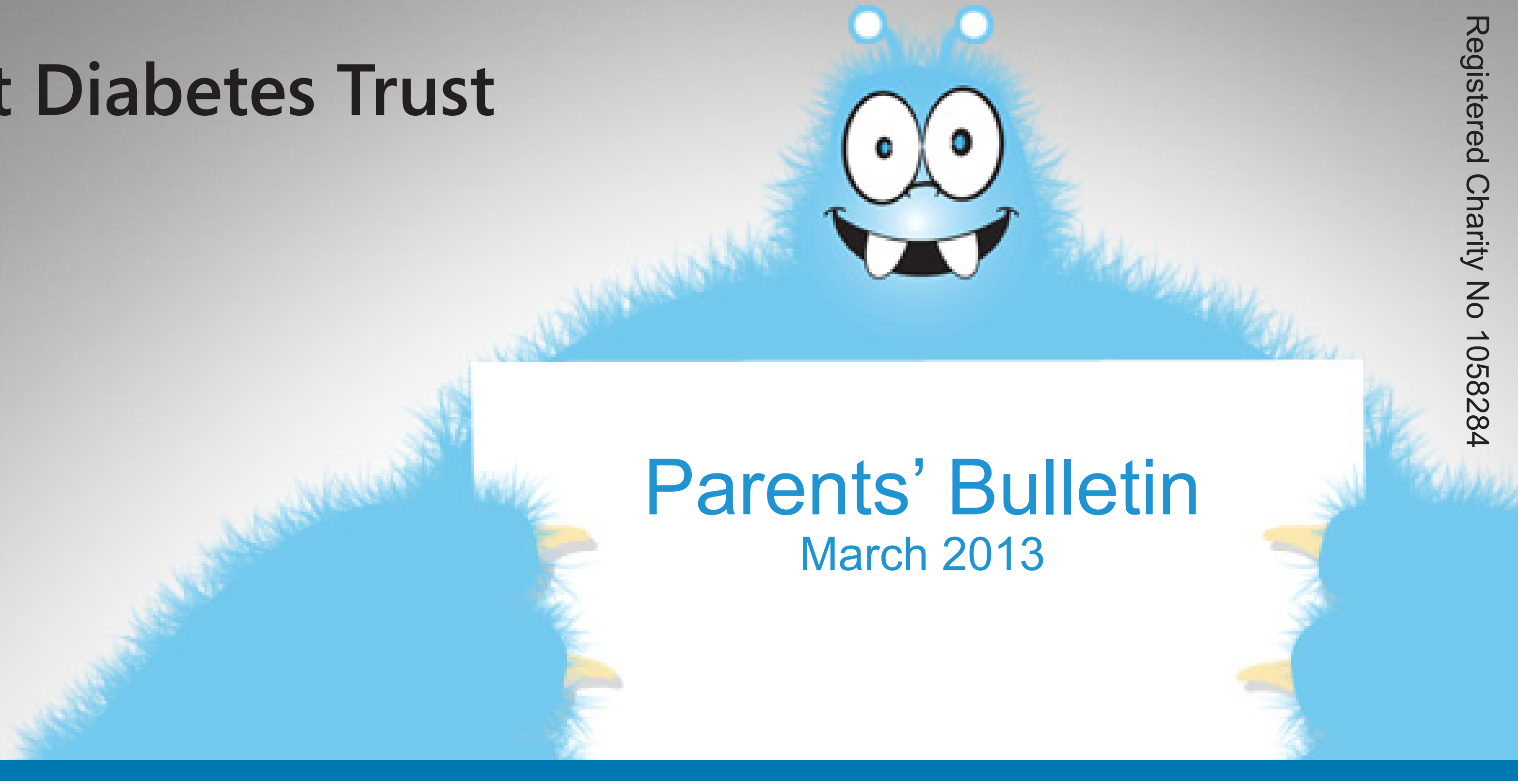
InDependent Diabetes Trust

Registered Charity No 1058284



# Parents' Bulletin

March 2013

## Protecting children's health in schools

UNISON and the Royal College of Nurses have carried out a survey of support staff and school nurses which reveals a worrying picture. This was published in November 2012. While there are many examples of good practice, a growing number of children with complex health needs are being put at risk because staff are being pressurised into caring for them without sufficient training, supervision or support.

Teachers' contracts do not include giving or supervising medicines so the responsibility often rests with school support staff. However, more than 1 in 4 [28%] of support staff said that they do not feel comfortable or competent to give pupils medicines or to support their health needs, some of which are really complex. This also applied to long-term conditions such as asthma, diabetes and epilepsy.

- The majority of support staff do not receive regular training and some reported never having any training before being expected to provide health care support to children.
- Nearly one in five support staff said that they feel forced to take on responsibility for giving medicines or healthcare procedures because they didn't want to let the children down.
- Two thirds of registered nurses who oversee healthcare provision in schools said that specialist care plans are not always in place.

**What are UNISON and the RCN proposals?**

- Every school child with health needs should have an up-to-date, individual care plan, drawn up with a healthcare professional.
- Staff must have specific training for each child, which must be supplied by an accredited healthcare trainer and be regularly refreshed.
- Schools and local authorities must ensure they match staff, with

sufficient training and pay, to the specific needs of the children in schools.

- Every school needs to have a clear policy on the management of medicines and health care support in schools, which is understood by staff, parents, and pupils.

However, they point out that there are budget cuts for schools which mean that the situation can only get worse, not better. UNISON also highlighted the need for individual care plans which are regularly reviewed. The RCN said that there is a clear need for more school nurses, community children's nurses and children's nurse specialists to adequately train and support staff in schools. There is a chronic underinvestment in these areas and one in six school nurses have seen posts cut in the last year.

The full report can be found at
**www.unison.org.uk/acrobat/21163.pdf**

**Where does this leave parents of children with health needs, including diabetes?**
In a difficult position is the simple answer. It is clear that the fault does not lie with teachers who by their contract do not have to administer medicines and perhaps are not covered by insurance if they do and anything goes wrong. Health professionals have to have insurance for these purposes. It is equally clear that many support staff are doing the job but are not fully trained and this is not their fault either.
It seems that it requires political will to keep children with health needs safe at school. It also requires assertive parents to ensure that their children are cared for appropriately.

The political answer was given on December 5th 2012 by Baroness Northover in answer to a Parliamentary Question on this topic. She said:
*"The Department for Education has produced Medical Conditions at School: A Policy Resource Pack to complement its guidance Managing Medicines in Schools and Early Years Settings. We want relevant school staff to be competent in managing pupils' health needs, and to feel confident in doing so. Schools should ensure that staff understand the school's responsibilities, have appropriate training and are able to access continuing support. Paediatric diabetes specialist nurses from local health services are able to give guidance and training on care of children with diabetes in the school environment for staff and pupils."*

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## Letter from a Grandma

Dear Jenny,

I read the article in the Christmas Bulletin, which I might add is great, regarding the increase in Type 1 diabetes connected to toxins and viruses.

Since my granddaughter was diagnosed I have always thought it had to be connected with the food we eat and considered it to be, not the junk food we eat, but the junk they put in our food before we buy it.

Has it ever occurred to the experts that only a few decades ago when we bought bread it was stale within a day or at the most two days and cheese after a few days had a green coat on it. Cakes and pastries now have a long shelf life and cooked meats last for ages.. These are only a few of the foods that seem ageless. So what are they doing to our food to make this happen? They are adding so much to help preserve, colour or flavour it that I feel sure that this must affect the pancreas.

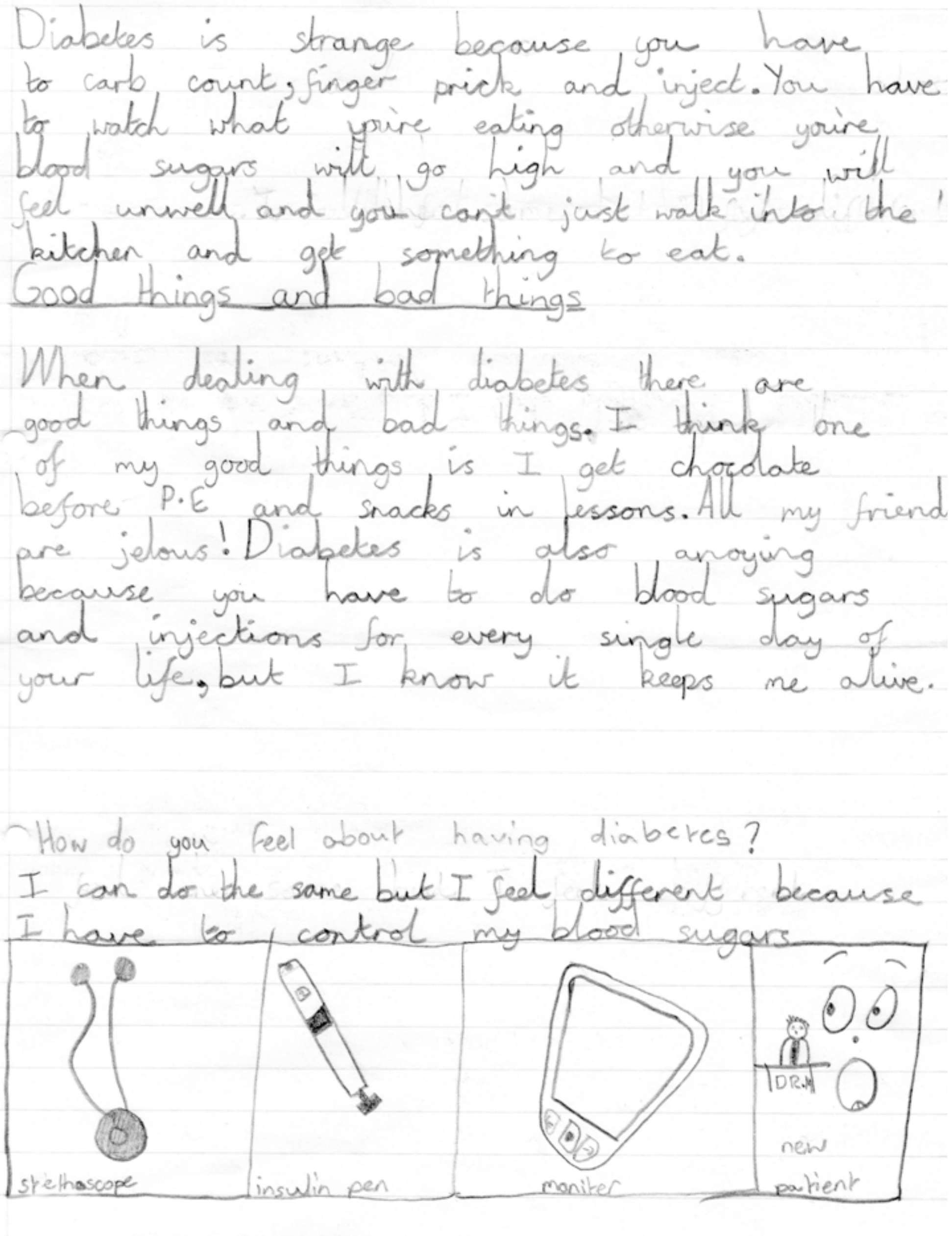
When my granddaughter was diagnosed the consultant said that it was hereditary, despite there being no history of diabetes on either side of our families. He said that diabetes was increasing 'at a rate of knots' but could not really explain this. Yet the only thing that really seems to have changed is the processing of food so is this the common denominator to everyone with Type 1 diabetes and a major contributor?

I wonder if any of the experts who read this may take this concept a little further? Although if it is found to be a contributor to the development of Type 1 diabetes, I can't see the food manufacturers wanting to change anything as I think they have gone too far when you can buy mushrooms already chopped, vegetables ready chopped and a salad in a bag full of gas to stop it wilting.

Help! Can someone do anything about this to see if there is any truth in my thinking?

Mrs D.S.
Yorkshire

## An eight year old says it all – a tear jerker for parents!



Diabetes is strange because you have to carb count, finger prick and inject. You have to watch what you're eating otherwise you're blood sugars will go high and you will feel unwell and you can't just walk into the kitchen and get something to eat.

Good things and bad things

When dealing with diabetes there are good things and bad things. I think one of my good things is I get chocolate before P.E and snacks in lessons. All my friend are jelous! Diabetes is also anoying because you have to do blood sugars and injections for every single day of your life, but I know it keeps me alive.

How do you feel about having diabetes?

I can do the same but I feel different because I have to control my blood sugars

Lauren Coles, Age 8
(Type 1 since 1 year old)

# A different world - diabetes in 1956 at 5 years old

Kevin was 5 years old when he developed Type 1 diabetes. He was very ill for months before his GP discovered it. He remembers his mum taking him to and from the doctor who one day asked Kevin to wee in a bottle and then said to his Mum, Kevin has diabetes. While Kevin didn't understand, he remembers only too well being rushed into Queen Mary's Hospital in Carshalton.

He lived in the hospital for about 2 years as his Mum, 2 brothers and 2 sisters all had very bad asthma and his Mum couldn't cope with diabetes as well. From the age of 8 to 13 he lived in hostel, Palingswick House, for children with diabetes and only went home for school holidays, when he was not supposed to tell anyone that he had diabetes.

He can still picture the inside of the building, dormitories/ bathrooms, wardens office/staff room/ kitchen/ dinning room/ TV room and stairs at the back going down to the room where they did their urine tests.

**Kevin at the front – with tattoos drawn on his body out of boredom!**

Kevin hated being at Palingswick House and he ran away with two other children. They knew enough about managing their diabetes to break into the medical room and take insulin and syringes for the three of them! They slept in Richmond Park for a couple of nights, but gave themselves up two days later as they found it difficult to get food.

However, there were highlights for Kevin - a famous footballer called Rodney Marsh who played for QPR actually played a game of football with them in the court yard and when he was about 11, the BBC made a documentary on Palingswick House and how they managed their diabetes and it was actually shown on TV!

While Kevin hated being at Palingswick House, he acknowledges that he learned a lot about his diabetes and believes he would probably not be alive today if he had not gone there. He studied at college for many years and qualified as an electrical engineer. He and his wife Heather have 6 children and 11 grandchildren.

He would love to hear from anyone who was also at Palingswick House during his years there – just get in touch with IDDT and we will put you in touch with him.

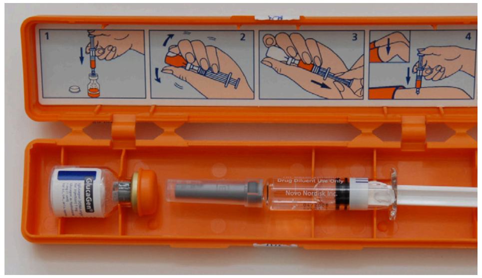
**And we also heard from Paul…….**
Paul has had Type 1 diabetes since 1960 when he was 9 years old. He too was sent to Palingswick House and recalls that there were between 50 and 60 children there at any one time from the age of 8 to leaving school. He too describes it as a lifesaver for most of the children but of course, he says he has seen many changes!

**How times have changed and what a lot we have to be grateful for!**

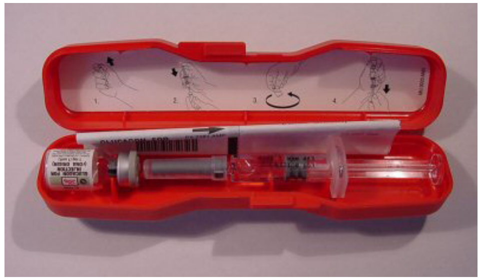
# Don't forget to check your glucagon kit

Glucagon is for our emergency situations of a severe hypo and in our family this was usually in the night. Like many families, just knowing glucagon was there was a comfort although we rarely had to use it. Speaking from this experience, it is a good idea to check that it is in-date in case you do need it. The old one can always be used to practice preparing setting the glucagon injection up because when you don’t use it much, it is easy to forget, especially in a panic of a severe hypo!

Glucagon is a potentially lifesaving treatment for a severe hypo where your child is unconscious. It is injected and it works by telling the liver to release sugar [glucose] into the bloodstream to quickly bring the blood sugar level back up. Once your child wakes up and is able to swallow it is important to give them fast acting sugar, such as fruit juice, followed by a snack or meal containing both protein and carbohydrates, such as cheese and crackers or a sandwich.



**Above is the Glucagen Kit by Novo Nordisk and below is the Glucagon Kit by Eli Lilly.**



Small children under 44 pounds can be given half the dose and if this does not bring them round after 15 minutes the rest of the dose can be give. Glucagon does have adverse effects in some children and adults – it can cause vomiting and severe headaches. I found with my daughter that these adverse effects were much less with half the dose.

If your child has severe hypos which may occur during the day, then it is worth considering asking your health professional for two glucagon kits, one for home and one for school.

## Bits and Pieces

### US issues codeine warning for children

In the US the Food and Drug Administration [FDA] has issued a warning about giving children codeine after operations for obstructive sleep apnoea when three children died. It is thought that the children probably rapidly metabolized codeine. The guidelines recommend the lowest effective dose and general caution.

### Sanofi introduces iPhone-enabled blood glucose meter

French pharmaceutical company, Sanofi, has developed the iBGStar, a gadget that can read blood glucose levels through an iPhone. The device can be plugged into the iPhone or iPod touch then users prick their finger with a lancet and press the blood on to the meter. The blood glucose test results will appear on the screen within 6 seconds. If necessary they can be emailed to clinics or parents.

An article in the Australian Telegraph does offer a some cautionary concerns, firstly, that while this emerging technology is exciting, it is important that there is an approval process to ensure the such products are of quality, are reliable and are accurate.

### Pets and allergies

Recent research carried out in Australia suggests that exposure to cats and dogs does not increase the risk of children developing allergies. The researchers followed 620 infants for 12 years and found that exposure to cats and dogs may be linked to a moderate reduction in risk of wheezing and hay fever after seven years. [Clin Exp Allergy

2012;9]

### The best child education sites

The GP magazine [07.01.13] contained an article by a GP who chose her favourite websites for her two young children. We thought this might be of interest to some of our readers. She points out that her choices are websites that are fun as well as educational. For her preschool children her choices are:

- **bbc.co.uk/cbeebies** is hard to beat and is largely fun. The games often have a choice of levels and the keyboard options are easily accessible for li8ttle ones who can't get to grips with the tracker pad on a laptop.
- **readingeggs.co.uk** has chapters called lessons but they feel like games to children. The site has a 'playroom' for 3 to 4 year olds and there are different steps for 7 up to 13 year olds. Early lessons start with individual letters, their sounds and shapes. Various activities introduce words beginning with that letter and each lesson ends with a storybook reviewing that letter. [You have to pay a subscription but can have a month's free trial.]
- **oxford.co.uk** is a more serious site designed to help adults teaching children to read with many free e-books.
- **edplace.com** is an educational resource for parents which offers a science section as well as English and maths. [You have to pay a subscription but various options are available.]
- **EducationCity.com** has phonics games as well as citizenship and understanding the child's role in the family, society and the world.

## Healthy eating for children – being cunning!

It's not always easy to encourage our children to eat healthy foods and this is quite understandable in the era of advertising and marketing. Research carried out in the US in children without diabetes showed that in children who did not eat healthy snacks, putting a cartoon sticker on healthy choices made them more appealing.

In the research 11 year old school children were offered apples and cookies for their lunch and the children were more likely to choose apples when they were 'branded' with a sticker such as Elmo out of Sesame Street.

When the snacks were not specially marked with a sticker, just under 25% took an apple. However, when the Elmo sticker was on the apples, 37% of children took an apple. Stickers on cookies didn't affect children's choice of the sweet snack.

The researchers suggest that we need to be as clever as the companies marketing less healthy foods – fighting fire with fire. This idea could be used in schools and at home.

### Renaming fruits and vegetables with catchy names

Yet another study has shown that renaming fruits and vegetables with catchy names convinces young children in school to eat them! Admittedly this was an American study and we might question the names but when the catchy names were compared to "Food of the Day" the results were quite dramatic!

**"X-Ray Vision Carrots,"**

**"Power Punch Broccoli," or "Tiny Tasty Tree Tops"**

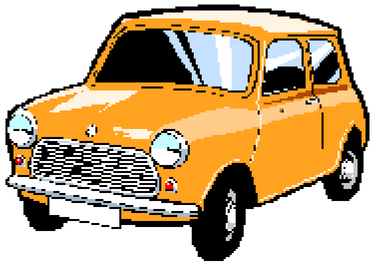
The results left no doubt about the effectiveness of this name change. For example, in one school 66% of the carrots labelled "X-Ray Vision

Carrots" were eaten compared to 32% when they were labelled "Food of the Day."

The researchers pointed out that giving foods an attractive name could be an effective and cheap way to improve children's diets both at school and at home. It just requires a bit of imagination which many parents will already be doing. Many years ago my mother used to mash carrots and make them into the shape of a sand castle with strategically placed cabbage for trees!

## Is your teenager coming up to the age for driving?

***For some, 17 is the magic age which could mean learning to drive – a big step!***



**Some facts from the DVLA**

Once the driving test has been passed, people with diabetes treated with insulin are given a medically restricted driving licence with lasts for a maximum of 3 years. Diabetes is not being singled out specifically as medically restricted licences also apply to many other long-term conditions.

As a result of changes in the EU law in August 2009, the DVLA has been considering changes to the driving regulations for people with diabetes, people with epilepsy and those with visual impairment. The changes for diabetes came into effect in October 2011 and they affect anyone taking insulin or medications that may cause hypoglycaemia.

**Changes to the standards for driving cars and motorcycles – Group 1 vehicles**

- There must not have been more than one episode of severe hypoglycaemia within the preceding 12 months. Severe hypoglycaemia is defined by the DVLA Driving Panel for Group 1 as one requiring the assistance of others.
- There must not be impaired awareness of hypoglycaemia. Impaired hypoglycaemia awareness is defined as an inability to detect the onset of hypoglycaemia because of a total absence of warning symptoms.

These changes led to confusion and misunderstanding, so on June 21st 2012, the DVLA issued new guidelines aimed at making it easier for drivers with diabetes treated with insulin to understand the new driving rules to comply with the European Directive introduced in 2011.

The revised application form makes it clear that hypoglycaemia is classed as blood glucose levels below 4 mmols/l and the new form now asks the following questions relating to hypoglycaemia:

- If you have NOT experienced an episode of hypoglycaemia, are you aware of what the symptoms are?
- If you have had an episode of hypoglycaemia, do you get warning symptoms? If yes, are you always aware?
- Have you had more than one episode of severe hypoglycaemia in the last 12 months? *Please only count episodes where you needed help. Do NOT count episodes where you were given help but could have treated it yourself.*

**Further points that have been clarified are:**

- You MUST sign the declaration that you will test before driving and every two hours when you drive. *[This is to let the DVLA know that you understand that you have to test while driving.]* This is a legal requirement and a licence will not be issued if this declaration is not signed.
- For numerous short journeys you do not have to test before each journey as long as you test every two hours while driving.
- The two severe hypos in the last 12 months include night hypos. IDDT and other organisations objected to this on the grounds that a night hypo does not affect the ability to drive the next day. However, despite the fact that we have a letter from the Minister

of Transport confirming that there is no evidence that night hypos impair driving the next day, this rule has stayed in place.

So if your 17 year old is about to learn to drive, he/she needs to be aware of the regulations that apply to everyone treated with insulin.
**For more information visit our website:**
**http://www.iddt.org/about/living-with-diabetes/driving/**
**or give IDDT a call on 01604 622837.**

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# The body's glucagon response to hypoglycaemia in teenagers

Glucagon is made by the body and is a counter-regulatory hormone produced by the pancreas along with insulin. It has the opposite effect to insulin in that it increases the glucose level in the blood. When blood glucose levels drop, glucagon is produced which triggers the release of glucose from the liver stores. If there is a severe hypo in someone with Type 1 diabetes, glucagon can be injected to trigger the liver to produce glucose.

In a small study researchers compared the glucagon response to hypoglycaemia in 28 adolescents with Type 1 diabetes with a control group of teenagers without diabetes. The participants' blood glucose levels were reduced to hypoglycaemia and the glucagon response was measured, as well as arginine, epinephrine, cortisol and growth hormone responses.

The glucagon response to hypoglycaemia was reduced in those with Type 1 diabetes with only 7% of those with Type 1 having a normal glucagon response compared to 83% of these without diabetes. This lack of response was lost on average at 8 months after diagnosis but also as early as one month after diagnosis. It was not associated with height, weight, BMI or HbA1c. The responses to hypoglycaemia of the other hormones were present in both those with Type 1 diabetes and those without it.

The researchers concluded that the glucagon response to hypoglycaemia in adolescents with Type 1 diabetes is influenced by the duration of diabetes and can be lost early in the course of the condition.

The findings are perhaps surprising as glucagon is produced at the same time as insulin and yet we know from other research and the well-known honeymoon period that insulin production goes on for months and even years in some people.
[Diabetes Care, accepted March 2012]

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# Research News

## Adherence to blood glucose testing in adolescents with Type 1 diabetes

As parents, we are lucky if our teenagers do not go through a phase of not testing blood sugars, or pretending they have when they haven't!

Research has investigated the possible reasons for this in thirty six 14 to 18 year olds with Type 1 diabetes for over a year. For 14 days, they carried hand held computers to record their location, companionship and attitudes toward companions at the times they usually checked their glucose, and again 30 minutes later to report whether they checked their glucose and, if not, why not.

The results took into account age, sex, duration of diabetes and pump use. The results showed the following:

- The odds of checking glucose was higher when participants expressed very strong desire to blend in with friends.
- Strong desire to impress others was associated with decreased likelihood of checking glucose.
- Location, solitude, type of companion, and attitudes toward companions were not significantly associated with checking

glucose.

**Researchers' conclusions**
Desire to blend in with friends may support glucose monitoring adherence and desire to impress others may be a barrier to testing in adolescents with Type 1 diabetes. This study did not show that any other factors were involved for this group of teenagers.

From a personal perspective, the sort of reasons my daughter didn't test were 'oh. I'm busy', 'it takes too long [albeit only a minute!]' or simply 'I can't be bothered'.

## Vitamin D deficiency warning

Following on from the short article in our December Parents Bulletin about Vitamin D intake limits, later in December, the Royal College of Paediatrics and Child Health [RCPCH], stated that a quarter of children, "at least" half of the UK's white population and up to 90% of the "multi-ethnic population" are deficient in vitamin D. The deficiency is said to be resulting in higher incidences of diabetes, tuberculosis, multiple sclerosis and rickets - a bone disease not really seen in the UK since the 19th century.

Apparently people only obtain about 10% of their recommended daily amount of Vitamin D through food and sunlight. The RCPCH says that more sunlight and/or eating more oily fish are not sufficient to solve the problem so they recommend the simple step of taking Vitamin D supplements. They are calling for:

- these supplements to be available at low cost but high quality,
- further investigations into Vitamin D fortification of foods,
- greater awareness among healthcare professionals and the public of the steps needed to address this growing problem.

Dr Peter Carter of the Royal College of Nursing said school nurses and health visitors are "excellently placed" to spread the awareness of vitamin D deficiency by working with families and teachers.

As with all supplements. giving your family Vitamin D supplements is something to discuss with your paediatric team.

## Family problem solving sessions

*Research in the US has found that a clinic-based programme for adolescents with Type 1 diabetes and their families helped the teenagers to develop the healthy behaviour needed to control their blood glucose levels. The researchers found that the teenagers benefitted from a 2 year programme of 3 or 4 meetings each year with parents and a health advisor to discuss shared responsibilities, goals and strategies for solving diabetes management problems that arose.*

As many of us know from experience, many adolescents have difficulty managing their diabetes. There are various reasons for this. The obvious one is that hormonal changes may affect insulin levels but then there are the other ones that are often difficult to deal with – they want to be like their friends who don't have diabetes, they are tired of having to live with diabetes and all this means or it can simply be that they are teenagers and what do teenagers do? They rebel and if they have diabetes, if we are honest, they have something to rebel against. So all of this can mean that they don't do what they are supposed to do to manage their diabetes.

This is not just a difficult time for teenagers, it is a difficult time for parents and the rest of the family too. As parents we worry about their future health, we worry that the bad habits they develop as teenagers may affect their future health or may stay with them. At the same time, as parents just going 'on at them' often makes matters worse not better and relationships within the family can be difficult.

**What happened in the US study?**
The study in the US, called the WE-CAN Manage Diabetes, included about 300 pre-teens and adolescents between the ages of 9 and 15

and their families. Half the families received WE-CAN treatment and the other half received standard care – regular visits with the doctor. The WE-CAN treatment was regular visits with the doctor but also the family meetings with the health adviser to discuss any difficulties with the diabetes management or any areas they would like to improve. The health adviser helped the families to work out a plan for solving problems, such as setting goals for checking blood sugars or eating more healthily.

**The results two years later……**

- The 12 to 15 year olds in the WE-CAN treatment group had significantly better HbA1cs than those receiving standard care.
- The WE-CAN treatment did not appear to improve HbA1cs in the 9 to 11 year olds compared to standard treatment.

The researchers concluded that this family approach form of treatment seems to work better with the older adolescents because it related to the problems they were having and that whose who needed this kind of help, gained the most from it.
[Pediatrics online, Sept 2012]

**Worth considering**
These types of problems are common in teenagers and as parents, we may feel inadequate or that the difficulties are our fault but not so – a lot of families go through teenage problems, ours did and we came through at the end of the day. However, I am sure that it could have been easier with some ‘outside’ help which many clinics nowadays can provide – certainly something to discuss with them.

* * *

## The UK has the world’s fifth highest rate of Type 1 diabetes in children up to the age of 14

Estimates by the International Diabetes Federation [IDF], show that 24.5 per 100,000 children aged 0 to 14 in the UK are diagnosed with Type 1 diabetes every year. Of the countries where this type of information is recorded, only Finland, Sweden, Saudi Arabia and Norway have higher rates.

- The UK rate is double that of France and Italy with rates of 12.2 and 12.1 respectively.
- The lowest rates are in Papua New Guinea and Venezuela, where the rates are only 0.1 per 100,000 develop the condition a year.

The reason for the wide variations in rates is not really understood but scientists believe that genetics play a part but Type 1 is not linked lifestyle and obesity.

Despite this high rate, the care of children with Type 1 diabetes in the UK needs to improve. According to recorded figures, less than 6% of children with Type 1 diabetes are getting the 8 health checks recommended by NICE and less than a sixth are achieving the recommended blood glucose levels.

**Just a cautionary note** - before making too many judgements about this level of care, it would be interesting to know how many children with Type 1 diabetes in other countries are achieving the recommended blood glucose levels. We have also to remember that not all countries have the same recommendations for blood glucose levels. For example in adults with Type 1 diabetes the UK recommended level for HbA1cs is 6.5% but in the US, it is 7.0% - who’s right?

## Long-acting analogues don't reduce DKA in children and adolescents

Research investigated whether long-acting analogues [Lantus and Levemir] reduced the risk of diabetic ketoacidosis [DKA] in children and adolescents. The researchers looked at the records of 48,110 young people 20 years old or younger between 2001 and 2008 looking for the incidence of DKA that required hospitalisation. They found that the incidence of DKA was significantly higher in those using LANTUS OR Levemir than those using intermediate [NPH] insulin. This risk remained significantly higher even after taking into account, age, of onset of diabetes duration, HbA1c, insulin dose and gender.

So the researchers concluded that long-acting insulin analogues are associated with higher rates of DKA when compared to intermediate conventional insulin. [Diabetes Care, Feb 2010]

## Thank you

### Christmas cards

We would like to say a big thank you to everyone who supported IDDT at Christmas time by buying IDDT Christmas cards – this was a great help to our funds!

### Unwanted insulin and other supplies for 2012

Thank you too for the unwanted, in-date insulin and other unwanted supplies you have sent during 2012. The totals are tremendous and very much appreciated in the clinics in Tanzania where, as you know, many families simply cannot afford the insulin their children need to stay alive.

### Dream Trust

Thank you to sponsors of children at Dream Trust in India. The number of children sponsored by IDDT supporters has risen too. Dr Pendsey at Dream Trust is extremely grateful for all the help the sponsors are giving.

## And finally...

We would like to take this opportunity to say a big thank you to the people who work closely alongside IDDT. Without the help and support these people give us, we would not be able to achieve all that we do. So, in no particular order, a big thanks to Veronica Wray (Veronica Wray Public Relations), Rupert Campbell – Black (IT-MK Limited), Oliver Jelley (Orange Juice Communications), Una Illing (U.S. Illing Accountancy Services), Stuart Lacey (Website Support), Nigel Frost (Newsletter Design), Chris Searle (Hamilton House Mailings) and Ron Naylor (Acorn Print Media).

**Don't be afraid to pick up the phone**

**01604 622837**

**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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