



## Parents' Bulletin

August 2011

### NHS Reforms – thank you for your part

We would like to thank all our members who lobbied their MPs about the proposed NHS Reform Bill. You made your feelings known at a time when it seemed that it was only doctors and nurses who were raising objections. While it is absolutely right that they should, people at the sharp end of the changes are actually us or our children, the patients. Who is better placed to be concerned than people with chronic conditions who have to use the NHS on a regular basis? So a big thank you to everyone.

The lobbying had to come to a halt when the government announced their 'listening exercise'. In June we heard the results of the re-think - the main recommendations from the independent NHS Future Forum were accepted.

Health Secretary Andrew Lansley said “The Forum confirmed that there is widespread support for the principles underpinning our plans for change: greater patient choice, ‘no decision about me, without me’, more control for doctors, nurses and frontline professionals, a focus on quality and results for patients, more information and more clout for the public...”

#### So what are the major changes to the original Bill?

- **Wider involvement in clinical commissioning groups.** A wider range of experts will be given the power and freedom to make decisions about health services for their local community by, for example, including nurses and specialists on the boards of clinical commissioning groups.
- **Stronger safeguards against a market free-for-all.** The health care regulator Monitor's core duty will be to protect and promote patients' interests, it won't be required to promote competition as

if it were an end in itself.

- **Additional safeguards against privatisation.** “We will never privatise the NHS, and will create a genuine level playing field to stop private companies ‘cherry-picking’ profitable NHS business. We will ensure that competition is on quality, not price.”
- **Evolution, not revolution.** “We will allow clinical commissioning groups to take charge of commissioning when they are ready and able, and a more phased approach to the introduction of Any Qualified Provider.”
- **Greater information and choice for patients.** The Government will make clear that the people who make decisions about local services have a duty to promote patient choice. And following current pilots, the Government will make it a priority to extend personal health budgets including across health and social care.
- **Breaking down barriers within and beyond the NHS.** A new duty for clinical commissioning groups to promote joined up services both within the NHS and between health, social care and other local services.
- **Investing for the future of the NHS.** “We want all providers to make a fair contribution to the costs of education and training of NHS staff, but we will introduce changes carefully and take the time to develop the details right.”

### What happens now?

- Relevant parts of the Health and Social Care Bill will go before Parliament for scrutiny of the proposed changes. More about the Government’s modernisation are available at <http://www.dh.gov.uk/healthandcare>
- The NHS Future Forum report can be found at: <http://healthandcare.dh.gov.uk/future-forum-report> This Forum will continue to lead on listening in the NHS, to provide a communication channel with the NHS.

## What We Want From Research

As parents, research is very important to us because we hope that it will eventually produce the answers we want for our children with Type 1 diabetes. We hope that there will be effective stem cell treatment, which, in many ways, means a cure because the body will produce insulin again. At the present time, we are years away from achieving this, so it is research to which we can only aspire.

In the meantime, perhaps research into the artificial pancreas is nearer. The artificial pancreas, also called the closed-loop system, is a combination of an insulin pump and a continuous glucose monitor which will automatically deliver the appropriate amount of insulin at the right time. The hope is that this will reduce the risks of hypos in the short term and reduce the risks of complications in the longer term.

We also want research that will make living with diabetes easier for our children, teenagers and when they become adults – research that finds out the best way to support them through some of the difficulties of living with diabetes and the times when it seems difficult to cope with the pressures. Along side all of this, we also want research that will prevent Type 1 diabetes so that future generations do not have to live with it and all its related issues.

My daughter has had diabetes for 35 years now and at last I am hopeful that there is research going on that seems likely to achieve at least some of what we want. Having said this, in those 35 years many improvements in the treatment and care of people with diabetes have been made and no doubt, will continue to be made. Progress does seem slow sometimes, perhaps especially for us because it is our children that have diabetes. The saying ‘Patience is a virtue’ seems very apt as far as research is concerned but whatever developments there are from research, they have to be proved to be safe before they can, or should be used. And this takes time...In the meantime, here are a few updates.



## Stem cell research – still a long way to go...



The researchers injected stem cells from rats into the embryos of mice that had been genetically altered so they could not produce their own organs and the mice developed rat organs. They say that this technique could allow pigs to grow human organs from patient's stem cells for use as transplants.

This could help to reduce the risk of the transplanted organ being rejected while also providing a plentiful supply of donor organs. Current organ shortages mean that patients must endure long waiting lists for transplants.

The researchers used types of adult stem cell known as induced pluripotent stem cells, which can be taken from a sample of tissue such as the skin and encouraged to grow into any type of cell found in the body. These cells taken from rats were injected into the embryos [called blastocysts] of mice without pancreases, so unable to produce their own insulin.

When the mice matured to adulthood, they showed no signs of diabetes and had developed a pancreas that was almost entirely formed from the injected rat stem cells. The scientists claim the rat stem cells grew in the niche left by the absent mouse pancreas and so almost any organ could be produced in this way. If this could be repeated using human stem cells, the technique could provide a way of treating diabetic patients by replacing their pancreas. They have, however, already managed to produce pigs that were able to generate human blood by injecting blood stem cells from humans into pig foetuses.

This technique has never been tested before, but this research has

shown it can work. For ethical reasons, it is not possible to make a human embryo without an organ, so embryos from animals such as pigs would have to be used.

As with all stem cell research, there is a long way to go before it could produce useable transplants. Professor Chris Mason, University College London, said: "...this could be a potential way forward albeit a very long shot requiring sustained resources and major finance for its testing and development. For something like a kidney transplant where it is not urgent, it would be highly attractive to be able to take stem cells from a patient, grow them in this way and deliver a personalised kidney."

[Research lead by Professor Nakauchi of the University of Tokyo, presented the study at the annual conference of the European Society of Human Genetics.]

### Artificial Pancreas – we are not quite there yet

The artificial pancreas, also called the closed-loop system, is what we are all waiting for because not only should it improve blood glucose control but it also means that people with Type 1 diabetes will be free from their daily injections of insulin.

The artificial pancreas combines the insulin pump with the continuous glucose monitor [CGM] in such a way that they can talk to each other. If blood glucose levels rise as measured by the CGM, then the pump releases insulin and if they are low then insulin is withheld. However, CGMs have not yet been perfected.

### Difficulties with Continuous Glucose Monitors

A recently published review points out that there are still a number of difficulties yet to be overcome with the continuous glucose monitor before it can be routinely used. [Hypoglycaemia Unawareness, Pract Diab Vol 28, No.5] These include the accuracy at low blood glucose levels, the time lag between blood glucose levels and subcutaneous glucose levels [CGMs generally measure the fluid in the skin and not the blood glucose levels] not to mention the life of the sensors and the cost. Newer 'real-time systems have a built in alarm when glucose

levels are low but these do not always wake the patient and false alarms are common.

The evidence from research according to the review

- Randomised controlled trials of these devices have been disappointing.
- Many patients stop using them after a few weeks because of the inconvenience of attaching and detaching the device.
- One systematic review showed that there was no improvement in control as measured by the HbA1cs but the number of night hypos was reduced.
- There is anecdotal evidence and some trial evidence that in well motivated patients, those with HbA1cs of less than 7.5% at the start of the study, CGMs can help to reduce the numbers of hypos.
- Some people with severe hypo unawareness have reported a dramatic reduction in the frequency of severe hypos.

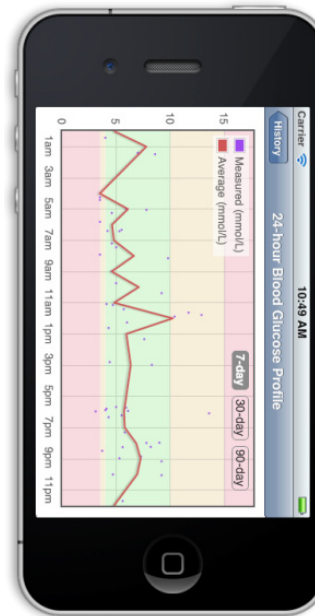
### **Trials of the artificial pancreas**

The most recently published trial of the artificial pancreas looked at 100 people who stayed in a carefully controlled situation in hospital overnight. There were two groups, one using the artificial pancreas and a control group who used a pump. The results are impressive:

- Control participants using a pump spent only 29% of the time with their glucose levels in the normal range and 14% of the time at dangerously low levels.
- The participants using the CGM system spent 67% of the time in the normal glucose range and no time at dangerously low glucose levels.

The big question now is what happens when people use CGM in a normal situation at home when they are getting on with their busy lives? This is the next stage of the research. It will take 4 years and will evaluate the artificial pancreas' ability to improve night time blood glucose levels at home, reduce hypos and also to test the system during the day with meals and exercise in adults with Type 1 diabetes. Other research is looking at the use of the artificial pancreas in pregnant women, when it is important to have good control.

## **New app for teens with Type 1 diabetes**



In today's world where iPhones and iPods just seem to be part of life and certainly something that seem to be just a natural part of life for today's children and young people. Apps are available to help those with Type 1 diabetes with diabetes management. Apps log blood glucose test results but there are others which allow you to log carbohydrates, food, medications and weight. So it is important to decide what you want the app to do before you buy and you should also check that blood glucose results are given in UK units mmols/L and not US units mg/dL. The apps are often free or up to around £5.00.

In June a new app was released designed with children and teenagers with diabetes in mind.

It aims to make their busy lives and the challenges of diabetes a little easier. It is called DiaPETic and is designed to that encourage glucose testing, track the results on a chart and help to provide a better understanding of the best diet to stay healthy.

DiaPETic is an iPhone and iPod Touch app that allows young users to create a pet avatar. Similar to other apps, users gather points that they can redeem for accessories for their pet avatar. The fun is in 'unlocking' new items, and your avatar can morph into a new animal over time. Watch a video on DiaPETic [http://www.youtube.com/watch?v=cHaa9f1\\_6kE](http://www.youtube.com/watch?v=cHaa9f1_6kE)

Other apps designed for children and teenagers with diabetes include Medtronic MiniMed's Carb Counting with Lenny, a free download on the Apple Store for iPhone, iPod Touch, and iPad, which features a nutrition guide and interactive games designed to reinforce healthy

eating.

In the US WellDoc has created an app for diabetes management used by an organisation called Visiting Nurse Service. It is being used in a two-year pilot programme with New York youngsters with diabetes who are given app-loaded smartphones to track the user's lifestyle, such as diet and exercise. This information is then instantly shared with a healthcare professional.

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## What's Happening With The New Hba1c Units?

The changeover to the new HbA1c units was all supposed to happen by June, but what actually happened? Unsurprisingly, IDDT received very mixed reports!

- Many areas have not been giving HbA1c results in the new and the old units as they were supposed to do to enable patients to get used to the new units. Many PCTs and doctors are still working in the old units.
- One of our members went to his hospital clinic and his results were given in the new units but his GP is giving his HbA1c results in the old units!
- Some hospitals are still using the old method of testing HbA1cs and then simply converting the results with the table. [So why bother with new units?]
- Academic journals will continue reporting HbA1cs in the old percentage units – Diabetologia has not started using the new units and Diabetic Medicine will continue using both methods.

### Confused – aren't we all?

In May it was announced that the date for when the new units only will be used has been delayed to October 1st 2011 with the statement

that this is a one off delay. But can this really be forced on doctors, hospitals and researchers if they continue to use the old units? We'll wait and see...

**Table showing the current DCCT measurements and the proposed new IFCC measurements.**

HbA1c (DCCT) Current measurement (%)	HbA1c (IFCC) Measurement from June 2011 (mmol/mol)
6	42
7	53
8	64
9	75
10	86
11	97
12	108
13	119

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## Teenagers - parents have a positive effect, especially dads

Researchers at the University of Utah studied 252 families of young teenagers with Type 1 diabetes looking at them every 6 months for 3 years to see what effect mothers and fathers had on diabetes management. They found a direct link between the level of parental involvement and the health of the child.

The researchers said that even though the adolescent can do the tasks involved in diabetes management themselves, the more the

parents are involved, the better is adherence to the regime. They point out that although children with Type 1 diabetes tend to take more responsibility for their diabetes management, young teenagers do tend to forget their medication but when a parent is more watchful, the child becomes more diligent. Interestingly, it appears that fathers have a specially important role and when they are involved, it seems very beneficial to the teenagers diabetes management.

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## Blood glucose test strips, again

IDDT receives many reports of people being denied their usual number of blood glucose test strips. It seems that the most common way this is done is through repeat prescriptions - the number of test strips just happens to get reduced!

For children and adults with Type 1 diabetes, this can be harmful and certainly worrying if the necessary tests cannot be done as and when required. In addition, the advice to test at least 4 times a day cannot be followed if only two packs of 50 strips per month are given - the math is not difficult!

### What to do if you don't get the strips you need

1. Contact your GP and discuss the number of strips you need and explain why.
2. If this fails take the matter up with the Primary Care Trust.
3. You can also contact the Patient Advice and Liaison Service [PALS] for their help and advice – they have offices within your hospital.

### Sheffield is being proactive and taking sensible steps – cheaper test strips!

No one doubts that the reason for cutting back on strips is cost, although this shows no joined up thinking because if those with Type 1 diabetes end up in hospital for lack of ability to test frequently, then the so-called savings on test strips are soon outweighed!

### Some sense at last!

It has been agreed across Sheffield [and other areas] that the most cost effective device for testing blood glucose is the CareSens N meter and CareSens N testing strips and lancets. So everyone with diabetes is being changed to this meter. The meter is being supplied free of charge by the NHS and prescriptions for strips are being issued once people have used up their old strips.

Looking online, the cost of the meter is £4.99 and 50 strips are as little as £12.95 and if GPs are in a particular buying group, they can purchase them at a further discounted rate. Strips for most meters are around £25.00 for 50 – expensive for people who either have to purchase the strips they need.

While Sheffield's decision may not please everyone and there are issues about patient choice, this is a sensible, cost effective decision. This competition may also force the other manufacturers to lower the prices of their test strips. So if you are having to purchase your strips, it may be worth considering changing to the CareSens N meter.

### CareSens N Meter and test strips, manufactured by Spirit Healthcare

- It requires only a small sample of blood.
- No coding is needed for the test strips.
- The strips use a highly specific glucose oxidase reagent that will only measure glucose.
- It is small, fitting easily into the hand and has an easy to read display screen, results in 5 seconds.
- 250 test results can be stored in the meter memory and it can be downloaded to a personal computer.
- Test range 1.11 to 33.3 mmols/l

## News

### Levemir can be used in young children

At present no long-acting insulin analogue is recommended for children between the ages of 2 and 5 years old. Lantus and Levemir are the two long-acting insulin analogues available and if they are being prescribed at present in this age group, then they are being prescribed as 'off label'. This means that the manufacturers carry no responsibility for them should there be any problems, this responsibility then rests with the prescriber [doctor].

Levemir is made by Novo Nordisk and results from a recently published trial show that it is similar to human insulin in 2 to 5 year olds with Type 1 diabetes but it is associated with a lower risk of hypoglycaemia. [Pediatric Diabetes, March 2011] Novo Nordisk is now applying for a label update for Levemir so that it can be used in children between the ages of 2 and 5 years.



*HumaPen*  
MEMOIR™

The first insulin pen with a memory

### Improvements to Lilly's HumaPen Memoir lead to UK shortage

In June, Lilly announced that they have suspended the supply of the HumaPen Memoir insulin

pen to make necessary improvements, so people using this pen will be unable to obtain replacements until 2012. There is no need to stop using the HumaPen Memoir but before you need a replacement you should contact your doctor or you can call Lilly's device helpline on 0800 783 6764.

## Approaches and Attitudes

### Doctors and parents being optimistic about the complications

A study published in March 2011 in Diabetes Care looked at both parents' and clinicians' perspectives about what, when and how young people with Type 1 diabetes [age range 8 to 18] and their parents should be taught about the complications of diabetes [retinopathy, nephropathy, neuropathy and cardiovascular disease]. It is hardly surprising that the results showed that this creates considerable anxiety for both young people and their parents. The study also showed that there was a wide variety of opinions about appropriate education involving complications and a feeling that this should be tailored to individual need.

Previous studies have not investigated young people's or parents' knowledge of complications, how they cope with this knowledge or how these variables affect outcomes in Type 1 diabetes. 'Outcomes' means measurements of HbA1cs, treatment adherence, quality of life and family conflict about Type 1 diabetes. This study addresses these gaps in research and found some key points:

- Parental knowledge of the complications did not affect any Type 1 diabetes outcomes.
- The youngsters with greater knowledge of the complications were more likely to adhere to treatment.
- More frequent optimistic family communication about the complications was associated with better results on all outcomes.

So the researchers concluded that optimistic family communication about the complications is more likely to produce better outcomes in terms of complications, HbA1cs, adherence to treatment, quality of life and less family conflicts about diabetes. They recommend that larger studies are carried out to confirm these findings and also to look at the type of educational and psychological support that should be developed to help with these issues.

### **Easier said than done?**

While this study may have been small, it has looked at some important issues for us as parents. When and how do we talk about complications to our children and teenagers?

As a parent I sometimes felt that the complications were used as a threat – if you don't look after your child's diabetes properly, your child will develop complications. This may have been meant to provide an incentive, or it may have been my feelings and not quite reality, but I felt it was important not to use the threat of complications with my daughter. At the same time, it was important that she learned about them.

In talking about the complications, I always treated them in the same way as talking to my children about 'the facts of life' – when the questions were asked, I answered as honestly as I could and at a level that was appropriate for their age. The difference with diabetes is that telling them felt hard but not telling the truth could lead to a lack of trust if or when they found out the truth from someone or somewhere else, which they surely will – newspapers and adverts not to mention 'well-meaning friends'!

### **Being optimistic?**

Sometimes it can be difficult for us to be optimistic about the complications of Type 1 diabetes when we think about our children's future. Perhaps the hardest time is at diagnosis and the following months when there is so much to take on and learn. It can also depend on how we are feeling at the time, what else is going on in life that may be causing added stress, and many other factors. I learned to file the knowledge away somewhere so that it did not loom in our lives on an everyday basis – not easy but taking each day as it came helped.

And today, we can afford to be optimistic for children with Type 1 diabetes. So much more is understood about Type 1 diabetes and there are so many developments in the pipeline that the future is brighter than it has ever been.

## **Once a parent always a parent**

It is frequently said that you never stop being a parent no matter how old your children are and it is true. At some point in our children's lives we learn to let go, but they are still our children, even as adults.

We are aware that some of our parent members who are receiving the Parents Bulletin probably have children who are now well into their teens, or even older, so if this applies to you, you may like to receive IDDT's free quarterly Newsletter either in addition to, or instead of the Parents Bulletin. Some parents with young children also like to receive the Newsletter because of the research information and up to date news items it contains.

### **Just to remind you, IDDT produces the following quarterly publications:**

- **The Newsletter [for people taking insulin, both Type 1 and Type 2 diabetes]**
- **The Parents Bulletin [for parents of children with type 1 diabetes]**
- **Type 2 and You [for people on diet and/or tablets]**

Included with this edition is a form for you to complete to let us know which publications you would like to receive – we are happy to supply any or all of them to you. Please help us to send you the information to suit your needs and return the form in the SAE provided or tel IDDT on 01604 622837, e-mail [enquiries@iddtinternational.org](mailto:enquiries@iddtinternational.org)

**Just a note: We are changing the publication dates of the Parents Bulletin to be in line with our other quarterly Newsletters to save postage costs, so the next edition of the Bulletin will be sent out in December 2011.**

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## NHS Direct launch new mobile phone app

June 1st 2011

NHS Direct has launched a free mobile app for people with Android Smartphones or iPhones so that people can download the new app to assess their own or someone else's symptoms by answering some simple questions.

After doing so, there may be instant on-screen self-care advice or instructions on the most appropriate course of action. The app is linked to NHS Direct's telephone service and, if a further assessment is recommended, users will be able to submit their contact details so that an NHS Direct nurse advisor can call them back.

The app includes access to 37 health and symptom checkers covering a wide range of problems including dental pain, diarrhoea and vomiting, abdominal pain, rashes, back pain and burns. There's also the opportunity to get more specialist advice on issues such as mental health, contraception, sexual health matters and pregnancy problems.

The app is available to download free of charge for Android phone users from: <https://market.android.com/> (search for nhsdirect). The app for the iPhone (including the iPod Touch and iPad applications) is available to download free of charge from the iTunes app store: <http://itunes.apple.com/>

The health and symptom checker is also available online at <http://www.nhs.uk/nhsdirect>

People who would prefer to speak to someone on the telephone can still call **NHS Direct** on **0845 46 47** any time of day or night.

## IDDT News



### Holiday Tips

If you haven't already had your holidays, don't forget that IDDT has a Holiday Information Pack with lots of useful information whether you are going abroad or staying in this country. There are handy tips about looking after insulin while away, hot weather and blood sugars, airport security and more. If this would be useful to you, give IDDT a call on 01604 622837 or e-mail [enquiries@iddtinternational.org](mailto:enquiries@iddtinternational.org)



### Going back to school

As the new school year approaches, once again teachers need to be reminded about the needs of children with Type 1 diabetes at school. It may be the first time your child has attended school since being diagnosed or has a different teacher - both of these situations leave us, as parents, anxious about our child. IDDT's free Teachers' Information Pack is designed to support parents as they can take the Pack to the school. It includes information about Type 1 generally, your child's particular needs as well as a poster for the staff room showing the warning signs of hypos. If you would like a Teachers' Information Pack and /or a Parents Pack, then contact IDDT: tel 01604 622837, e-mail [enquiries@iddtinternational.org](mailto:enquiries@iddtinternational.org) or write to IDDT, PO Box 294, Northampton NN1 4XS.



### IDDT's Annual Conference

**'It's My Diabetes'**

**Saturday, October 15th 2011**

**Kettering Park Hotel and Spa**

### Never heard of Kettering?

Our conference has moved to a different part of the country this year in order to give different people a chance to attend. You may not have heard of Kettering

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but it is a central location for many people and it has good road access from all directions. From the north using the M1 and A14, from the north west, M6 and A14, from the south M1, A45 and A43 and from the east using the A14. By rail Kettering is an hour from St Pancras, London.

## The Programme



We are delighted say that we will be joined by additional speakers – Dr Mabel Blades, Consultant Dietician and Mr Michael Holden, CEO of the National Pharmacy Association. As usual there will also be plenty of time for discussion groups. As always, we will be looking at working

together to making living with diabetes a little easier and giving people the chance to talk over their hopes, fears and their feelings about diabetes.

The Conference Programme and application form are available from: <http://www.iddt.org/wp-content/uploads/2011/04/16557-IDDTAnnualConfProg2011Web.pdf>.

We do hope you will join us and help to make this another successful Conference. If you have any queries or would like more information call Rita at IDDT on 01604 622837 or e-mail [rita@iddtinternational.org](mailto:rita@iddtinternational.org)

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If you would like to join IDDT, or know of someone who would, please fill in the form (block letters) and return it to:

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## From Your Editor – Bev Freeman

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