



Insulin Dependent Diabetes Trust

Parents' Bulletin February 2009



Welcome to you all!

Win an iPod Shuffle or £100 of vouchers for your school

We had a massive response to our Free Goodie Bag campaign and we hope you are all enjoying them.

In case you had not noticed, all the fantastic stuff in your Goodie Bags has our mascot on it but in the IDDDT office we keep arguing over what we should call the mascot. So we thought we would ask you to decide on a name.

You or your class can enter the competition and the rules are simple:

- Choose the name that you think suits our mascot.
- Put the name of the mascot on a piece of paper with your name and address or your school's name and address. Don't forget to let us know if you would like the vouchers for your school or the iPod shuffle for yourself.
- Put it all in the Free Post envelope provided and post it straight back to us.
- Alternatively e-mail all the above information to bev@iddtinternational.org
- Every child or class is allowed one entry.
- The winning name will be pulled out of a very large hat by a member of the IDDDT Team.
- All entries must arrive at the IDDDT office by 2nd April 09.

Family members of the IDDDT Team and the Trustees will not be eligible to enter as individuals

Ask Dr Laurence

I would like to introduce IDDT's medical adviser Dr Laurence Gerlis who has very kindly agreed to do a regular page called 'Ask Dr Laurence' in our Parents Bulletin. The aim is to let you ask Dr Laurence questions that you feel need to be answered between hospital visits. Take a look at his long list of achievements and see if there is anything you would like to ask him.

Dr Laurence Gerlis graduated in Medical Sciences from Clare College, Cambridge with Double First Class Honours where he won the William Butler Prize in Medicine. Dr Gerlis won a Price Scholarship to The London Hospital where he won the Sutton Prize in Pathology and the Arnold Thompson Prize in Paediatrics. Dr Gerlis runs the Samedaydoctor walk-in medical centre and private GP service in Central London. He is a specialist in endocrinology. He has also worked as a radio and TV doctor, recently appearing on the Alan Titchmarsh show on ITV and he is a regular contributor to London's LBC and BBC radio. Dr Gerlis was one of the founding Trustees of IDDT and has been IDDT's medical adviser for the last 15 years. He also has a brother with Type 1 diabetes, so he too has had first-hand experience of living with diabetes in the family.

So just e-mail your questions for Dr Laurence to:
bev@iddtinternational.org

Ministers announce free school meal trial

Health secretary Alan Johnson has announced a pilot scheme offering free healthy school meals for all primary school children. Universal free school meals will be tested in "at least two" local authority areas in England and in a third area, current eligibility will be extended to include more children from poor families. The pilot scheme, will start

in September 2009 and run for two years. The cost of the scheme, £20 million, will be split equally between the two government departments responsible for the pilots – the Department of Health and the Department for Children, Schools and Families. Ministers will invite councils to bid to be involved in the pilots and they will be expected to match the government funding, taking the total budget to £40 million.



Almost all of us who have access to the internet have heard of e-bay, the on-line auction site, and quite a few of us have used it to buy and sell items – over 20 million people at last count!

What a lot of people do not realise is that every time they sell an item on e-bay they can raise money for charity – including IDDT – and it's really rather simple.

You Win – Every time you list an item for charity, you'll get a fee credit on your basic insertion and final value fees equal to the percentage you donate. So if you donate 50% of your selling price to a charity, eBay will waive 50% of your fees.

We Win – Every time you sell an item, Missionfish will collect your donation and after deducting a small fee to cover administration, pass your donation on to IDDT. For more details:
e-mail martin@iddtinternational.org

Brothers and Sisters

When we launched our Goodie Bags in November of last year we were very touched by the number of you who praised not only your children with diabetes but also their brothers and sisters for coping so

well. Having a child diagnosed with diabetes is a traumatic and life-changing event for all concerned and it was heart-warming to see how many of you acknowledged the role brothers and sisters play in supporting each other and the feelings that they all have about living with diabetes.

I have a sister with diabetes who was diagnosed when she was five and I was six and a half. Without giving our ages away, we are both now adults (allegedly!) and have a very good relationship but that is for IDDT not to say there have not been some rough patches along the way. Don't get me wrong – we have always been friends, argued like any brother and sister but always been friends. But living with diabetes opens up a range of experiences and emotions that can be confusing and upsetting for the brothers and sisters of the child with diabetes and they need a lot of support as well.

I can remember when my sister was diagnosed and taken into hospital on the children's' ward. At the time other children were not allowed on the wards and I can remember spending what seemed like hours sitting on a bench outside the ward, feeling very bored, worried, confused and wondering what was going on behind the closed doors. My Mum obviously sat down with me at some point and explained what was going on but to be honest I don't remember the conversation or even how much of it I took in at the time but the practical impact of what had happened became very obvious very quickly. My parents explained that my sister was going to need extra care and attention and that they would need my help to do this.

They involved me as fully as they could with the management of my sister's diabetes – syringes, needles, insulin were all explained. There was no secrecy or fear about her diabetes and I was allowed to even stick a needle in my own leg on several occasions so that I knew what it felt like and probably more importantly, so that my sister knew that I knew what it felt like. Nonetheless, there were times when I did feel jealous of the extra attention she was getting. Most of the time I knew this was because she was ill and feeling jealous was selfish and so then I felt guilty. I realise now that the extra attention was absolutely

necessary but when you are only six you can't always rationalise your feelings that well. My parents must have realised this and did what they could to balance things out – enter Grandma.

Our Grandma lived in Yorkshire and I would go and spend a week with her or she would come down and stay with us and I would get spoiled rotten. I also remember going to London with my father, going to Madame Tussauds and London Zoo, where I had my first Doner Kebab!

Hypos could be difficult to deal with and still are. All brothers and sisters argue but throw a low blood sugar into the equation and things get a bit more complicated. An argument would happen, upsets would occur and it wasn't until somebody realised that my sister was hypo that there was the reason for the argument. A few glucose tablets later and my sister was back her normal self, blissfully unaware of what had happened while everybody else was left feeling angry, hurt, upset or all three. It can still happen today but we are all more aware of it and as adults are able to deal with it a lot better.

Hypos don't always just leave you with "left-over" feelings, they can be frightening too. I can remember having to help my mother deal with a severe night hypo and what I now know was a seizure. I was a teenager at the time and can remember trying to get jam around the inside of my sister's cheeks while she was rigid. The whole experience left us frightened, exhausted and shaking. I can still remember it vividly so I guess it could be said that it was a traumatising event. I'm not sure if my parents had managed to protect me from this before but the first time I saw it, I was very frightened and I guess that there are going to be lots of other children out there who have had the same experience. We spent a lot of the next couple of days talking about what had happened, why it had happened and how it had left us feeling.

Growing up with a sister with diabetes has not always been easy but we lived with it. It did not spoil our family life and in many respects gave us the opportunity to explore the feelings and emotions that it

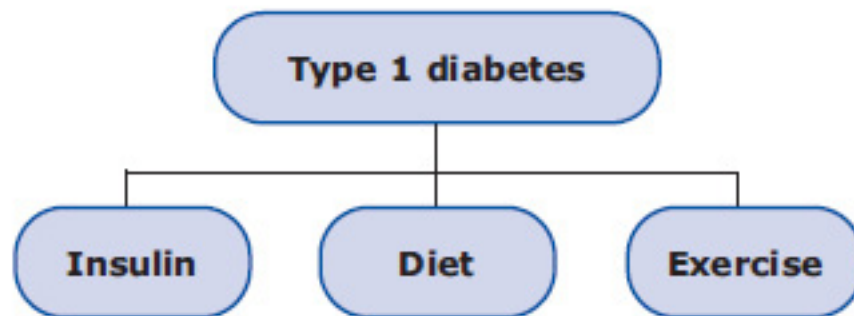
generated. By being open and sharing these feelings with each other, we have, thirty years on, a healthy mutual respect and are friends.

.....

Exercise

Exercise is good for all kids because it lowers the risk of cardiovascular disease, so in kids with diabetes it may hopefully reduce the risk of longterm diabetic complications. Lack of exercise seems to contribute to insulin resistance and a tendency to be over weight. Arguably two of the most important things exercise does for children and adolescents is improve self-esteem and helps to strengthen the body's natural defence mechanism. Younger children seem to get their exercise by running around and enjoying themselves whereas older children are different – some love sport and others enjoy a slower pace with books or computers. It is important to consider the needs of individual children and adolescents and adjust their insulin treatment and carbohydrate intake according to what suits them best.

Three important factors in the treatment of Type 1 diabetes



In the treatment of Type 1 diabetes there are three important factors – insulin, diet and exercise. All three are important because they all

affect blood sugar levels and they all affect each other. So in Type 1 diabetes there is an important relationship between insulin, diet and exercise and to achieve good diabetic control we have to try to balance all three. Diabetes is much easier to manage if we understand about carbohydrates, about exercise and about insulin. So in this article we are going to look at exercise.

Tips to help understand the effect exercise can have on blood glucose levels

- Exercise can cause hypoglycaemia as the body uses up the available glucose to provide the energy for the exercise.
- Hypoglycaemia can occur 12 – 14 hours, or even longer, after exercise. This happens if the body uses up any circulating glucose to try to replace the glycogen stores in the liver that were used up during exercise. [The liver stores glucose as glycogen for emergencies – see the notes at the end.]
- Exercise also increases the sensitivity of the body tissues to insulin, especially the muscles and this can continue for 8 to 10 hours after the exercise.
- Exercise increases the absorption of insulin from the injection site.
- If your kids exercise regularly you and they will begin to learn how much blood glucose levels change with varying activities. If they only exercise occasionally blood glucose may drop more than you would expect during and after exercise.
- Regular blood glucose monitoring is important when exercising to avoid both highs and lows. Try to take notes of what you do when your
- kids do different types of exercise and what works for them and what doesn't. This will help to teach you and your child the effects different
- types of exercise have on blood sugars.

Hypos and Exercise

Heavy exercise can cause the glycogen stores in the liver to be depleted. These stores of glycogen are released in emergency and turned into glucose, so if the stores are depleted, the risk of

hypoglycaemia is greater. This is one of the reasons why there is a risk of hypos several hours after exercise has been carried out. If this is a problem, try to rebuild the glycogen stores by eating before during and after exercise. This can be done by:

- Eating a meal of slow-acting carbohydrates about an hour before exercising will help to keep blood sugars steady during exercise. Examples: porridge, cereal or multi-grain bread.
- Eating fast-acting carbohydrate immediately before and after exercise will help to prevent hypoglycaemia. Examples: a piece of fruit, fruit juice or biscuits.
- If your child's exercise session is longer than 30 minutes they may need extra food. The recommended extra is 10-20 gram for 30 minutes of exercise.

Some tips that may help with exercise at school

- Try to find out the times of PE lessons and try to encourage your children or teenagers to eat 1-2 hours before the lesson begins so their blood glucose level is OK before they start.
- If possible, get your child to test their blood before the lesson begins, so they know whether they should eat more carbs before they start. This could help until you all get used to exercise and its effects while at school.
- If the exercise session last longer than 30 minutes, more carbs may be needed eg a banana.
- Try feeding them high carb meals after exercise, maybe extra bread.
- When you, or your child, become more confident, you could also think about reducing the pre-meal short-acting insulin before exercise, especially if there is a weight problem. You could also consider lowering the insulin dose in the evening after exercise.
- If your child has ketones this shows that the bodies cells are starving, so exercise is not advised until control is resumed.

Notes – the role of the liver

Some insulin must be present in the body at all times because insulin

is essential to enable the body's cells to take up glucose to provide the energy needed. As we know, if there was no insulin in the body the glucose will remain in the bloodstream and the blood glucose levels will remain high and continue to rise.

Exercise cannot be used as a substitute for insulin even though they both reduce blood glucose levels. When blood glucose levels drop and extra glucose is needed, the cells will send signals to the liver via hormones and adrenaline. This then triggers the release of glycogen to increase the output of glucose to combat hypoglycaemia.

It is worth remembering that after a severe hypo, it can take up to 3 days to restore the liver's stores of glycogen. This makes the likelihood of a second hypo greater.



Research

Routine admission to hospital at diagnosis for children with Type 1 diabetes – a Cochrane Review

Some children are diagnosed with diabetes in an acute condition, meaning they are very ill due to very high blood glucose levels [ketoacidosis] and therefore have to go into hospital. However, children who are not ill are often diagnosed at home and do not go into hospital or may go into hospital for only a very short time. Diagnosis is a very difficult time for the child and the parents, a time when not only do they have to come to terms with the diagnosis but also a time when they have to learn an awful lot in a short space of time.

The question has been asked about the advantages or disadvantages of routine hospital admission as opposed to home care at the diagnosis of children with Type 1 diabetes. [ref 1] This was addressed in a Cochrane Review – Cochrane Reviews are high quality reviews of all the studies carried on a topic to provide evidence to help

ecision making.

What did the review find?

- That there is not enough high quality information to answer the question.
- The studies assessed suggest that if adequate out-patient/home care management can be provided, this does not lead to any disadvantages in terms of metabolic control, acute diabetic complications and hospitalisations, psychosocial issues and behaviour or total costs.

The review made recommendations for further research:

- That there is a need for high quality randomised controlled trials to answer the question.
- That studies are required to distinguish between children who need brief hospitalisation [because they are acutely ill] and those who do not need hospitalisation.
- Studies must follow the children and families for at least two years.
- Cost assessments are needed to take into account the costs of the medical services, the costs of setting up a home care system and costs to parents and families.

These research recommendations highlight the uncertainties that exist around what is best for children when they are newly diagnosed. If children with diabetes and their families are to get the best care and treatment, these unanswered questions need addressing. We need to know what type of care causes the least number of problems in both the short and the long-term.

Having been through diagnosis of our children, we can think of advantages and disadvantages of both hospitalisation and home care. While our own experiences are undoubtedly valuable, they do not provide robust evidence for decision making.

When my daughter was diagnosed over 30 years ago, it was standard practice for children to be in hospital for 2 weeks and this was at a time

when parents couldn't stay on the ward overnight. Simply being an in-patient for a child can be a traumatic and damaging experience. How long do the effects of this last? Is this the same now that parents can stay with their child overnight? Does it depend on the age of the child? But at the same time, in the 2 weeks in hospital, we had numerous visits from the dietitian, from doctors and a lot of support from the staff on the ward so we had plenty of opportunity to ask questions. Selfish it may sound, but as parents we could also go home at night and cry for our daughter but not in front of her.

We all learned that diabetes is a serious condition, would she have learned this if she had returned to school within a couple of days of diagnosis? I am sure that two weeks in hospital is too long but children have a week off school with chicken pox, so are there mixed messages here? Are there the psychological effects different according to whether children have home care or hospitalisation?

These are all unanswered questions and we need the answers. Do you have a view?

We'd love to hear your views and experiences – write to, or e-mail:

Bev at IDDT
PO Box 294
Northampton
NN1 4XS

e-mail bev@iddtinternational.org

Ref 1 Cochrane Review available at
www.cochrane.org

Hall of Fame

Oliver

Oliver was diagnosed with type 1 diabetes at just 5 years old, two days after Christmas 2006. Oliver had an extremely tough time when he was diagnosed but has bounced back and has carried on – no matter what life and his diabetes has thrown at him.

His younger sister Alexandra has been very patient with the situation, even though she is only 4 she knows where his finger pricker, insulin and medical kit are in an emergency and accepts that he can behave oddly, be tearful and get sweets at times she isn't allowed.

His diagnoses has changed the whole family's lives so IDDT think they all need a huge well done for all coping so incredibly well.



Class 5EG

The kids at Cedar Road Primary School in Northampton (Class 5EG) have been supporting kids with diabetes by learning more about the condition. All the kids listened and learned about diabetes and what to do if someone they know had a hypo. A big thank you to the kids and the school for taking the time to listen and learn.



Grace

Grace was diagnosed on December 4th 2007 at age two and a half. She has just had her first HBA1C test and she was extremely brave so IDDT have decided she needs a huge well done and we wish her good luck with her results.

Here is a picture of Grace on her pony during the summer. She won lots of rosettes and some trophies too. Grace and Chalky are the Thelwell Champions!!



Alex

Alex, aged 5, was diagnosed with type 1 diabetes in 2005 at the age of 2. Twelve months later he was diagnosed with coeliac disease. Despite all this Alex is a happy young boy and lives life to the full every day. Alex's mum Pippa and all of us here at IDDT Children's Club would like to give Alex a huge shout out and let him know how proud we all are of him.

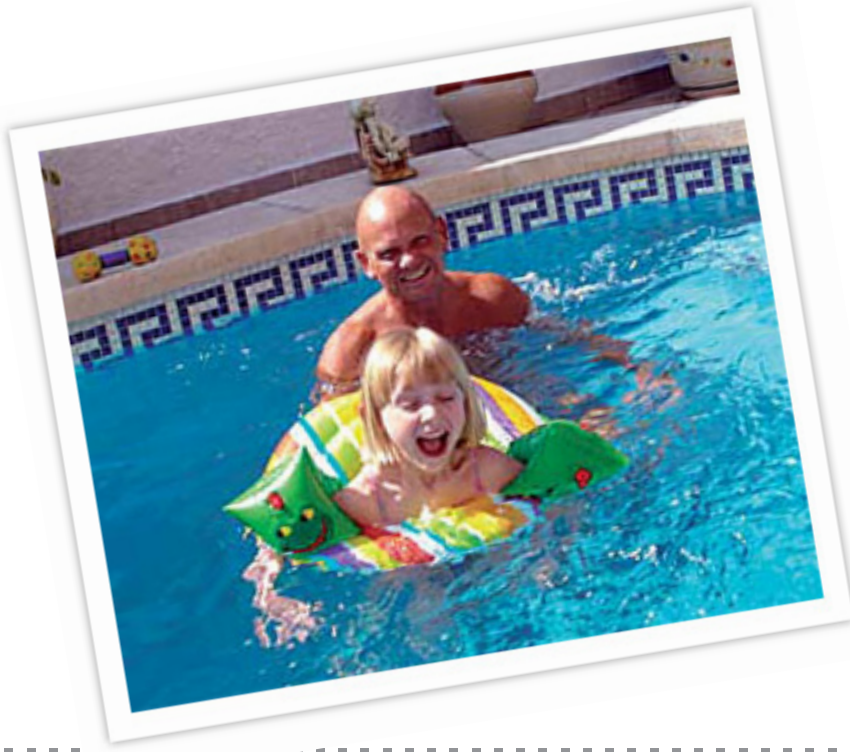
WELL DONE ALEX



Emma

Emma is 5 years old and has had diabetes for just over a year. She

is a happy, brave little girl and her mum and all of us here at the IDDT Children's Club are very proud of her. Emma has just started school and Rainbows which is a huge step for anyone so we would like to give her a massive shout out and hope she continues to shine like the star she is.



Letters Page

From Veronica and Simon Williams + Oliver Williams (7yrs) + Alexandra Williams (4yrs), Coventry.

My son Oliver was diagnosed with type 1 diabetes at just 5 years old, two days after Christmas 2006. He had been taken to our GP the previous week who told us he was suffering with tonsillitis and the loss of weight and insatiable thirst was nothing to worry about, this was all

down to tonsillitis and growing. By Christmas day he had no energy and was even finding the stairs too much so my husband would carry him up and down the stairs, the day ended with him vomiting up the small amount of dinner he had consumed.

On Boxing Day we were so worried about him, we took him to the walk in surgery who once again diagnosed tonsillitis and a stronger set of antibiotics along with the advice that he should drink plenty of sweet drinks!

The following day he awoke and was short of breath, he spent most of the day asleep on the sofa with his dad carrying him up and downstairs. By the evening, he was struggling to breath and my husband rushed him into hospital, I stayed at home staring at the clock and looked after my daughter. Within 30 minutes my husband Simon phoned to saying 'it's serious' and after numerous middle of the night calls to parents to arrange childcare, I rushed to the hospital.

I got to the hospital and found Oliver covered in wires and tubes and had people rushing around him. He was in a state of severe hyper – ketoacidosis and was almost comatose, he had no idea we were even beside him. I was mortified, Oliver was such a healthy child and to become so unhealthy so quickly was shocking life-changing news. After he was transferred by blue light ambulance with doctors and nurses and us following behind. We stayed in the University Hospital HDU (high dependency unit) for a further 5 days while they stabilised him and educated us.

It was during this time I asked, what would have happened if he hadn't been brought in when he was? The reply was, 'YOU DON'T WANT TO KNOW!'. I understood immediately what this meant, he very nearly died.

Since his diagnosis he has suffered with virtually every childhood school illness possible but has bounced back. He is a very active, happy child and we have been able to venture abroad for the first time since his diagnosis.

His diagnosis has changed all of our lives and we know that battles over care at school may be ongoing, our family unit is strong enough to cope.

I wanted to share our experiences with you as I'm sure you and others understand how we feel, emotionally over the past couple of years we have all been through an emotional roller coaster. For months since diagnosis I have been very angry at the medical profession for missing his diagnosis and allowing him to get so poorly before anything was done.

Should life really be this difficult and what can we do to change this? Let us know your experiences, good or bad or something you feel may help others. E-mail your thoughts to bev@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
NN1 4XS

Name: _____

Address: _____

Postcode: _____

Tel No: _____

.....

From Your Editor – Jenny Hirst

IDDT welcomes the submission of letters and editorial articles for consideration of publication in future issues of the IDDT Newsletter. The editor and trustees do not necessarily endorse any opinions or content expressed by contributors and reserve the right to refuse, alter or edit any submission before publication. No part of this publication may be reproduced in any form without the prior written permission of the editor.

Insulin Dependent Diabetes Trust

PO Box 294
Northampton
NN1 4XS

tel: 01604 622837

fax: 01604 622838

e-mail: support@iddtinternational.org

website: www.iddtinternational.org