closer to home. If you've never heard of Barbara Holborow, look her up. The poor woman had a horrific experience with her first pregnancy, when almost nothing was known about how to manage diabetic pregnancies and has spoken about it [here](#). There are some really inspiring videos of her work advocating for (and taking home!) neglected children and her work as a judge in NSW. [More...](#)

That's it for this month's special look at all things research.

Hit reply if you have any stories of your own or interesting news and views to share with us, or suggestions for future issues.

All the best,

Kate & Mel

The Type 1 Diabetes Network Inc.

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