Insulin Dependent Diabetes Trust

Parents' Bulletin November 2008

Registered Charity No 1058284

The new member of the IDDT team wants to give you one of our free 'Goodie Bags'

Here at IDDT we are very proud to introduce our new mascot. We are hoping our mascot will be able to educate and support children with and without diabetes all across the country.

There are many children in the UK that have Type 1 diabetes and this is through no fault of their own. They have to deal with multiple daily injections and blood tests in order to control their condition. Here at IDDT we feel these children and their brothers and sisters need a reward for coping so well with these difficult and life changing situations. All children with diabetes and their siblings are entitled to a free 'Goodie Bag'.

We also want to acknowledge your children's achievements by giving them certificates. We are opening a Hall of Fame on our website where you can nominate your child for their achievements eg their first injection, first blood test, dealing with their diagnosis or their first day at a new school. No matter how big or small the achievement, we want to hear about it and let your children know how proud we all are of them. We also don't want to forget brothers and sisters as well.

They also have a lot to deal with and they deserve a shout out as well.

The 'Goodie Bags' are supported with IDDT Parents Bulletins, produced every quarter to give parents tips and basic information about diabetes in childhood. IDDT hopes to make the whole family's life a little easier.

Look out for details of our fantastic competition to name our new mascot! For your free 'Goodie Bag' and membership contact
E mail bev@iddtinternational.org
Tel 01604 622837
write to IDDT, PO Box 294, Northampton NN1 4XS

Going the Extra Mile For ID

Over the past two years we have had a dedicated team of runners and supporters who have been working hard to raise awareness for IDDT at The British 10K London Run. This has helped over 9,000 people to receive the support and information they need to make living with diabetes a little easier.

People have received our information and have described it as 'invaluable, easy to understand and life saving.' IDDT want to help many more people in this way. We are looking for people to promote and raise money to help IDDT in anyway they can.

So how does 'Going the Extra mile for IDDT' work? Everyone can do their bit to help, all you have to do is run or walk as little or as much as you want wearing our IDDT T-shirt. These T-shirts will have all our details on them to let people know how to get in touch with IDDT. The more miles you walk or run wearing our T-shirt the more people will see it. You never know you may change someone's life for the better.

We also have many promotional products that you can hand out at local events. These will let people know we are here to help.

After the British 10K London Run in July we will total the amount of miles we have all run or walked and hopefully help another 9,000 people get the support they need.

Here are a few suggestions of how you can help:

- Walk to work, to school or just around the shops wearing your IDDT promotional T-shirt.
- Get everyone in your child's class to do a sponsored walk around the playground and add up how far you have all walked collectively.
- Tell your local paper what you are doing and get them involved in supporting you.
- Run at an organised event and get your family and friends to hand out IDDT balloons, bugs and pencils at the end of the race.

We can supply you with all the information you need to get started such as T-shirts and promotional products. You never know you may help someone receive the life changing information that they need. Simply decide whether you want to be a runner, a supporter or both and get involved.

The more people that know about IDDT the more people we can help with our

- Information leaflets
- Newsletters
- Parents Bulletin
- Parents Packs
- Teachers Pack
- Type II Pack
- General Information Pack
- Pregnancy Pack
- Kids Goodie Bag
- Nurses Information Pack

Do you know your child's hypo(glycaemia) warnings?

Insulin is produced by the beta cells in the pancreas. In people with Type 1 diabetes the body does not produce its own insulin, making the blood sugars rise abnormally high (hyperglycaemia). When this happens insulin injections are needed to lower the blood sugar level. If the blood sugar level drops below normal then this is called hypoglycaemia or hypo.

Normal blood sugar levels in non-diabetic people range between 4 and 7mmols/l. Hypos are usually said to occur at 3.8mmol/l. Opinions vary about the level at which a hypo occurs. For example some people will say that your child will not be hypo unless their blood sugars are 3.5 or even 3.0mmols/l but there is research which has shown that at 3.8 and below, people can be confused and do not function as well.

There are more ways to recognise a hypo than blood sugar readings alone. Your child's body will have its own way of giving warnings that a hypo or low blood sugar is occurring and it is important to recognise your child's hypo warnings.

Hypo Warnings
According to Professor Dr Arthur Teuscher, a leading diabetologist, autonomous or adrenaline type warnings occur first, at blood sugar levels around 3mmol/l. If blood sugars continue to drop, then neuroglycopenic (brain) symptoms occur at around 2mmol/l.

Your child may have one or more of the following warning signs:

Autonomous or adrenaline hypo warnings at around 3mmol/l

- Sweating
- Tremors
- Hunger
- Palpitations
- Anxiety
- Shivering
- Sense of warmth
- Tingling around the lips and mouth
- Weakness

Neuroglycopenic (brain) hypo warnings at around 2mmol/l may be more prominent

- Inability to concentrate
- Confusion
- Dizziness
- Difficulty speaking
- Drowsiness
- Blurred vision
- Impaired cognitive function
- Behavioral changes and irrational behavior, including aggression, unmotivated laughter, confused speech, absences, erratic behavior, yawning and becoming silent.

Hypos can be classified roughly into three levels

Mild hypoglycaemia
When blood sugar readings are around 3.4mmo/l, the body's adrenaline is stimulated and should give out early adrenal warning signs.

Moderate hypoglycaemia
In more serious hypos the same adrenal events should occur but the brain signals will begin to dominate as the level of glucose in the brain drops. In these situations the hypo can still be treated orally but assistance may be necessary because of confusion.

Severe hypoglycaemia
Severe hypos will always need outside help from yourself or sometimes paramedics may need to be called. Your child may be unconscious and so food or liquid should not be given to avoid the risk of choking.

For situations like this emergency glucagon injection kits are available and with the correct training, you can give this to your child. Glucagon releases glucose from the liver to raise blood glucose levels.

Dr Teuscher also warns that 'sudden hypoglycemia accompanied by unconsciousness may occur at times without warning, particularly with the use of human insulin'. [A Voice For Choice, pg 14] However, severe hypos can occur with all types of insulin.

Loss of warnings [or hypoglycaemia unawareness]
Hypoglycaemia itself, or the avoidance of it, is an acute daily problem for people with diabetes but when accompanied by loss or partial loss of warnings, it can have a dramatic effect on the lives of both the person with diabetes and their families. There can be a marked reduction in the quality of life for all concerned.

Total loss of warnings – is a condition where the warning signs of an impending hypo are not present. When the blood glucose levels drop there are no warning signs that the person must eat. This makes the likelihood of severe hypos much greater. People with total loss of warnings have to rely on the help of others.

Partial loss of warnings – occur when warning symptoms are present sometimes but not at other times. In some ways this is more difficult to manage than total loss of warnings because the person may not even be aware that they have some loss of warnings so have unexpected and unheralded moderate or severe hypos.

Reduced warning symptoms – is where the early warning signs of hypoglycaemia are lessened [sweating, trembling etc] and then the blood glucose continue to drops to the stage where the neuroglycopenic (brain) symptoms are not obvious to the patient [confusion, behavioural changes etc]. This means that the person often requires the help of others to treat the hypo.

The effects of loss of warnings – these vary but information gathered from the experiences of people with diabetes and their carers suggests that loss of warnings may result in the following:

- A feeling of insecurity and loss of independence.
- Embarrassment.
- A fear of leaving the home.
- Being a danger to oneself and others.
- Aggressive or violent behaviour.
- Family conflict.
- A deliberate raising of blood glucose levels to avoid such situations.

Causes of loss of warnings or hypo unawareness – there are several known causes of loss of warning signs of hypoglycaemia.

- Duration of diabetes – long-term diabetes can result in loss of warnings.
- Hypoglycaemia itself can cause loss of warnings and therefore the risk of more hypos is increased. This then becomes a vicious circleof hypos leading to loss of warnings and more hypos!
- Intensive therapy with multi-daily insulin injections and aiming for near normal blood glucose levels, has been shown to cause a threefold increase in the risk of severe hypoglycaemia. [DCCT, 1991] This increased hypoglycaemia can therefore increase the risk of loss of warnings as above.
- Changing insulin types can cause a loss or change in warning symptoms.
- 'Human' insulin can cause loss of warnings of hypoglycaemia. This is often not readily admitted by many healthcare professionals but since the early 1990s, Patient Information Leaflets in 'human' insulin packs have included a warning of that 'human' insulin can cause changed or loss of warnings of an impending hypo.

Treating a Hypo

- Hypoglycaemia in its early stages [mild hypo] is treated with a sugary drink or sugary food. This should then be followed with some longeracting carbohydrate to prevent another hypo.
- If the hypo is not treated at this stage then there may be confusion,

behavioural changes, helplessness and an inability to function properly occurs [moderate hypo].

- If not treated at this stage with glucose or GlucoGel, then coma occurs and this may or may not be accompanied by seizures [severe
- hypo]. Severe hypos need treating with glucagon or intravenous glucose and this may mean admission to hospital.

Note: GlucoGel is a sugary gel that can be squeezed into the mouth around the cheeks and gums. It **MUST NOT** be given if the person is unconscious or unable to swallow because they could choke. It is available on a doctor's prescription.

Some Golden Rules

Always have some form of quickly absorbed glucose with you - fruit juice, jelly babies or sweets your child likes to eat as a treat. If it is difficult to make the child eat or drink, then GlucoGel can be used, which is easier than the more old-fashioned method of rubbing jam around the cheeks and gums!

Children, and adults, with diabetes are renowned for denying that they are hypo when they actually are. If you are suspicious that they are hypo, always treat with sugary food or drink.

If you are a parent or carer and are unable to treat an unconscious hypo, call emergency services or your GP for immediate medical assistance.

If the hypo is accompanied by vomiting, drowsiness and difficulty breathing, then seek urgent medical advice.

For our Hypoglycaemia leaflet, please contact
bev@iddtinternational
call 01604 622837
write to IDDT
PO Box 294
Northampton
NN1 4XS

Facts about HbA1cs

The HbA1c is a test used to measure blood glucose control over an extended period of time, usually classed as average blood sugars over 6 to 8 weeks. It is a measure of the percentage of the haemoglobin in the red blood cells [haemoglobin] that have glucose bound to them.

How it works

Glucose molecules in the blood attach themselves to the haemoglobin molecules in the red blood cells that transport oxygen around the body.

Haemoglobin molecules are produced in the bone marrow and are normally destroyed and recycled in the spleen after approximately 120 days. So during the red blood cell's life span, glucose is bound to their haemoglobin. The HbA1c test measures the haemoglobin molecules that have glucose attached to them over this period of time so giving an average of blood glucose level.

It is important to remember:

- the test only shows the amount of glucose attached to the hemoglobin molecules. The HbA1c test does not identify the blood glucose levels that are normal or low as these levels do not result in glucose attaching to the haemoglobin.
- The blood glucose level the week prior to your child's HbA1c's will not be included in the reading as this fraction of the test is not stable.
- HbA1c's reflect only the average level of glucose in the blood so it is possible to get the accepted HbA1c reading even though daily readings are erratic and a combination of high and low readings.
- The HbA1c test does not measure or reflect the number of hypos or low blood glucose levels over the last 6 to 8 weeks, so sometimes
- HbA1c target levels appear to be being met and are praised at the clinic, when in fact, there may have been a lot of hypos.
- So the HbA1c test is not the ideal answer.

- Trying to work with a combination of daily blood glucose readings and the HbA1c seems to be the best option.
- As Professor Stephanie Amiel told delegates at an IDDT Conference some years ago: “It is important to remember that good control is the avoidance of low blood glucose levels as well as the avoidance of highs.”

Many children go through periods of high blood sugar readings for a variety of reasons. These reasons can be incorrect insulin dose for food intake and exercise taken, stress, growth spurts or puberty. During these periods you may find that your child seems to have more infections. The reason for this is that the white blood cells that defend the body against infections are not as effective. When blood glucose levels are running high, your child may also experience urinary tract infections and skin infections.

Infections

Infections and childhood illnesses such as chickenpox, can also cause raised blood sugars. Sometimes the blood sugars are high prior to an illness and before your child appears to be ill and this can be a warning that something is brewing!

Of course the obvious answer is to do your best to control your child blood glucose levels but this can be easier said than done. So here are a few tips.

- Good contact and communication with your diabetes specialist nurse.
- Remember the only reason for high blood sugars is not enough insulin.
- With help from your nurse, be prepared to adjust your child’s insulin dose.
- Be aware of how their bodies are changing.

Thank You from the Dream Trust Clinic

As you know IDDT works jointly with the Dream Trust Clinic in India to make sure that the children in the Nagpur area get the insulin they need to stay alive. The cost of insulin and medical care is beyond the reach of many poor families. Not only do we collect unwanted, in-date insulin to send to the Dream Trust but many of our members are kind enough to sponsor the insulin and medical care that is so vital for children with diabetes.

We would like to welcome Snehal Kale to our list of children being helped by our members and thank her sponsors Christine Lowson and Joyce Quinn.

Nikita Sakhare has been sponsored by Lucy Godiman. Nikita and her family have sent a huge thank you to Lucy as now they know her insulin will always be there to keep her alive.

If you would like more information on how to help children in India email bev@iddtinternational.org

write to
Bev Freeman at IDDT,
PO Box 294
Northampton
NN1 4XS

Thank You from the Dream Trust Clinic!

Recommend a School

One of IDDT's main aims is to not only to support families with diabetes but also to create a better understanding of diabetes within the community. To do this we would like your help by you recommending schools in your area. We will then send them a free Teachers Packs. This pack will help create a better understanding of diabetes and build communications between parents and teachers of children with diabetes.

All the schools in your area will experience a child with diabetes at some point and they may need help but do not know where to go. IDDT want to be there for all schools and providing them with free information on diabetes on a yearly basis.

If you feel you can help please give IDDT the names and address of as many schools as you know and help us to support children with diabetes.

Research News

Infections in early life not the cause of childhood Type 1 diabetes
It has been suggested that the 'hygiene theory' could be the cause of later development of Type 1 diabetes in children. In other words that infections resulting in treatment with antibiotics in early in life could lead to childhood Type 1 diabetes. Research using the General Practice Research Database checked the frequency of GP recorded infections and prescriptions for antibiotics in the first year of life of a group of 367 children with Type 1 diabetes and a matched group of 4579 children without diabetes.

It was found that:

- there was no evidence of an increased risk of development of Type 1 diabetes in children who had at least one infection in the first year of life or in those children prescribed antibiotics in the first year.
- There was little evidence of a difference in the risk of Type 1 diabetes after different types of infections eg gastrointestinal, conjunctivitis or upper and lower respiratory tract infections.
- Analysis of infections in the first 2 years of life came to similar conclusions.

Therefore the researchers concluded that there is no evidence of an association between infections in early life and the subsequent development of childhood Type 1 diabetes. [Diabetes Med Jan 2008]

Research finds new 'killer' cells linked to the cause of Type 1
In a study part-funded by Juvenile Diabetes Research Foundation (JDRF), Mark Peakman, Professor of Immunology at King's College London, has discovered that white blood cells that are normally involved in combating virus infections can kill the insulin-producing beta cells. [Journal of Clinical Investigation, Sept 2008] The researchers discovered a previously unknown molecule that beta cells 'display' to the immune system and that these molecules are present in people living with Type 1 diabetes. Working with other researchers they

showed that these particular 'killer' cells are very specific and kill only insulin producing beta cells.

Professor Peakman explains: 'We need to better understand why these rogue white blood cells have chosen to target beta cells for destruction. But the really unexpected finding was that the molecule on the beta cell was displayed at much higher levels when we made the beta cells work hard, by exposing them to high levels of glucose. This mimics the conditions that emerge when someone is developing clinical diabetes. Under these conditions in our experiments, beta cell killing was more than doubled. During this early phase of disease development in a patient, there are probably fewer beta cells, and each one has to work harder to maintain blood glucose levels. This could be bad news for the beta cell. Our study shows that the beta cell could be contributing to its own destruction.'

Professor Peakman believes that this research could eventually benefit people with type 1 diabetes in two ways. Firstly, now that a particular killer cell has been identified, researchers can start to look for ways to stop these killer cells from working. Secondly, more emphasis could now be placed on preserving beta cells in the early stages of the condition – for example by using early, intensive insulin therapy to allow beta cells to rest and avoid the attentions of the killer cells.

Risks of siblings and parents developing diabetes

A non-US study surveyed 1,777 people with Type 1 diabetes diagnosed before the age of 16. It showed that the overall risk of siblings developing diabetes by the age of 10 was 3.9% increasing to 7.7% by the age of 20. The risk was significantly higher for siblings of children diagnosed before the age of 6.

The risk in parents was 2.2% by the age of 30, higher in fathers [3.1%] than in mothers [1.3%] and in both cases the risk was higher when their child was diagnosed before the age of 6. The researchers recommend counselling for at risk families. [American Diabetes Assoc Conference, June 2004]

Maternal age and birth order

A study in the Czech Republic showed that the risk of developing Type 1 diabetes increases with higher age of the mother at the birth of the child and with lower birth order in the children. [Exp Clin Endocrinol Diab 2004 Jun;112(6)]

Is prevention possible for at risk family members?

It is possible to detect whether family members are at risk of developing diabetes and some time ago research was carried out to see if regular small injections of insulin in these family members would prevent diabetes. The results were negative. Now Australian researchers are giving 100 people with a close relative with diabetes treatment with inhaled insulin for a year to see whether this stops the development of diabetes. Inhaled insulin is more powerful than injections and the hope is that this will boost the immune system preventing the body destroying its own insulin producing cells.

Severe hypoglycaemia and long-term memory in children with Type 1 diabetes

This study compared 42 children with Type 1 diabetes and 25 of their siblings who were given a spatial memory tasks with short and long delays and other neuropsychological tests at the beginning and after 15months. Severe hypos and other medical complications were recorded during this period. 14 children experienced at least one severe hypo during the 15months. The results showed that severe hypos were statistically associated with decreased long-delay spatial memory performance but not with shortterm spatial memory or with verbal or object memory, attention or motor speed. [Pediatr Diabetes 2004 Jun;5(2)63-71] A further reason for the avoidance of severe hypos!

Mothers assess the self-care abilities of their children

The purpose of this study [ref 1]was to provide an insight into mother's perceptions of their children's development of diabetes-related capabilities and identify factors that influence these capabilities. An 84 item questionnaire was used to seek information on self-care issues such as independence in management, parental involvement,

dietary adherence, precision in skills, attitude to diabetes and ability to manage abnormal blood glucose levels. 88 parents represented 46 boys and 42 girls with diabetes aged between 6 and 18.

The results showed that mothers believed:

- children demonstrated higher levels of selfcare abilities, independence, precision, and ability to manage blood glucose levels as they aged
- older children had more negative attitudes towards their diabetes than did younger children
- girls learned skills earlier and were more independent in diabetes-related self-care, yet they had more difficulty than boys in complying with dietary requirements
- there were instances that indicated the some children engaged in behaviours that were potentially life-threatening or at least not good for their future health.

The researchers suggest that the findings will help health professionals to recognise age and gender differences in children and adolescents with diabetes and to establish realistic expectations for the way they look after their diabetes. They also suggest that professionals should encourage parents to stay in touch with their children's diabetes self-care into the adolescent years and should provide opportunities for communications with others with diabetes.

Comments from Jenny who has been there and worn the T-shirt!
I have only had a daughter with diabetes so cannot comment on how different boys with diabetes are. I would agree with the key points that are made and the recommendations but one of the things that I always find difficult with studies like this is that no one tells you how to do it!

For instance, *'stay in touch with their children's diabetes self-care into the adolescent years'* sounds great advice but how do you do it when your adolescent wants you to mind your own business? How do you handle the instances where children or adolescents *'engage in potentially life-threatening behaviours'* or perhaps more importantly, how do you try to prevent them from repeating such behaviour? Unfortunately there are no rules on how to handle these situations and usually no previous experience to guide us. I think that it is important to recognise that the study was looking at parents' perceptions which may well be different from the perceptions of their children. So we can try to understand how they feel about their diabetes and remember that this will vary according to their age. Perhaps sometimes our expectations of them are too high and we should relax a little to enable the lines of communication to remain open. Obviously as parents we want the best for our children and we want to avoid complications later in life but to children and adolescents, this seems a long way off, so we can't expect them to have the same priorities that we have. They may be fully aware of the risks of complications later in life but reminding them or using these as a threat, will not help. Looking back it seems to me that the important thing is to try to stay friends and to keep talking with our children and adolescents. As parents, we can only do our best and my explanation to my now very adult daughter is that I did my best, sometimes I got it right and sometimes not but I always did my best.

Ref 1 Am J Matern Child Nurse 2007, Jul-Aug;32(4):223-9

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