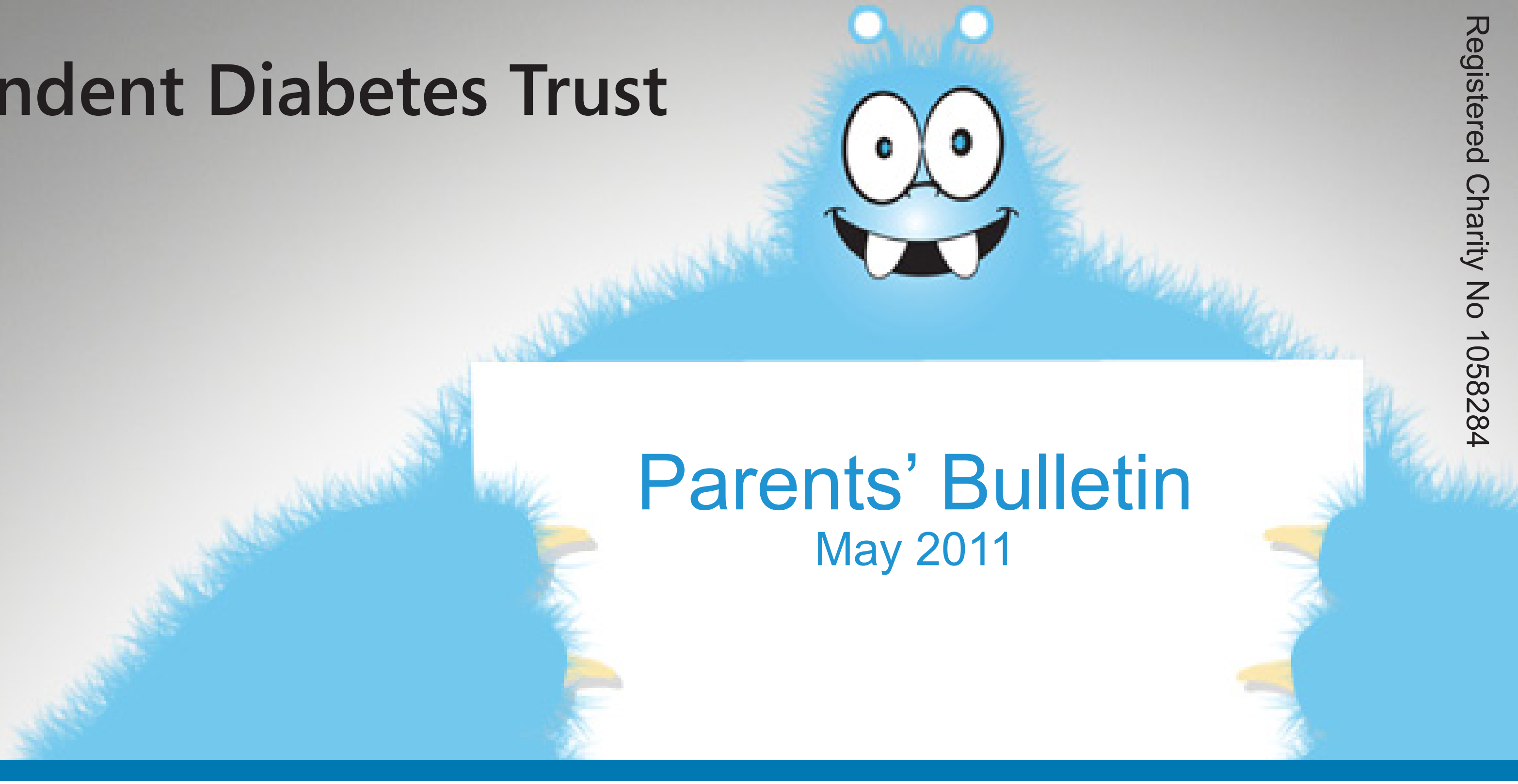
Insulin Dependent Diabetes Trust

Registered Charity No 1058284



Parents' Bulletin

May 2011

Getting Schools to Understand More about Type 1

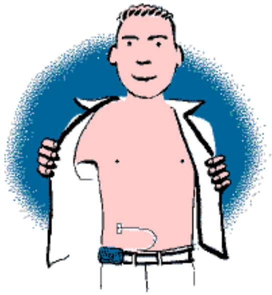
There are now 1500 schools across the UK using IDDT's Free Lesson Plan and Teaching Resources to help children and teaching staff learn more about diabetes. IDDT have travelled the country promoting the Lesson Plans and Teaching Resources so teaching staff and pupils can have a better understanding of diabetes and to try to break down some of the misconceptions that surround diabetes.

Two years ago we had many reports from parents that schools simply did not understand diabetes and that some schools were fearful of teaching the children because of their diabetes. IDDT did some research and found the best way to remove these fears and prejudices was to educate. IDDT and head teacher, Pam Gillett, put together 5 Lesson Plans for the schools to use in their PSHE lessons to teach children about diabetes. This not only teaches the children but also means the teachers themselves have to learn more about diabetes.

We would like to thank all the schools that have come on board with the Lesson Plan Project and hope that many more in the future will do the same.

For more information about IDDT's FREE Lesson Plans please contact bev@iddtinternational.org

TES Conference in Manchester 2010



Choosing not to have a pump

By Dr Jane Essex

If you have had to do battle to obtain a pump you may be surprised to learn that some people have been offered a pump under NICE guidelines and decided not to accept it. Other pumpers decide that they need a brief 'pump holiday'. And a very few others, having used a pump for a considerable period, decide to discontinue pump use. You may be wondering why?

If these decisions do surprise you, I imagine that you are a 'new recruit' to insulin pumps. Keenness of the convert may make non-users reluctant to share their decision. Awareness of the financial investment of a pump can make people feel they have to persevere when they are no longer happy with it. After spending so much time learning how to use it effectively, you may simply feel that it's a waste of that effort to discontinue. However, it is important that pump users feel that they can discontinue use when they choose to; remember unless your clinical situation has changed dramatically, for instance you have had successful islet cell transplantation, you will remain eligible and can reapply for pump funding. Most commonly though, people take a shorter break and the pump sits in a drawer waiting to be 'rehabilitated' by altered circumstances or a change in attitude on the part of the user!

Some of the reasons that people stop pump using are that their needs have changed, most commonly a pregnancy is over. Sometimes the former pump user feels that the negative aspects, for example its visibility, inconvenience of carrying it, sore sites, outweigh the gains. Some people don't think they get the outcomes they had hoped for and feel frustration, whilst others simply find the regime too 'high maintenance' for them to sustain over a long period. Psychological reasons seem to account for the greatest number of people stopping pump use, and it's important to listen to your child, so that you will detect when they need a break from their pump. A managed break will leave the option for resuming pump use available in the future.

Having read these articles about pumps, I hope that you will feel more informed about the scope and limitations of the technology. The decision on whether your child should use a pump or not is a reversible one. What can be connected, can be disconnected and vice versa. Knowing when it is time to take the pump off for a while is probably the ultimate sign that you truly are using it in your child's best interests.

Needle-free delivery System

Occasionally I dream of a needle free delivery system that does not sting, does not leave massive bruising and makes me feel confident enough to know that all the insulin needed has been correctly administered. This would be wonderful and I know that with each generation of needle-free insulin delivery systems we are getting just a little closer to this dream but unfortunately we are not there yet. The Royal College of Nursing states that needle-free insulin delivery systems should be reserved for people with true and severe needle phobia (which is rare) [Royal College of Nursing, 2006; Graveling and McIntyre, 2009]. However there is one system that is available on prescription and that is the Injex®. The Mhi-500 and SQ pens were available in the UK on an NHS prescription but this is no longer the case as it was withdrawn from the Drug Tariff in June 2010.

The Injex® system works by delivering the drug via a fine stream of fluid (under pressure) that penetrates the surface of the skin, but it is not without its faults:

- Faster absorption of insulin may occur when compared with needle injection.
- Some people may experience bruising of the skin, caused by the high pressure.

If you are interested in the Injex® the following products and accessories are prescribable:

- Starter Set — contains one needle-free delivery system, reset box, transporter, nine disposable 10 mL vial adaptors, and 165 ampoules.
- Monthly Refill Pack — containing six disposable 10 mL vial adaptors and 100 ampoules.
- Ampoule Pack — contains 50 ampoules.
- 10 mL Vial Adaptor Pack — contains 20 x 10 mL vial adaptors.
- [Prescription Pricing Division, 2010c]

Sorry, Wilbert's Picnic has had to be cancelled

Wilbert's Picnic in the Park due to be held at Wicksteed Theme Park in Kettering has had to be cancelled. IDDT cannot apologise enough to the families who were planning to join us for the day and we will try to make it up to the children who were looking forward to coming along. It was a pre-book ticket only event and we simply did not have the numbers to continue with the event.

We could give the reason as 'unforeseen circumstances' and to some extent that would be true, but the real reason is the lack of numbers of families wanting to come along. There simply aren't enough to have the fun day out that we had planned. Yes, this was unforeseen by IDDT, we thought that we were offering a day's fun for the family at a very reduced rate with the chance to meet other families who have children with diabetes.

So we are going back to the drawing board
In doing so, we'd like to hear from you. Can you let us know why Wilbert's Picnic in the Park did not appeal to your family?

- Was the venue difficult for you to get to?
- Does this sort of day out just not appeal to your children?
- And perhaps the biggest question of all, what would you like IDDT to do for families with children with diabetes?

Again, I can only apologise to the people who were planning to come along – we are disappointed too as we were all looking forward to meeting the children.

My Life with Diabetes – 61 years of Carb Counting

This is a book by Tony Huzzey who was diagnosed with Type 1 diabetes when he was 12 years old – 61 years ago. IDDT can proudly claim that Tony has been a member of IDDT almost since we first formed.

He has lead an enjoyable, successful and socially useful life which makes interesting reading in itself but he recounts his life with diabetes in a way that makes readers realise that his diabetes was just another facet of his life which did not override his ambitions, his triumphs or his enjoyment of life.

At 12 years old, Tony was treated by the famous Dr Laurence who himself had Type 1 diabetes. From the outset Tony was encouraged to 'fight back' by accepting personal responsibility for the maintenance of his own health and this he undoubtedly did! In 1950, the treatment of diabetes was very different from now but what really struck me was the simplicity of the treatment and the success of the treatment as Tony followed the rules. I wondered if he followed the rules because of the simplicity of the treatment and he was able to understand what was happening to his blood glucose levels and why? If so are there some messages here for today’s treatment?

My daughter has had Type 1 diabetes 35 years, although we didn’t have to sharpen needles and there was a lot of similarity to Tony’s management of his diabetes, for instance, no blood glucose testing. The overriding thing that struck me about Tony’s life and my daughter’s life was the simplicity of managing diabetes. He managed it by the basic golden rules – twice daily insulin, carb counting and exercise. If his blood sugars were high, his first thought was not to inject more insulin which would have a knock on effect later, but it was to go for a walk or a cycle ride. Yes, the diet was somewhat restricted - but it worked. He did not have to worry about injections at lunch time at school or at work, he ate similar amounts of carbohydrate at each meal and he was on less aggressive animal insulin, so the pattern of his blood sugars was regular and predictable. And 61 years later he’s here telling us all about it.

The book provides parents of today’s generation of children with Type 1 diabetes with a different perspective of basic diabetes management, remembering that he did not have the luxury of blood glucose testing. It provides some thoughts about managing the highs and the lows of diabetes and above all it shows how with encouragement and self confidence, he led a fulfilling and happy life. Diabetes today must seem a huge burden to children, so much testing, so many injections and of course, the risks of hypos with tight control. Old fashioned Tony’s way may seem, he does not come over as being under pressure in the same way that diabetes management seems to be to today’s children.

‘My Life with Diabetes’ by Tony Huzzey. ISBN 078-1-907611-83-4 Price £9.99, and is available at Amazon.

* * *

Diabetes in Tanzania – how IDDT helps

For the last few years IDDT has been working with the International Diabetes Federation (IDF) and the Tanzania Diabetes Federation (TDA) to provide much needed aid to children and young adults with type 1 diabetes in Tanzania. The TDA started its child sponsorship program in 2005, supported by organisations like IDDT and the IDF, who collect and send-on vital supplies, including syringes and blood glucose testing equipment.

The vast majority of families of children with type 1 diabetes live on very low incomes and simply cannot afford to provide adequate food for their children, let alone purchase the insulin and equipment they need. This very often means that parents discourage their children from having daily multiple insulin injections, resulting in high rates of hospital admissions of children with diabetic ketoacidosis. It also means that the children also have HbA1c levels that are very high, thus increasing the risk of developing the complications of diabetes. Add to this the fact that many families cannot afford the costs of travelling to and from their clinic, simply makes the situation even worse.

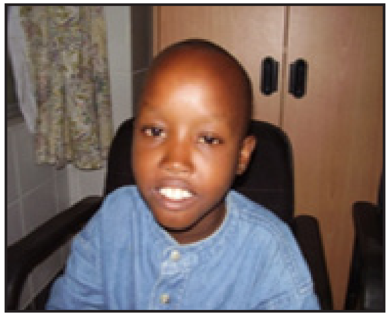
The sponsorship program was started in 2005 by Dr Kaushik Ramaiya at the Muhimbili National Hospital with just 30 children. Since then the project has continued to expand and now supports 260 children in 5 hospitals. The program has been able to support the training of doctors and nursing staff, as well as develop a comprehensive education program for children and their families. Thanks to this the program has made some major achievements, including:

- A reduction in the incidence of diabetic ketoacidosis.
- A reduction in the number and duration of hospital admissions.
- A decrease in mortality rates.
- A decrease in the number of school days lost.
- An increase in body weight of children with type 1 diabetes.

In addition to building on these achievements, the TDA is looking to secure funding to help towards the travel costs of poor families who need to attend the clinics, further helping to improve their quality of life.

Here are some of the childrens' stories in their own words:

Evance Mmasi



Age 8

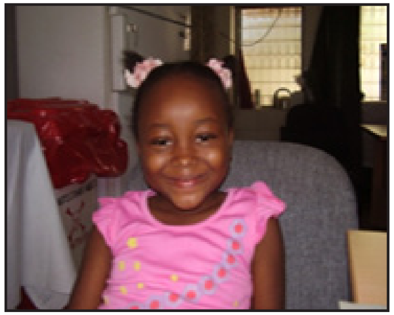
Age 14

My name is Evance Mmasi, 14 years old male. I am the 11th born in the family of twelve. I am in standard three now. Currently I am staying with my elder brother, my parents are in Moshi. They are so poor that they could not afford to take care of my condition because I had recurrent admissions with similar complaints most of the time and no diagnosis was reached.

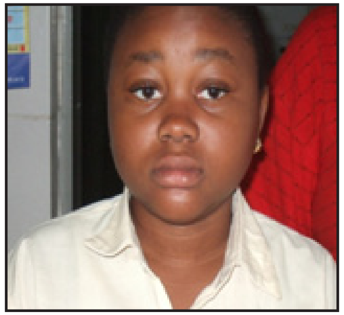
Finally I was diagnosed as having diabetes in October 2005, when I was admitted at Kilimanjaro Christian Medical Centre, Moshi .Since then I've been taking insulin. No one has Diabetes in my family. Insulin was so expensive for the two months I used it. Fortunately my brother was told about this program, I thank you so much for your support. There are other children out of Dar who are facing similar condition like I had. Please extend your support to other parts of Tanzania!

Anita Bulindi

My name is Anita John Bulindi, I am 15 years old female. I am the second born in the family of three. I have lived with diabetes for 10 years; I am in Form Four at Shaban Robert Secondary School. There is a family history of Diabetes (My paternal uncle). In 1999, I was admitted with diabetes ketoacidosis that is when I was diagnosed as having diabetes.



Age 10

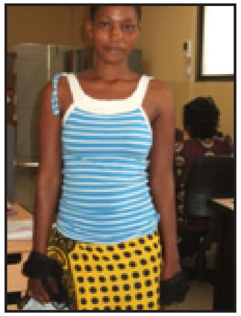


Age 15

Since then I was started on Insulin. Unfortunately I can not afford Insulin and my mother has developed mental illness in 2007. I thank the child sponsorship program, for the help they are giving us. They give us medicines and carry out regular laboratory investigations. Please keep it up.

Mariam Hassan

Age 10



Age 15

I am 19 years old. I am the 3rd born in the family of 6 Children. I have completed standard seven now. I have joined the microfinance program from TDA. I am going to establish small business. I was diagnosed with diabetes in October 2005. No one in the family has diabetes mellitus.

My family can not afford to buy insulin, so I have to move all the way from the outskirt of Dar es Salaam to come to this diabetes clinic to get Insulin. At least the transport fare is far cheaper than the cost of insulin. Thank you so much for the support. I wish this support is extended to other areas out of Dar es Salaam so that other children with Diabetes can benefit too.

How YOU can help

There are two 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 or equipment that they have.

Insulin Dependent Diabetes Trust
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E-mail: enquiries@iddtinternational.org

Diabetes And Eating Disorders

The number of people estimated to have eating disorders seems a little unclear but it has increased considerably over the last 30 years or so. Eating disorders are known to be more common in young women but men can have eating disorders too and they can develop at any age in men and women.

Research has shown that teenage girls and young women with Type 1 diabetes are two and a half times more at risk of developing the eating disorders, anorexia or bulimia than those without diabetes. There is a wide range of eating disorders but research suggests that as many as 15% to 40% of 15 to 30 year olds regularly omit or manipulate their insulin injections to lose weight. A commonly used term for this manipulation or omission of insulin is Diabulimia. Eating disorders and diabetes are both complicated conditions when they occur on their own but together the results can be very serious.

Men can have eating disorders

Although not widely recognised, men get eating disorders too. Again the figures are not really known but it is thought that between 10% and 25% of eating disorders are in men. Figures from the NHS Information Centre suggest that 6.4% [2.7 million] men show signs of some sort of eating disorder. Males of any age can develop eating disorders but they are most likely to begin between the ages of 14 and 25although it is not unusual to have an eating disorder in middle age. Recent research in Sweden has shown that young adolescent boys with Type 1 diabetes have a higher drive to be thin than their peers without diabetes.

Risk factors

Many of the risk factors for developing eating disorders are similar in men and women. Certain eating disorders are a coping mechanism or an underlying expression of emotional stress. One of the most powerful triggers for eating disorders in both sexes is dieting and as many as 70% of the general population of young people will diet at some time in their young lives. But for young people with Type 1 part of their everyday lives is having to think about food and their diet, so perhaps it is not surprising that if dieting is a trigger, eating disorders in people with Type 1 diabetes are likely to be common.

What are the consequences of eating disorders and Type 1 diabetes?

The short-term consequences are severe dehydration, muscle loss, diabetic ketoacidosis which can quickly escalate to high cholesterol, skin and yeast infections and disruption of the menstrual cycle. The long-term consequences are even more serious with a hastening of the complications of diabetes – retinopathy, neuropathy, gastroparesis, thickening of the artery walls, a type of liver disease, stroke and even death.

The services for people with Type 1 diabetes and eating disorders

Despite how common insulin manipulation or omission appears to be, it can be difficult to diagnose and there are no NHS guidelines on how to treat or deal with these issues. The services vary and in some parts of the country there are no facilities at all for people with diabetes and eating disorders.

- A new organisation has formed in the UK called 'Diabetics with Eating Disorders' [DWED] and they can be contacted as follows: e-mail info@dwed.org.uk or on their hotline, Monday to Friday after 7.00pm on 0208 808 3832 or visit their website www.dwed.org.uk
- Another useful site: www.nationaleatingdisorders.org
- For eating disorders in men: www.mengetedstoo.co.uk

Needle Phobia

The term needle phobia is used frequently and more often than not, it is used incorrectly. People over the years have said to me while I have been blood testing or doing an injection, 'How do you do that, I couldn't I have a needle phobia.' To this I smile politely and think 'Injecting isn't a lifestyle choice you know!' The fact is for the majority of us, injections and blood tests hurt, they are unpleasant and we don't like having to do them however, if we didn't the end result would be 100 times worse!

A True Definition of Needle Phobia

The condition was officially recognised in 1994 in the DSM-IV (Diagnostic and Statistical Manual, 4th edition) as a specific phobia of blood, injection and injury type. Phobic level responses to injections cause sufferers to avoid inoculations, blood tests, and in the more severe cases, all medical care at any cost.

According to Dr. James G. Hamilton, author of the pioneering paper on needle phobia, it is likely that the form of needle phobia that is genetic has some basis in evolution, given that thousands of years ago humans who meticulously avoided stab wounds and other incidences of pierced flesh would have a greater chance of survival.

Signs of needle phobia can be different depending on the age of the child and in order to get true diagnosis you will need to take your child to a psychologist. It is also important to note that if your child does have a needle phobia, it is important to see a psychologist as quickly as possible to avoid the problem becoming permanent. If you have concerns about needle phobia speak to your GP in order to get a referral to a registered psychologist.

Can Advice about Needle Phobia Help?

I have never had a needle phobia myself but while I was reading up about it, I found that much of the advice used to help overcome needle phobias was similar to how my mum (35years ago) encouraged me. The list below is by adapted from the work of Marianne Helgesson:

1. Parents' attitude to needles is very important. Parents should do their best to show no fear and to be sure that the blood tests or injections are necessary; otherwise you can never convey the necessity of the blood test or injection to the child.
2. A child should know exactly what is going to happen and why. It has been well documented that many children with diabetes believe that injection and blood test are a form of punishment for something they have done wrong. Try to state clearly to the child

that the blood test or injection is necessary and is certainly not due to anything the child has done or not done. Try to also explain that the person doing the blood test or injection is not ‘being mean’ they are doing it so the child can remain healthy and well.

3. Be honest about the pain. Let the child know that you understand that both injections and blood tests are painful no matter how much we would like them not to be.
4. Indicate the acceptable limits of protest such as: It’s ok to cry but you must not pull away.
5. Suggest diverting activities such as choosing a plaster when the deed is done. The plaster diversion is very short lived but star chart seem to work over a longer period.
6. Don’t smile to encourage. The child may believe that you are laughing
7. Afterwards comfort, praise and take time to talk to the child.
8. Expressing what has been difficult through play and drawing may help but stay with the child when playing and drawing in order to be able to correct misunderstandings and to help the child come to terms with the experience.

For adults it is sometimes difficult to see things from a child’s perspective this quote from a child many years ago demonstrates this:

‘*Why do adults smile at me when they are sticking needles in me? Do they enjoy hurting me*?’ It is easy for a child to misinterpret an adult’s smile which is meant for comfort. In my view it can sometimes be a comfort to a child to know that someone else understands how injections and blood tests feel.

If you have any bright ideas of how to raise awareness of childhood diabetes,contact Bev on 01604 622837 or e-mail bev@iddtinternational.org

Hall of Fame

Harri and his mum Helen have raised £3000 for IDDT and Pulmonary Hypertension Association. They ran a Charity Band night with an auction for good measure. A massive thank you to both of them for all their hard work and support.

Matthew Rooney aged 8 has Type 1 diabetes. He and his Year 3 classmates walked for a week wearing IDDT pedometers and T-shirts. Thank you to Matthew, his friends and of course, the teachers who helped him to organise the event. The class walked a fantastic 545,000 steps for IDDT in their walking week.

For future inclusion in the Hall of Fame please email bev@iddtinternational.org

Notice Board

IDDT’s Conference - 15th October 2011
For details contact bev@iddtinternatiomal.org
Tel: 01604 622837
Or visit the IDDT website

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
NN1 4XS

Name: ____________________
Address: ____________________
____
Postcode: ____________________
Tel No: ____________________

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From Your Editor – Bev Freeman

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