Insulin Dependent Diabetes Trust

Registered Charity No 1058284

# Parents' Bulletin

March 2012

## Ninety Years since the first injection of insulin

2012 is the 90th anniversary of the first injection of insulin and what followed made the difference between diabetes being a death sentence and the life children and adults with diabetes have today. It wasn't until the 1940s that long-acting insulin was developed and highly purified insulin was not available until the 1970s.

For parents of today, 1922 may sound a long time ago, but when my daughter was diagnosed in 1975, it was only just over 40 years earlier that insulin was discovered and lives were saved, so I remember feeling a certain amount of shock that if she had been part of her grandparents generation, she probably would not have survived.

I met people who had been diagnosed just before the discovery of insulin and who had been hanging on by using a horrendous diet to just stay alive. Later, I met someone who as diagnosed at the age of 11, just after World War II, and I found his story unbelievable by today's standards. He knew he had an illness but was not told what it was for several years. He just used to go to the hospital in the mornings on his way to school, have an injection and then go on off to school. The last time I saw him he was a healthy 50 plus year old, so it worked for him.

**What about the injections?**

They were done with a large glass syringe and a needle that was thick and huge by comparison with today's needles. When my daughter was diagnosed, this whole syringe and needle was stored between injections in industrial spirit in a plastic tubular container. Friday night was 'boil-up night' - the syringe and needles were boiled in a pan

to keep them sterile! It was a few years before plastic disposable syringes became available and then we had to buy them as they were not available on the NHS! Of course, with the introduction of pen injection devices much later, syringes are now classed as 'old fashioned'. Having said this, some people still prefer them – they have greater confidence that the insulin has actually gone in because they can see the syringe is empty and they are smaller than pens. It's all about personal choice...

**How did we measure what was going on with glucose levels?**
Inaccurate though it was, the only way was by testing urine until the late 1960s when Dextrostix® were developed. These were paper strips on to which a drop of blood was placed and timed for 1 minute. The strips changed to a blue colour which was then measured against a colour chart to give an approximate blood glucose level. Although this was better than urine tests, for most people you generally only knew if you were very high or very low! Again these strips had to be paid for.

Then in 1970, a scientist developed the first meter – a reflectance meter which simply read the reflected light from the blue colour of the Dextrostix. The darker the blue, the less light would be reflected. The reflected light was sent to a photoelectric cell which gave you a read out, from a swinging needle. The real drawback was not just the cost, about £300 which was a lot of money in the 70s, but it was huge and certainly not something that could be used at home. Our local parents' group raised funds to have one on the Children's Ward at our hospital and it was wonderful. This was fairly soon followed by home glucose monitors, once the medical profession could be convinced that patients were actually capable of using them without medical supervision. Things have moved a long way since 1922!

# Pump News

**Three-year comparison of HbA1cs on pump treatment and multi-daily injections**

The aim of this study was to find out the impact of insulin pump therapy [CSII] on HbA1cs in children with Type 1 diabetes and to investigate whether CSII is associated with an increased risk of acute complications of diabetes. All the children were on multi-dose insulin injections [MDI] throughout the recruitment period, then split into two groups matched for duration of diabetes and HbA1c levels at the start of the study.
The results were perhaps somewhat surprising:

- The HbA1cs in the CSII group were lower than the MDI group but only by a small amount - 7.56% compared to 7.98% respectively.
- There was greater variability of HbA1cs from standard in the MDI group than the CSII group.
- The rate of hospitalisation for acute complications was similar in both groups.
- The duration of hospitalisation was on average 1.25 days shorter for those on CSII.

The researchers concluded that insulin pump treatment may improve glycaemic control and reduce its variability. However, a change from multi-daily injections to pump therapy does not alter the risk of hospitalisation but may reduce the annual duration of hospitalisation in children with diabetes. [Acta Diabetologia DOI: 10.1007/s00592-011-0332-7]

**Pump use in young children and in adolescents**
A study investigated the clinical and metabolic effects of insulin pump therapy on children with Type 1 diabetes before and after 2 years of using the pump. [PMID: 17646722]

47 children were divided into two groups: Group A, 20 pre-pubertal children with an average age of 7 and Group B, 27 pubertal children with an average age of 14. There was no difference in weight in either group before and after use of the pump.

**In Group A, those with an average age of 7 years:**

- The frequency of episodes of mild hypoglycaemia significantly reduced during pump therapy in Group A only.
- The HbA1c levels significantly improved in Group A after 6, 12 and 24 months of pump use.

**In Group B, those with an average age of 14**

- There was no reduction in the frequency of mild hypoglycaemia.
- HbA1c values were reduced only after 6 months of pump therapy in Group B and not at 12 and 24 months as in the young children.
- No significant correlation was found between the percentage of the basal insulin, rate of insulin and the number of daily boluses. Differences in timing of the highest insulin requirement were observed between the two groups. Group A had a higher insulin basal rate late in the evening [20:00-24:00 hrs], while Group B had a higher insulin requirement early in the morning [03:00- 07:00 hrs].

Perhaps this study demonstrates that the difficulties of trying to obtain 'good' control in adolescents with Type 1 diabetes?

**Access to insulin pumps**

A Parliamentary Question asked the Secretary of State for Health whether he has plans to bring forward proposals to increase access to insulin pumps for people with Type 1 diabetes. The response was that NICE guidelines and international evidence are clear on the use and benefits of pumps. In addition:

- Dr Rowan Hillson, the National Clinical Director for Diabetes is chairing a working group which is considering steps to be taken to increase uptake of pumps.
- The NHS Operating Framework for 2011/12 also highlights the need to do more to make pumps available.
- The NHS Technology Adoption Centre has published guidance for the NHS to help to drive up pump availability in line with NICE guidance.

Note: visit IDDT's website to check NICE Guidelines relating to diabetes – the Insulin Pump guidance can be found on IDDT.org here: **http://www.iddt.org/nice-guidelines/**

**On the way - new meter to help with night hypos for pump users...**

In January, Medtronic received approval in the US for the first remote glucose meter to work with Medtronic's MiniMed Paradigm Real-Time Revel System, an insulin pump with built-in continuous glucose monitoring. It displays blood sugar readings and also information on the insulin pump battery life and amount of insulin remaining.

This will enable parents to check blood glucose levels from another room while their child is sleeping.

It is estimated that three out of four hypos occur overnight and some parents get up several times a night to check their child's blood glucose levels. The bedside monitor has an alarm that alerts the parent or carer to changes in blood sugars so that they can take action or go back to sleep if everything is OK. It could easily be used for adults with Type 1 diabetes as they could leave the alarm by their bed so that it wakes them if the blood sugar levels are dropping. The meter is called the 'mySentry' and is costs about US$3000.

Medtronic's most advanced insulin pump, the Paradigm Veo, includes an automated safety feature called low-glucose suspend that shuts off the insulin flow when glucose falls low. The device, connected to patients through a small catheter placed just under the skin, is sold in 50 countries outside the United States.

## Research

**Diabetes Vaccine may be a step closer**

Researchers in Australia are a step closer to developing a vaccine for Type 1 diabetes after showing that a nasal spray can stop the body's immune system from attacking the insulin-producing cells in

the pancreas. The vaccine is not intended as a treatment for people who already have Type 1 diabetes.

The tests are taking place in young people who have a family history of Type 1 diabetes and who have developed antibodies to the condition. The spray suppressed the immune response to insulin in 52 children with newly diagnosed Type 1 diabetes by stimulating an immune response in the lining of the nose.
[Diabetes, June 2011]

### Infant formula linked to Type 1 diabetes in children

According to a study carried out in Finland, if an infant is switched from breast milk to highly hydrolyzed infant formula, the baby has a reduced risk of developing Type 1 diabetes.

The researchers studied babies who carried the HLA genotype which puts them at risk of developing Type 1 diabetes later in their lives. The study showed that the babies who were switched to hydrolyzed formula had a 50% lesser chance of developing diabetes that those who transferred straight from breast milk to foods such as cereals and fruit.

### Type 1 diabetes and other autoimmune conditions

According to a study published in Diabetes Care, 25% of 491 children with Type 1 diabetes exhibited thyroid disease-related antibodies and that one in eight of them had thyroid disease at the time of their diabetes diagnosis. About one in eight of the children had coeliac disease-linked antibodies, and one-quarter of them had the condition. Researchers also learned that 1% of the children exhibited Addison's autoantibodies, and one child had the condition.

### Gluten not linked to babies' risk of Type 1 diabetes

Some previous studies have suggested that babies exposed to gluten as part of their diet in their first year might be more prone to developing Type 1 diabetes later in their childhood. Recent research has shown that for children at higher risk of Type 1 diabetes, a gluten-free diet in the first year of their lives does not lower their chances of developing Type 1 diabetes. The study only included 150 children who had one parent or a sibling with Type 1 diabetes, but the researchers believe that even in a larger study, the results would still be the same.
[Diabetes Care online, April 2011]

## IDDT Certificate

If you would like to show how proud you are of your child, then apply for an IDDT Certificate for them - it could be doing their first injection or going to a school disco and managing the extra exercise and excitement.

## Hall of Fame

Maybe you would like your child to join our Hall of Fame on our website – take a look at some of our Hall of Fame members by visiting:
**http://www.iddt.org/hall-of-fame/**

To get a certificate for your child or to be on our Hall of Fame, contact **bev@iddtinternational.org**

### Harrow College Heath Week

IDDT was invited to attend Harrow Colleges Health week to help teach their students about diabetes. Every year the college hosts an exhibition and workshops to promote all kinds of health issues to the students who are between the ages of 16 and 19. They were all interested in learning more about diabetes. Many of the students were training in Health and Social Care and took away information to help them with their course work. Well done Harrow

College for helping the next generation learn more about diabetes.

### Miss Temples' class

A huge thank you to Miss Temples year 8 class for choosing IDDT as their charity of the week. The class prepared a presentation showing the whole school about the difference between Type1 and Type 2 diabetes. This was followed by a role playing activity showing how someone could be diagnosed with Type 1 diabetes by the symptoms and what to do if the symptoms occur. The class then spent the whole week fundraising in their break time by setting up stands including name the teddy, a raffle and henna tattoos. A big thank you to you all for raising nearly £100 for IDDT.

## A Date for Your Diary

It may seem like a long way off but we thought we would take this opportunity to let you know about IDDT's 2012 Annual Conference. Once again we will be holding the Conference at the Kettering Park Hotel and the venue has been booked for Saturday 13th October.

As usual there will be talks from a range of speakers on a variety of subjects that will be of interest to people living with diabetes, as well as both formal and informal opportunities to meet other people who live with the condition and to share knowledge and experiences.

As a relatively small organisation, we are very aware that this is difficult for parents to attend as we are not able to offer childcare but perhaps one parent could attend or both parents with grandparents who could take the children out for the day. We had some really positive feedback after last years' event, so we hope that you will be able to come along and make this years' event even more of a success.

## Hiding vegetables in food

We all want our children to eat a healthy diet but perhaps we all know that they don't always want to! A study in the US looked at changing the diet of 3 to 6 year old children and although the study was related to preventing obesity, the methods used to increase consumption of vegetables could be used for all children.

In the experiment 39 children were served meals that contained extra vegetables. The vegetables, such as broccoli, cauliflower, tomatoes and squash were puréed and added to familiar foods such as pasta dishes or chicken casserole on three separate days. The study showed:

- the children ate the same weight of food,
- the vegetable intake nearly doubled,
- the nutritional value of the meals went up but the dishes contained 15 to 25% less calories.

It could be argued that the hiding of vegetables is deceptive and implies that whole vegetables are 'not nice' but … [American Journal of Clinical Nutrition, July 2011]

# Bits and pieces of news

## Continuous glucose monitoring in children

A recently published study has shown that only 19% of children with Type 1 diabetes between the ages of 4 and 9 who used a continuous monitor reduced their HbA1c by at least 0.5% without any severe hypos compared with 28% in the control group. The researchers also found that only 41% of patients used the devices for an average of 6 days per week by the end of 26 weeks. [Diabetes Care, Jan 2012]

## Diabetes risk is seen for children of mums with low vitamin D levels

Children whose mothers had the lowest levels of 25-hydroxy-vitamin D during pregnancy had a more than twofold higher risk of developing Type 1 diabetes compared with those born to women with higher vitamin D levels. [Diabetes Care, Dec 2011]

## Study of Diamyd Medical's diabetes vaccine

A total of 50 healthy children have entered this study. They all have an autoimmune process going on where the insulin-producing beta cells in the pancreas are being destroyed. The study is to find out if a vaccine, called Diamyd, can delay or halt the progression of the condition so that the children do not develop the symptoms of Type 1 diabetes. If treatment with Diamyd reduces the risk of Type 1 diabetes developing, a larger study will be carried out. [Press release, Jan 2012]

## Stem cells could kick-start the pancreas

Scientists have discovered that stem cells found in the umbilical cord can re-educate the immune T-cells in Type 1 diabetes. T-cells can counteract mutant or damaged cells in the pancreas. This re-started insulin production and reduced the need for insulin by 38% in 12 weeks.

We have to be aware that this was a very small study involving only 15 people and while it is interesting, specific stem cell research for Type 1 diabetes is a long way off!

## Diabetes and Asthma

According to a study published last year, children with diabetes may have a higher than average risk of having asthma. It has also shown that having both conditions seems to cause greater difficulty with keeping blood glucose levels under control. The study was carried out in the US and the results showed that:

- 11% of 3 to 21 year olds with diabetes had asthma whereas about 9% of children and young people without diabetes have asthma.
- In 311 young people with Type 2 diabetes [as a result of obesity] the difference was greater – 16% had asthma compared with 10% of those with Type 1 diabetes.
- Children with Type 1 diabetes and asthma were more likely to have HbA1cs which could be as high as 15.5% compared to 9% in those who did not have asthma.
- When the young people were using asthma medication high blood sugars were seen in less than 5% compared with 30% of those with Type 1 diabetes not taking asthma medication.

The researchers commented that the higher rate of asthma in young people with Type 2 diabetes is probably not surprising because there is an asthma/obesity link. They also added that the reason young people with Type 1 diabetes and asthma have poorer blood glucose levels suggests a "real biological connection", although it could simply be just harder for children with more than one chronic condition.

Nevertheless, the advice is if parents notice potential signs of asthma, such as wheezing, coughing or breathing problems not related to a cold, they should talk to their doctor.
[Pediatrics, Sept 26, 2011]

# NHS News

### ‘Children’s and Young People’s Outcomes Strategy’

The Secretary of State for Health, Andrew Lansley has announced that later this year there will be a new focus on improving care for children and young people. It is being called the ‘Children’s and Young People’s Outcomes Strategy’. It will focus the health service on improving health results for children including those needing primary, hospital and urgent care, and children with long-term conditions. According to Mr Lansley, it will identify health issues that matter most to children and young people and how a modern NHS will meet those needs. Apparently this will be done by bringing together people and resources from across the NHS, social care and wider children’s services to develop a clear set of goals.

To inform the strategy, a group of independent experts from Local Government, the NHS and charities will hear views from children, parents, carers and wider families as well as health professionals. This group will have 52 members invited by the Secretary of State and will meet once a month over a three month period with appropriate stakeholders (January to March), before reporting back and submitting their recommendations to the Government later in the year.

### Department of Health issues guidance on exercise in young children - even babies who can’t walk should exercise

The UK Department of Health has said that even babies need exercise. As part of the campaign which started in July 2011, guidelines have been issued saying that children under 5, including babies who can’t even walk, should be physically active for at least 3 hours a day, spread throughout the day. They also said that parents should reduce the amount of time this age group watch TV or are strapped into a stroller. Most children will achieve this level of activity simply through play or walking to school/pre-school.

How do babies exercise? By playing on their stomachs as this encourages them to use their muscles and helps bone development or by swimming with their parents

For children between the ages of 5 and 8 years, the Department of Health recommends at least one hour of exercise a day and this should include intensive activities to strengthen muscles and bones.

## Verbal and academic skills in children with early onset Type 1 diabetes

Research carried out in Finland assessed if verbal and academic skills in children with early onset Type 1 diabetes were different from those of children without diabetes. The study involved 51 children with diabetes, average age of 9 years 11 months, with 92 children of the same age without diabetes looking at specific tasks – phonological processing, short-term memory, rapid automised naming, reading, spelling and mathematics.

Phonological processing is an auditory processing skill relating to words but occurs in the absence of print. It involves detecting and discriminating differences in speech sounds. It might show itself as errors in speech production or in misperception of spoken language and in school, there may be difficulty associating the speech sounds to letters when reading and spelling.

The results showed that children with early onset diabetes were prone to minor learning difficulties in their early school years due to difficulties in phonological processing. They were slightly poorer with spelling accuracy and mathematics and they learned to read later. The good news is that reading and incidence of dyslexia by the age of 9 to 10 were similar in the two groups.

While this research may be disturbing for parents of young children

with diabetes, knowing that this may happen means that you are better able to understand and explain the situation to teachers if problems of this type occur. [Dev Med Child Neurol 2010 Mar 19]

## Stevia – A Sweetener That May Be Useful To You

Stevia is a natural herbal sweetener that is 200 to 300 times sweeter than table sugar by weight but has no calories or carbohydrates. It contains substances called “glycosides” which are responsible for its sweetness. The stevia extract is taken from the stevia rebaudiana plant originally native to South America where it has been used for sweetness for hundreds of years.

Produced as a sweetener, it can be found in most of the major supermarkets under the name of ‘Truvia’. It is also made in pure powder extract form, soluble tablets, sachets and even liquid extracts.

## Carb Counting made easy – for just £2.99

Many people have told IDDT that they would like more information about carbohydrate counting and food types. So we have done something about it!

You can purchase from IDDT ***Collins Gem ‘Carb Counter’*** for the discounted price of £2.99 including p&p. It is an easy to carry around little book with details of over 2000 foods, their carbohydrate values and also details of their fibre, protein and fat content.

Some of our members are already using this little book because it was recommended by their diabetes clinic.

**If you would like to order a copy of ‘Carb Counter’, just call IDDT on 01604 622837, email enquiries@iddtinternational.org or write to IDDT, PO Box 294, Northampton NN1 4XS. If paying by cheque, please make it payable to ‘IDDT’ or we accept credit cards over the phone.**

## The Health and Social Care Bill

If Government Whips do their job and MPS vote along party lines, it looks as if the proposed Health and Social Care Bill will go through parliament and be approved. IT will mean major changes in the NHS and effectively the dismantling of the NHS as we know it. If you would like to know more about it, please request a copy of our March 2012 Newsletter in which there is more information.

IDDT has also produced a new leaflet, ‘Know Your Rights’ to help us all to know our rights as patients within the NHS. If you would like a copy, please don’t hesitate to give us a call on 01604 622837.

## Insulin for Life

Last year IDDT continued to work with an international organisation called Insulin for Life, to collect unwanted, unopened and in-date insulin and diabetes supplies and to distribute these to clinics in developing countries. We also continued to co-ordinate our Sponsor a Child Scheme. This scheme allows people to sponsor a child that is cared for by the Dream Trust Hospital in India, By making a regular monthly donations sponsors can support the hospital to purchase the insulin and diabetes supplies that are so desperately needed just to stay alive.

In 2011 we managed to collect and distribute over 8,000 pens, cartridges and vials of insulin and send them to those who need them. All this insulin came to a value of over £25,000 and without organisations like Insulin for Life, it would simply have gone to waste.

Similarly the support for the Dream Trust has gone from strength to strength with over 75 sponsors supporting 28 children to provide the £17 a month needed by each child to buy life-saving insulin.

For more information about how we help developing countries visit: **http://www.iddt.org/here-to-help/helping-developing-countries/** or contact us using the details at the end of this Bulletin.


Some of the Children from the Dream Trust Hospital celebrating World Diabetes Day in November last year.

How **You** can help:
There are three ways in which you can help.

- Perhaps you have recently changed your insulin or equipment and now have supplies that you no longer need – then send them direct to us and we will ensure that they are sent to those that need them.
- Ask for one of our "Look in Your Fridge" posters to give to your doctor and/or nurse and ask them to send us any unwanted insulin that they have.
- Consider sponsoring one of the many children whose diabetes is cared for by the Dream Trust in India. It costs as little as £2 a month to sponsor a child. For more information on the Dream Trust visit www.dreamtrust.org or contact IDDT for more information.

**IDDT produces a wide range of FREE information leaflets, including information on Carbohydrates, Hypoglycaemia in Children, Looking After Your Insulin and our most recent 20 page booklet, 'Diabetes – Everyday Eating'. These can be sent by post or downloaded from our website.**

**Don't forget IDDT's FREE Hospital Passport if your child has to go into hospital. It provides information to hospital staff about your child's regime, meals and timing, their likes and dislikes and details of any allergies.**

**For more information contact us.**
**Insulin Dependent Diabetes Trust, PO Box 294, Northampton NN1 4XS**
**Telephone: 01604 622837**
**Email: enquiries@iddtinternational.org**
**Or visit our website: www.iddtinternational.org**

**If you would like to join IDDT, or know of someone who would, please fill in the form (block letters) and return it to:**

**IDDT**
PO Box 294
Northampton
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Name: ———————————————————————————

Address: ———————————————————————————

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## From Your Editor – Bev Freeman

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