



# Insulin Dependent Diabetes Trust

Parents' Bulletin August 2009



## Wilbert's Been All Over London



Well done to all the IDDT runners and their supporters. All our runners completed the British London 10K run on Sunday 12th July. They were all wearing our new stepping out T- shirts with Wilbert on the back. Wilbert was seen passing Big Ben, The Houses of Parliament and Tower Bridge.

All the money raised will be going towards IDDT's Lesson Plan for Schools Project. See the 'Back to School' article inside for more information.

For more details of how to get involved in the 10K London Run 2010 and for details of how to donate take a look at our website: [www.iddtinternational.org](http://www.iddtinternational.org) or contact Martin on 01604 622837 or e-mail [martin@iddtinternational.org](mailto:martin@iddtinternational.org)



## Life is for living – trying to get the balance right

Like most parents, I can remember my daughter's diagnosis with Type 1 diabetes as clearly as if it was yesterday, although it was nearly 34 years ago. Bev was just 5 years old when she was diagnosed. She went into hospital for two weeks which was normal at the time as we had no home blood glucose monitoring and no diabetes specialist nurses.

Two weeks was probably too long, but being in hospital had advantages: we had time to adjust to the shock of diagnosis, I had time to cry without my children seeing me and we had two weeks of education about diabetes from the paediatrician, the dietitian and the nurses on the ward. Hospitalisation also made us realise the seriousness of Type 1 diabetes and it also made our friends and the school realise this too. How very different from today's diagnosis where children can be back to school in a couple of days. I worry that this rapid return to apparent normality gives other people, and particularly schools, the impression that diabetes is not very serious – children are absent for longer with a cold!

The dietitian played a very key role in teaching us about how to manage diabetes. We were taught to carb count and to adjust diet, exercise or insulin – the standard treatment for everyone with Type 1 diabetes. It worried me when all this changed to the high carb/low fat diet in the 1980s and to what seemed like eat what you like and just inject insulin – almost the opposite of what we had been taught! It didn't make sense to me – eating high amounts of carbohydrates when the one thing that Bev's body couldn't do was to use them properly. We bucked the system and stuck with counting carbs but, not following the recommendations meant that I felt a great responsibility for Bev. If I was wrong and 'they' were right, how would I feel, how would Bev feel? As it happens, treatment has done a full circle and carb counting is back, so I am relieved of that worry!

For me the most important development was the introduction of home blood glucose monitoring – at last a method of knowing what the blood

glucose levels were at any given moment in time! There was quite a debate about whether more finger pricks in addition to injections, would have a psychological impact on children with diabetes. The words of wisdom from our paediatrician were 'common sense in all things – don't become addicted to testing and don't forget that life is for living!' So we had to find the balance between looking after Bev's future health and not making life too difficult for her here and now – not easy!

There were many more brands of insulin and a wide range – short, intermediate, long and very long [36 hours]. If one regime did not seem to control blood glucose levels well enough, then our paediatrician tried others until we got the regime that offered the best control with the least number of hypos. With a carb controlled diet and twice daily injections of short and long-acting insulins, a lunchtime injection was not necessary – the shortacting insulin lasted over lunchtime when the longer-acting insulin kicked in. Bev went through her school life without injecting at school and was absolutely fine and still is.

Remembering our paediatrician's words that 'life is for living' and as the Mum of a now well and truly grown up daughter with diabetes, I worry when I hear the problems that children and parents are having at school over frequent testing and lunchtime injections. Using rapid-acting insulin analogues which have a short duration of action makes lunchtime injections essential but is this really providing them with the best quality of life? The battle with teachers, who understandably don't feel able to take on the responsibility for testing and injecting, runs the risk of the child with diabetes, and their parents, being classed as 'difficult' – something which cannot be good for any child.

I worry about children and teenagers who are testing and injecting rapid-acting insulin every time they eat anything – morning snack, afternoon snack as well as their pre-meal injections and their long-acting insulin. This regime is said to be more flexible but is it really when they can't eat without testing and injecting? This is a very different life from their peers without diabetes and very different from the life my daughter had with diabetes. It is far removed from the

carefree life that we hope our children can have – at least as carefree as we can make it. Will there be long-term psychological effects on this generation of children with diabetes? I don't know, nobody does as they have yet to grow up. If these insulins had ever been proved to be better or shown to reduce the risks of complications then to me there choice would be simple – children with diabetes would have to go through frequent testing and injecting and any possible effects from this, but up to now research has not shown this.

One of the biggest challenges for me when Bev was too young to make her own decisions, was hitting the balance of trying to reduce the intrusion of diabetes into her life but at the same time taking care to try to reduce the risks of long-term complications. These are difficult choices and for a long time now she has been making the choices for herself – they are her choices and I respect them.

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## Back To School

It's hard to believe that it is already time to think about getting back to school as the summer is drawing to a close and a new school year dawns. The beginning of a new school year also means a new set of teachers, which for most families is fine, but if your child has diabetes it could be riddled with problems. Over the last 15 years we have listened to our parent members and put together a Teachers Information Pack to help both teachers and parents.

The Teachers Information Pack can be given to your child's form teacher or any teacher that you feel will benefit from learning about children with type 1 diabetes. The pack includes information and posters about how to deal with hypos, an easy to read fact sheet about diabetes and a template Care Plan for your child. If you would like your free Teachers Information Pack, simply call Bev on 01604 622837 or e-mail [bev@iddtinternational.org](mailto:bev@iddtinternational.org)

## Lesson Plan Project

The Guy Culverwell Trust was formed by a group of close friends, Pamela Vythelingum, Simon Beckley, Gary Cook and Sheriden Sleaf, in memory of their good friend Guy, who sadly passed away last year. Guy had Type 1 diabetes from being a child, so they wanted to raise money to help to support and educate children with diabetes.

The Trust has been very active over the last few months and has raised over £7000 in total as well as generous £750 in matched fundraising from Barclays Bank. [www.guyculverwelltrust.com](http://www.guyculverwelltrust.com)

This fantastic amount of money has enabled IDDT to start developing our new Lesson Plan Project. The money raised has also gone a long way to hire a new adviser, Pam Gillett who is a recently retired head mistress. Pam will be writing the Lesson Plans for both junior and senior schools and will also help schools to implement the Lesson Plan. The aim of this project is to raise awareness of diabetes, show the effect diabetes can have on young people and try to help the whole school support any children with diabetes in their care.

As a listening organisation we want to hear from you about things you feel could be included in the IDDT Lesson Plan to improve your child's life at school. E-mail your ideas to [bev@iddtinternational.org](mailto:bev@iddtinternational.org)

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## Support For Teenagers To Stay Positive

Teenagers living with a long-term conditions such as diabetes can now access free local workshops enabling them to meet other young people in a similar situation, have fun and build their confidence and skills to manage their health better.

The Staying Positive Programmes are series of 3 workshops for young people living with a long term health condition, aged 12-18 years,

run by trained young people aged 15 -25 years, who are also living with a long-term condition. Topics covered in the workshop include communication with friends, family, teachers, health professionals, boyfriends and girlfriends, socialising, exercising safely, siblings, school, careers. Also covered is the future, feeling down and depressed and the transition from child to adult services. Fun activities are built into every workshop, such as drumming or digital photography.

Workshops are run at weekends or during school holidays with a responsible adult on site. An external evaluation of the Staying Positive Programme (Oxford University 2007) reported the key to the success of the workshops is that they are run by young people who also live with a long-term condition.

Staying Positive was developed by Dr Kathy Hawley in conjunction with the Expert Patient Programme CIC. The award winning programme is being developed in London, the Birmingham area, the North West and the South West during 2009. For further information about the programme contact Cathy McMahan, Project Manager on 01225 731326/07500 039701 or email [catherine.mcmahan@eppcic.co.uk](mailto:catherine.mcmahan@eppcic.co.uk)

For information on workshops running in your area  
email: [sam.lane@eppcic.co.uk](mailto:sam.lane@eppcic.co.uk)  
website: [www.staying-positive.co.uk](http://www.staying-positive.co.uk)

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## Hall Of Fame

These two scary tigers are Bethany and Lewis. Bethany was diagnosed over 11 months ago but this has not got her down and she has continued to take everything in her stride. Her little brother Lewis has been a great help to his sister by supporting her with pricking her finger.



Well done to both of you. Everyone here at IDDT is very proud of you.

Send your photos to [bev@iddtinternational.org](mailto:bev@iddtinternational.org) or check out our Hall of Fame page on our website.

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## Ask Dr Laurence - your questions answered

**Question:** My seven year old daughter was diagnosed over eighteen months ago and although we rotate her injection sites, she already has lumps. The hospital does not believe us when we say that we do rotate the sites. But we do! Could it be the type of insulin that is causing the lumps?

**Answer:** *This is possible- also if she is a bit nervous of injections, you may not be giving the injections deep enough. I would advise a change of insulin to see if it makes a difference.*

**Question:** My daughter constantly complains of genital itching could this be anything to do with her diabetes?

**Answer:** *Candida (thrush) is common in diabetes especially if there is sugar in the urine. There are some simple over the counter remedies for this infection.*

**Question:** I read through IDDT that analogue insulins have no proven benefits over other insulins, does this mean they are unsafe?

**Answer:** *It is true that insulin analogues and human insulin have never been shown to have any advantage over purified pork insulin. There have also been reports of other issues relating to insulin analogues. I have always held the view that pork insulin is as good as it gets and there is no reason to give anything else.*

If you have any questions for Dr Laurence, please send them to Bev at IDDT, PO Box 294, Northampton, NN1 4XS or e-mail [bev@iddtinternational.org](mailto:bev@iddtinternational.org)

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## IDDT Understanding Your Diabetes Day

This year IDDT's Day Out with Diabetes is being held on 10th October 2009 at The Paragon Hotel in Birmingham.



Our 'Day Out With Diabetes' is for everyone who has a connection with diabetes, whether you have diabetes, you live with someone with diabetes or you are a healthcare professional helping people with diabetes. We are here to help and support you all.

The day is not only about giving information but helps people to have a better understanding of diabetes and to meet other people in a supportive and

friendly environment.

We have something for everyone within our range of discussion groups and presentations which will be by experts on exercise, different insulin therapies and people who have grown up with diabetes.

For more information see the enclosed brochure or e-mail Bev on [bev@iddtinternational.org](mailto:bev@iddtinternational.org)

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## Don't Say No To Ice Cream

We all know only too well that too much of the sweet stuff is no good for any of us but for kids, summer isn't summer without the occasional ice cream. Kids with diabetes are no different and of course they can eat ice cream but the usual rules apply – think ahead and experiment to find out which types of ice cream affect blood sugars in different ways. There are two main types of frozen treats – lollies and ice cream. Lollies are like frozen fruit juice and often contain added sugar. The effect on the blood glucose level is the same as drinking sweetened juice except it takes longer to lick a lolly than to drink a glass of juice. Lollies can be a perfect way to deal with low blood sugars while at the beach or playing games in the park.

Ice cream as opposed to lollies are not suitable in dealing with low blood sugars. This is because ice cream is made from dairy product and so contains fat which causes the stomach to empty more slowly. This means the effect on the blood sugars will not be seen for around 45 – 90 minutes depending on the amount of fat contained in the ice cream. However, you will need to make sure that the lolly is not sugar free or a low sugar variety as this will have little or no effect on blood sugars! This also makes my guilty pleasure of a coke float achievable with one scoop of vanilla ice cream in a glass of diet coke.

## Precise Carb Counting Benefits Children With Type 1 diabetes

Research carried out in the US has shown that parental precision at carbohydrate counting is associated with improved blood sugar [glycaemic] control in children with Type 1 diabetes. [Diabetes Care, June 2009] On average parents estimate of the amount of carbohydrates their child consumed was 20% higher than the actual carbohydrate values. The researchers found that there were lower HbA1c levels [0.8%] with precise measuring of carbs and more frequent blood glucose testing.

In an interview about these findings the researcher said: *“Over the last 10 to 15 years, the adoption of new insulins and methods for insulin delivery (e.g., insulin pens and pump therapy) has facilitated diabetes care for youth with type 1 diabetes. Our findings suggest, however, that careful attention to meal-planning remains important for diabetes management... I hope that these findings highlight the importance of ensuring that families living with type 1 diabetes are properly educated in this area.”*

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## Carb Counting made easy - for just £2.99

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 a copy, give IDDT a call on 01604 622837 or simply send a cheque with your request to: IDDT, PO Box 294, Northampton, NN1 4XS

## We Have Reached over 1 million Steps to Help Raise Awareness of Children with Diabetes

Well done to all our steppers who have all been helping to raise awareness for children with diabetes. Our champion steppers since the last Parents Bulletin are Sally Barr and the Davies family who have helped to take our steps to over 1 million.

We now have kid’s t-shirts so the whole family can get involved. Go on join in and do your bit to raise awareness for children with diabetes. You can get your free Wilbert t-shirts and pedometer by contacting bev@iddtinternational.org or by giving me a call on 01604 622 837. For more information on our Stepping out campaign check out our website.

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## Does the ‘honeymoon period’ vary in duration?

As many parents will have experienced, after diagnosis of Type 1 diabetes, children often go into partial remission, known as the honeymoon period, where the need for insulin drops, sometimes to none at all. This can be a worrying and confusing time for parents – at diagnosis you have been told that your child will need insulin everyday and a few weeks later, they seem to need hardly any insulin at all.

Researchers in the US have investigated whether there are different rates of partial remission in different age groups – pre-school, school age children and adolescents with Type 1 diabetes. In other words do all children and adolescents go through the honeymoon period? They also looked at whether there are any clinical characteristics associated with increased partial remission rates. They looked at 152 consecutive patients newly diagnosed in 2004 and found the following:

- Young children [26.8%] and adolescents [29%] had low rates of remission compared to school aged children [56%].

- There were no differences in the rates of diabetic ketoacidosis [DKA], autoantibody frequency or HbA1cs at diagnosis between the groups.
- DKA at diagnosis was associated with less likelihood of having partial remission.

The researchers concluded that young children and adolescents had low rates of partial remission ie fewer numbers of these age groups experienced honeymoon periods that in school aged children. They suggest that the causes for this could be [a] in young children that metabolic control was poorest and [b] in adolescents that higher doses of insulin because of insulin resistance. They also suggest that the low frequency of the honeymoon period in young children could be a sign of more beta cell destruction in this age group.

[Pediatr Diabetes 2008 June; 9:197-201]

- Be patient if younger children cry with injections – it’s pretty scary.
- If we are going out with friends, prepare essentials for us but don’t overload us with food and snacks.
- Don’t keep asking if we have glucose with us every time we leave the house – it’s really irritating!
- Support us in what we want to do – don’t say you can’t do that, how will you manage injections and testing.
- Instead take time to discuss how we are going to manage our diabetes and still have fun like the other kids.

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## Oh Dear –We Parents Can Be A Nuisance!

It’s very easy for us parents to be somewhat obsessive about our child’s diabetes. But it is also very understandable – as caring parents, we are concerned about their health and their future. But sometimes our children must get fed up of us, particularly when they are getting to the stage of independence.

I came across some of the comments of children and adolescents with diabetes, their dos and don’ts for parents. They made me feel uncomfortable because I know I did some of the things that irritate them the most! Here are just one of two.

- Don’t go into overdrive is we are having a hypo – just hand us the juice.
- Never groan at your child when there are high test results. We usually know they are high and it is often not our fault. When it is our fault, gently remind us not to eat that last slice of cake.

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 – Jenny Hirst

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