

Over 10,000 people from 160 different countries converged on the Melbourne Convention Centre in the first week of December for the 2013 World Diabetes Congress. It was an intense week with over 400 speakers, 200 sessions across 7 different streams, 1,000 poster presentations a global village full of diabetes associations from all around the world and all the pharmaceutical companies spruiking their wares.

Lots of empowered and engaged consumers attended the conference and brought their voices to the conversation about diabetes. There's still a long way to go in integrating and valuing the "patient/consumer" into medical conferences but this was a great start and people with diabetes are really doing their part. The IDF have invested in a young leaders program so it was encouraging to see young people from all over the world at the conference exchanging ideas and developing projects to implement "at home." One of my highlights was connecting with so many Australian type 1s. It was wonderful to catch-up with people I've met over the years in person and online, from the Type 1 Diabetes Network of course, Diabetes Counselling, Hypoactive and the Twittersphere and to meet new people, equally passionate about type 1 diabetes.

Disappointingly a lot of health professionals demonstrated that they don't really understand what it's like to live with diabetes, and they blithely spoke of compliance and "bad control" as though diabetes is simply a matter of following a set of instructions and to have a less than perfect A1c is a moral failing. Amongst this there were glimmers of hope and encouragement from a number of others though. It might be my bias showing but those with years of experience and the highest levels of education appear to recognise and be empathetic about the difficulties of managing insulin dependent diabetes and they know the failings of even the most modern treatment regimes and insulins. For example. Professor Jay Skyla gave a really interesting talk on the history of diabetes and its treatment. I nodded along about the impure long acting insulins that were introduced in the 1950s and were standard until the very end of the '70s that allowed one shot a day (convenience was valued above control in those days, I spent the first 10 years of my diabetes life on one shot a day) but then he spoke of the failings of the Actrapid/Protaphane regimes and I wanted to punch my old doctors in the face. Why did leading diabetologists leave me thinking that the overnight lows and postprandial excursions were my fault and everyone else was doing just fine thank-you very much when these were being acknowledged as well known failings of these insulin regimes? I take some comfort in the fact that perhaps in a few decades time our struggles today will be acknowledged when even better

treatment options come along, for example, the artificial pancreas mentioned below.

Another highlight from Professor Skyla's talk and one that I am going to adopt is the term "unrestrained creativity". Professor Skyla, a diabetologist/endocrinologist from the US used the term "unrestrained creativity" as his preferred term rather than intensive insulin therapy or intensive control. I have always felt that it takes creativity to manage type 1 diabetes and this is the first time I've heard a health professional acknowledge that, so that's my new term and I'm officially a fan girl of Professor Skyla.

Progress towards an artificial pancreas was some encouraging news to come out of the Congress. The safety and efficacy of these has been proven in a number of trials, now they just need to work on the convenience and portability and then of course affordability, but they are progressing! This session was also interesting in that it showed data from some of the trials of the artificial pancreas, some patients' insulin needs varied markedly from one night to another, one set of data showed a 100% increase in insulin need for one patient from one night to another. Professor Peter Coleman (a lovely endo from Melbourne) remarked in question time that that "showed why we are all struggling". The presenter wouldn't conjecture as to what caused this variation as there was no actual data collected. It was expected but nonetheless disappointing that this session was preceded by a talk on "the cure; where are we at". This session was a little downbeat and reflected the failure or extremely limited success of various trial cures, for example, encapsulated islet cells. One of the researchers was asked when he thought a viable cure would be available, he responded "I will be very disappointed if we don't have something in 15 years", the Moderator responded "we were told ten years in 1983". Hmmm, so nothing new there.

The presence of so many international delegates was fascinating and challenging. Hearing stories from developing nations where insulin is difficult to access, let alone blood testing equipment and the life expectancy of children with type 1 is just a few years, receiving just enough insulin to prolong life is heartbreaking. You realise that shitty as it is that you have diabetes, you have won the international birthright sweepstakes by being a diabetic in a country like Australia. The Life for a Child program, an IDF initiative and Australia's own Insulin for Life charity deserve our support.

It was encouraging to see some recognition and discussion of stigma associated with diabetes. Again, the international perspective on this was challenging. In many countries diabetes is still seen as a disgrace and people

keep their diabetes a secret. It was interesting to hear Pakistani cricket legend (yes I'm a cricket tragic) Wasim Akrim speak of "coming out" about his diabetes in order to overcome stigma and raise awareness in Pakistan. He noted that in Pakistan there is a real fear of death associated with taking insulin that obviously creates major barriers to good diabetes care.

From an Australian perspective, the most interesting work seemed to be coming from a newish group, the Australian Centre for Behavioural Research into Diabetes. Of most relevance to us was their research into stigma associated with diabetes, and specifically the experiences of adults with type 1 diabetes. They showed that type 1s do experience some significant forms of stigma, including things like loss of power when they are first diagnosed - but the biggest thing to come out was the strong desire to differentiate ourselves from Type 2s. No surprise there, but the research is connected with informing how public awareness campaigns about diabetes are conducted in the future, and together with a similar study into Type 2s experiences, they are generating a strong evidence base that those campaigns are creating a stigma around diabetes which is having a detrimental effect on both type 1s and type 2s. I really look forward to more work on the psychological aspects of diabetes coming from this group, especially because their research seems to be linked both with a solid understanding of what issues are important to people with diabetes, and with action and making change.

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It was great to experience this diabetes event in Australia and to be part of the international dialogue about diabetes. Here's hoping that the 2013 Congress is just the beginning of consumer involvement and consumers can be fully integrated into the conference, including the trade displays and poster presentations in future conferences. I'm already looking forward to Vancouver 2015, bring it on!