



# Insulin Dependent Diabetes Trust

Registered Charity  
No 1058284  
Issue No 60

*April 2009 Newsletter*

## RESEARCH WARRANTS FRONT PAGE HEADLINES

### *The link between a common virus and type 1 diabetes*

A link has been found between a common family of viruses [enteroviruses] and Type 1 diabetes. Type 1 diabetes has a genetic component, but other factors are also involved. There has been speculation that viruses may trigger the immune reaction which leads to Type 1 diabetes.

This study found evidence of the enterovirus in the pancreatic beta cells of 60% of 72 young people with Type 1 diabetes who died soon after diagnosis. There was virtually no sign of the virus in the tissue of 50 deceased children without diabetes. Enterovirus infections usually cause common cold symptoms or vomiting and diarrhoea, but may have a role in the process by which the immune system recognises the beta cells as foreign so triggering Type 1 diabetes.

The hope is that it may be possible to create a vaccine against these viruses to prevent Type 1 diabetes developing. There are more than 100 different strains of enterovirus, so much more research is needed to identify those that are involved and then how the infection alters the beta cells. A long way to go, but promising as a future prevention of Type 1 diabetes. [Diabetologia, 06.03.09]

### *74% rise in new cases of diabetes from 1997 to 2003 in the UK*

Almost 5 million medical records of adults and children over 10 years were analysed to show a 74% rise of new cases of diabetes between 1997 and 2003. The majority of new cases were Type 2 diabetes and were linked to being overweight or obese and were not due to increased diagnosis or to the aging population. Not all people with Type 2 diabetes are overweight, but about 80% are at diagnosis.

Of the 42,642 people who were newly diagnosed between 1996 and 2005, 1,250 people had Type 1 diabetes. A positive finding was that this number remained constant over 10 years, suggesting that Type 1 diabetes in people over 10 years old is not increasing. Other studies have shown that the increase in Type 1 diabetes is in young children, 5 and under. Losing weight can reduce the risk of Type 2 diabetes by 58% so effective ways of helping people to lose weight are needed. Apart from the health implications, the NHS is already spending 10% of its budget on diabetes, can it afford more if this rise continues? [Journal of Epidemiology and Community Health, Feb 2009]

### *Diabetes drugs given 'too soon'*

This was not high profile research but no less important, as it suggests that one in three people with Type 2 diabetes are given medication too soon instead of being encouraged to eat better and do more exercise.

NICE guidelines for Type 2 diabetes recommend that lifestyle changes should be made before starting medication. The Royal College of GPs holds the same view, yet this study found 36% of the 650 participants were put on tablets within a month of being diagnosed and 13% were on two types of tablets within the first few weeks of diagnosis.

When presenting the study at a Diabetes UK Conference in March, Dr Rob Andrew, senior lecturer at Bristol University, said, "*When people are diagnosed, they're ready to make a lot of changes but if you give them a tablet, you're saying it is not their lifestyle that is the problem*". He added that incentive payments to encourage GPs to reduce blood glucose levels in patients with diabetes, a lack of NHS resources for lifestyle support and a cultural attitude that people will not make the necessary changes, are probably all to blame.

The chairman of the Royal College of GPs, said "*It is a reminder for GPs and nurses managing newly diagnosed diabetes that lifestyle advice is the most important component.*"

# Blood Glucose Testing

## **Choosing a home blood glucose monitor**

Although most blood glucose meters look similar, they are not created equal and it is important to obtain the right one for you. Today, most meters require a sample of blood the size of the tip of a ball point pen [some even smaller] and the results are produced in seconds but everyone is different and what works for one person, may not work for another. Here are a few tips to help you choose the right monitor for you:

- ◆ **If possible, do a trial run before you buy.** Many diabetes specialist nurses will have a selection of different meters for you to try. Talk to your nurse about your needs and if you know other people with diabetes, ask them about what works for them.
- ◆ **Think about the test site.** People usually draw the blood from their finger tips but if this is particularly painful, some meters allow you to test at other sites eg palms, arms, calves or thighs. If you do use these other sites, it is important to remember that the results may well be different from finger tip tests.
- ◆ **Consider record keeping.** Most meters store test results, some provide averages over different periods of time, some pre- and post-meal tests and some have additional computer packages, so if you are computer savvy, you can track blood glucose trends. But all these options do not mean that you have to scrap your paper log if that works for you.
- ◆ **Take into account any visual difficulties you may have.** The size and boldness of display numbers varies between meters, so if you are visually impaired check the size of the display numbers. If your sight is impaired so that you can't read any of the meters, there is a talking meter – the SensoCard Plus. This is available free of charge and the test strips are available on an NHS prescription.
- ◆ **Calibration of your meter.** The accuracy of your meter is important and so it is important that it is calibrated correctly. Meters vary – some have a calibrator with each pack of test strips, some have a code number that has to be entered and some of the newer meters automatically code. So if coding is confusing or time consuming, think about getting a new meter that automatically codes.

## **Important points about monitoring**

Generally meters have roughly the same degree of accuracy and it is important this is maintained. If you are in doubt about your meter's accuracy, you can take it to your clinic and ask them to check it by a test they can carry out. This test and your test should be within 15% of each other. Most meters come with a control solution with a known glucose level, so you can use this to check your meter.

It is also important to keep your meter clean. Dirty meters can give inaccurate readings so it is important to wash your hands before testing. Old meters that have been stored at extreme temperatures can also give inaccurate results.

## **Continuous blood glucose monitoring**

These are new devices and usually your hospital diabetes team will tell you if you would benefit from using a continuous blood glucose device [CGM]. They measure blood glucose results over a 24 hour period to give trends in blood sugars, likely times of hypos or hyperglycaemia and information about how blood sugar levels react to insulin, food and exercise. However, the continuous glucose meters are not accurate enough to rely on the results to make insulin dose adjustments, so 4 finger prick tests a day are still necessary. CGMs measure blood sugar levels every 5 minutes through a sensor that is inserted under the skin, usually in the stomach area, and is attached all the time it is in use, so you can't go swimming or have a bath while wearing it.

## **Choosing your lancets**

Most people use an automatic lancing device to obtain the drop

of blood needed for testing and many blood glucose testing kits automatically come with a lancing device.

This is a spring loaded device containing needles that are released at the press of a button. They usually have adjustable settings to allow you to control the depth of penetration. Here are a few things to consider when choosing your lancet device:

- ◆ Ease of use.
  - ◆ Needle gauge [thickness].
  - ◆ How well you can draw blood with it and how painful this is.
  - ◆ Whether it allows you to test in alternative sites [if you do].
- Some people find getting a drop of blood is difficult so it is worth trying a different lancet to see if this helps. You should not reuse your lancets as this blunts them which makes pain more likely and increases the risk of infection.

## **A few tips for blood glucose testing**

If you have trouble getting a good blood drop of blood for your home blood glucose monitoring, here are a few tips that might help:

- ◆ Warm your hands – rinse in your hands in warm water and rub the dry. This can improve circulation and so make it easier to get a good drop of blood.
- ◆ Shake your hands up and down – again this helps to get the circulation going.
- ◆ Moisturise your hands and fingers regularly – keeping the skin soft makes finger pricking easier.
- ◆ Use the sides of your fingertips – this is less painful and if you gently push on the pad of the end of your finger so that the sides push out, you can get a better sample.

## **Another reason to wash your hands!**

Diabetes Health [January 2009] had a very interesting little article about blood glucose testing by diabetes educator, Cindy Young. She had a patient whose blood glucose levels before lunch were always higher when he was at work than when he was at home. They discovered that the difference was at work he washed his hands in no-rinse hand gel but at home he used soap and water. So Cindy decided to do her own non-scientific research in her own kitchen. She tested her own blood sugars after handling various foods and as she does not have diabetes, she expected these to be stable and in the normal range. She washed her hands with soap and water and tested 4.4mmols/l but when she put lotion on her hands after washing, the result was 4.8. After handling various foods the results were as follows:

- ◆ milk: 5.1
  - ◆ raspberries: 5.1
  - ◆ peanut butter: 5.1
  - ◆ red peppers: 6.5
  - ◆ sweet wine: 6.7
  - ◆ grapes: 24, grapes followed by wiping not washing hands: 7.3
- The message here is clear: always wash your hands, or use alcohol wipes but let your hands dry, before blood glucose testing.

## **Research shows that pain stops many people from testing**

In a pharmaceutical industry sponsored survey of 1,003 adults with Type 1 and Type 2 diabetes using insulin, 4 in 10 people admitted to not testing their blood sugars as often as advised by their doctor. The main reasons given were:

- ◆ Having to re-prick to draw a blood sample.
- ◆ Experiencing pain during testing.
- ◆ Wondering if the results are accurate.
- ◆ Trouble drawing a large enough drop of blood.
- ◆ Having to re-test because of an error message.

If this applies to you, it may be worth thinking about a new meter that may be more accurate and requires a smaller drop of blood. Your diabetes nurse should be able to advise you about this and your technique.

## Hypoglycaemia Research

IT IS FREQUENTLY reported that hypoglycaemia is the most common day to day worry for adults and children with diabetes, and their families. Most of us would agree with this but there appears to be no easy answers. Hypoglycaemia is caused by the treatment of diabetes and not diabetes itself, so we are faced with some very difficult choices:

- ◆ Tight control of blood sugars reduces the risk of long-term complications but at the same time, it results in a threefold increase in the risk of severe hypoglycaemia. [Diabetes Control and Complications Trial [DCCT], 1991].
- ◆ Research has also shown that recurrent episodes of hypoglycaemia, especially at young ages, can lead to hypoglycaemia unawareness [no hypo warnings]. This leads to many problems including loss of independence.

So avoidance of hypoglycaemia is a balancing act and difficult choices have to be made. **Hypoglycaemia is still an unresolved problem in the era of insulin analogues and pump therapy.** Sadly, despite the introduction of insulin analogues and insulin pump therapy, recent research suggests that the problem of hypoglycaemia in Type 1 diabetes is still unresolved. [Diabetes Care 31:S140-S145, 2008] The researchers state:

*“Although the introduction of the new insulin analogues in diabetes therapy and the use of continuous subcutaneous insulin infusion raised hopes for a solution to this problem, these modalities have not been associated with the expected reduction in hypoglycaemic episodes. The findings suggest that the prevention of hypoglycaemia in patients with type 1 diabetes lies in biologically controlled insulin secretion, as in islet transplantation, or the development of an autonomous closed-loop system that efficiently mimics the action of the pancreatic b-cells and maintains blood glucose levels within the desired range.”*

This study supports the findings of other reviews reported in previous Newsletters – that neither the newer insulins nor pump therapy reduce the numbers and severity of hypos for the majority of people. As yet there is no insulin or treatment that succeeds in doing this.

### ***A drug that may prevent night hypos***

Night hypos are a worry for many people with diabetes. A recent small study has shown that a drug, terbutaline, given at bedtime may help to prevent them in people with intensively treated Type 1 diabetes without causing glucose levels to be too high the next morning. [Diabetes Care, December 2008]

The researchers had previously tested a 5 milligram dose of terbutaline but blood glucose levels were high the next morning. So in their recent trial with 15 patients with good glucose control and an average age of 29, they tried low and high terbutaline [2.5 or 5mg] and a placebo on three separate nights at 10.00pm.

The trial was too small to show statistically significant differences between placebo and low-dose terbutaline but the researchers noted that the target dose of terbutaline is between placebo and less than 5mg. They also concluded that larger, controlled studies may show terbutaline to be a safe and effective method of preventing night hypos in Type 1 diabetes. Let us hope that someone does this research!

### ***Hypoglycaemia and intensive treatment of Type 2 diabetes***

We know that tight control and aiming for near-normal blood glucose in Type 1 diabetes increases the risks of hypoglycaemia [low blood sugars] but does this apply to Type 2 diabetes? A small study was carried out to find out if intensive treatment of Type 2 diabetes with oral medications had similar effects and if previous episodes of hypoglycaemia resulted in loss of hypo warnings. Fifteen people were treated with a combination of three medications, metformin, glipizide XL and acarbose, for 6 months and hypos increased and there was loss of warnings:

- ◆ The HbA1cs dropped from 10.2 to 6.7 but rates of hypoglycaemia increased to 3.2 episodes a month.
- ◆ Previous episodes of hypoglycaemia blunted the warnings of hypoglycaemia.
- ◆ Hypoglycaemia with a drop in blood glucose levels to only 3.3mmols/l was sufficient to cause loss of hypo warnings. [Diabetes, online December 10, 2008]

## Follow Up From January 2009 Newsletter

### ***‘Diabetes’ – NHS Choices improves its information***

In our January Newsletter we told you of our concerns about the NHS Choices website, [www.nhs.uk](http://www.nhs.uk) We are very happy to be able to report that since we contacted Ian Maidment (National Co-ordinator – Patient Information) in November, significant improvements have been made to the site. Many of the factual errors have been corrected and there are now clearly distinct pages for Type 1 and Type 2 diabetes – something that we wanted to achieve to raise public awareness of the distinction between the two conditions.

### ***Expiry dates of insulin***

In the same Newsletter [From Our Own Correspondents], Mr B.G. enquired about what expiry dates mean when only the month is given – is it the beginning or the end of the month? Many thanks to Helen Whiteside, Specialist Clinical Pharmacist at St James University Hospital, Leeds, for sending us the answer:

As a rule in pharmacy the expiry date is taken as the last date of the listed month but if the product is labelled with a use by date,

the product should be used up by the last day of the previous month. For example:

Expiry 10/09 Product expires on 31/10/09

Use by 10/09 Product expires on 30/09/09

### ***Avandia and Actos – again!***

We have already reported the increased risk of bone fractures due to osteoporosis with the family of drugs known as thiazolidinediones – brand names Avandia and Actos. Researchers have reviewed 10 previous drug trials involving 14,000 patients. They found that for one in every 20 women with Type 2 diabetes in their 70s who took these two drugs for at least a year, had a chance of a fracture. For women in their mid 50s, it was one fracture for every 55 women taking the drugs. This is more than double the normal risk in these age groups. These drugs only have a modest blood glucose lowering effect and have already been shown to increase the risk of heart attacks and are not recommended as first line treatment for Type 2 diabetes. [Canadian Med Assoc Journal, online Dec 10, 2008]

# A Round Up Of The Changing NHS

## Martin Hirst reports

### ***Patients to get their own "personal health budget"***

Patients are to get their own health budgets so they can pick and choose what NHS services they want. Ministers will include legislation in the Health Bill going through Parliament, to allow the scheme to be piloted in England later this year. Individual health budgets were a key recommendation in Lord Darzi's report on the NHS last year.

Personal care budgets have been used in social care since the mid-nineties and include direct cash payments to an individual, as well as notional budgets that the patient can place in the hands of a social care professional. To date, over 60,000 elderly or disabled people have taken up the option. However, the scheme has not been without controversy when it emerged that money had been spent on football tickets, gym membership and a two week holiday in Spain!

Under the proposals patients will have to reach agreement with their Primary Care Trust (PCT) before buying treatments. Treatments will have to adhere to guidelines set by ministers, but could include alternative therapies such as acupuncture and reiki. Although patients will be given the money directly, there will be safeguards to ensure that the cash is not spent on unapproved treatments, which could include that payments will only be made into a separate bank account, created for the purpose. Where direct payments are handed over to individuals, the way they are used will be carefully monitored and people will receive help from professionals about what services are available.

The plans have been greeted with a cautious welcome by most and nearly all agree that careful piloting prior to national implementation will be necessary. A series of 20 pilot schemes will run over 3 years. Nevertheless, many questions have been raised:

- ◆ Should patients be allowed to spend their personal budgets on non cost-effective treatments?
- ◆ Should individuals be allowed to top-up their care?
- ◆ Should patients be allowed to invest personal budgets to be spent at a later date?
- ◆ Who will decide what the initial payment level will be?
- ◆ Who will decide how to measure cost-effectiveness?
- ◆ How will the decision be made as to what kind of treatment a patient is allowed to purchase, with tax payers money, and from whom?
- ◆ What will happen when a patients budget runs out?

These are all important questions which need to be answered.

The government envisages that the money will be primarily allocated to people with long-term health conditions such as diabetes and MS because their needs are "most easily predictable".

Firstly, we all know that this is simply not the case and needs change from day-to-day. Secondly, is it really fair to expect someone who is newly diagnosed or the carer of someone who has just been diagnosed, to have to take responsibility for the purchase of their care while also dealing with the emotional impact of diagnosis?

### ***Healthy food grant for pregnant women***

Expectant mothers who are due to give birth on or after 6th April 2009 are now eligible to claim a one off government grant of £190 to help towards the cost of healthy food in their final trimester.

While this is a laudable action by the government, designed to give children the best possible start in life, it may raise the

eyebrows of the diabetic community and others whose conditions are managed in part or totally with a diet based regime. People may well question why they are not entitled to financial help towards the cost of their diets when they rely on them to maintain their short and long-term health.

NICE guidelines regarding children with Type 1 diabetes state "*they should be encouraged to eat five portions of fruit and vegetables a day as part of a healthy lifestyle.*" Adults with diabetes are similarly advised to eat healthily. Does it cost more for a pregnant woman to eat healthily than someone with diabetes? We think maybe not.

### ***Just taking a look at the figures raises questions!***

By giving £190 to cover 3 months healthy eating for pregnant women, the government is effectively acknowledging that healthy eating costs an extra £63 a month, which equates to £756 per year per person. So for an average family of 4 the extra cost of healthy eating is £3024 per year. It seems hardly surprising that people are not doing it, especially low income families!

But what about people with diabetes? The basic treatment of Type 1 and Type 2 diabetes is insulin or tablets, exercise and diet, the latter being healthily eating. Many years ago there used to be a dietary allowance for people with diabetes but it was abolished on basis that food didn't cost people with diabetes any more than the rest of the population. Now it seems that healthy eating does cost more, so while fully acknowledging the needs of pregnant women, it seems logical that adults and children with diabetes should receive the same treatment?

### ***GP's offer extended opening hours***

The Department of Health [DoH] announced that over 69% of GP surgeries are now offering patients extended opening hours – usually an extra three hours a week in the evenings and at weekends. Health Minister, Ben Bradshaw was quoted as saying "I am pleased to see that over 69% of GP practices across the country are now providing early morning, evening or weekend opening to reflect local patients' needs. Flexible and convenient opening hours provide millions more appointments and make it much easier for patients to see a GP".

In 2008 the government set a target of 50% of practices to offer extended opening hours. This has followed a protracted debate between the British Medical Association [BMA] and the government, which at times has threatened to get ugly and is probably best described as an uneasy peace.

The alternative, which the Government said it would impose if no agreement was reached, would have allowed primary care trusts [PCTs] to commission GP services from other providers, taking thousands of pounds away from GP practice budgets.

The BMA says it has opted for the "lesser of two evils". On February 9th, Dr Laurence Buckman, chairman of the GPs' Committee said: "This is neither a climb-down nor a U-turn, but recognition that between two bad alternatives, one is worse than the other." However, access to these extended hours still seems to be something of a lottery, with your likelihood of benefitting being dependent on where you live.

### ***The go ahead for self-referrals, including dietitians***

Up to now patients could only visit specialists if referred by their GP but in October 2008 Alan Johnson, Secretary of State for Health revealed plans for patients to refer themselves to certain specialists without the need for a GP referral. This is intended to offer greater flexibility and speed up the referral times but a

BMA spokesman warned that this has the potential to improve patient access to health services only if there is good communication between doctors, patients and allied health professionals in addition to sufficient capacity – in other words enough of the health professionals to meet the demand. *The specialists involved in self-referrals are physiotherapists, podiatrists, speech and language therapists and importantly for people with diabetes, dietitians.*

#### **Hospitals to be penalised for mixed-sex wards**

The Health Secretary Alan Johnson has called for hospitals to scrap mixed-sex wards by the financial year 2010 – 2011. Hospitals which fail to do so could lose up to 2% of their income if they cannot prove that accommodating patients on mixed-sex wards is clinically justifiable. For practical reasons, intensive care units and A & E departments are exempt. Currently, 15% of hospital trusts still use at least one open plan mixed-sex ward. The government is making immediately available a "privacy and dignity fund" of £100 million to allow hospitals to make the necessary changes to their accommodation.

#### **Hospital-wide mobile phone bans should be lifted**

The Medicines and Healthcare products Regulatory Agency [MHRA] has published new guidance that calls for hospitals in England and Wales to consider liberalising the use of mobile phones. The guidance suggests that NHS Trusts should consider giving patients, staff and visitors the widest possible use of mobile phones where this does not interfere with medical equipment or other people's privacy. It does specify that mobile phone use should continue to be restricted in areas where critical care equipment is used and these areas must be clearly marked for both staff and patients.

#### **10-fold increase in people opting for private hospitals**

Patient choice within the NHS was launched at the beginning of 2006 which included the right to opt for either an NHS or a private hospital for non-emergency treatments, such as hip operations. In the early summer of 2007 just over 300 patients a

month were opting for private hospitals but in 12 months the figure had increased 10-fold to just over 3,500 a month and rising. Patients opting for private hospitals have the same access to drugs or procedures available in NHS hospitals but they benefit from individual rooms, free parking, lower rates of hospital infections and higher staff-to-patient ratios. This is effectively private treatment paid for by the taxpayer. There are now 147 private hospitals on the approved list which have agreed to NHS prices.

It was believed that this choice would drive up the standards by getting hospitals to compete with each other but NHS staff have expressed concerns that this could leave NHS hospitals with cash shortages and put care patients may need in the future under pressure. Perhaps it says more about the state of NHS hospitals than anything else!

#### **The National Programme for IT**

In January the Public Accounts Committee (PAC) published a damning report on the progress being made to computerise NHS patient records. The report states that the completion date of 2014 -15, four years later than originally planned, is now in serious doubt. Two of the four companies responsible for the implementation of the programme have not renewed their contracts, leaving the remaining two providers with substantial commitments. Questions are being raised about their capacity and capability to meet these commitments. The estimated cost of the programme of £3.6 billion, now looks to be in doubt and systems that are in place are not providing value for money.

The report also states that the expectations of clinical staff have not been met and there is still some way to go to secure the support of staff using the system. In February, Andrew Way, chief executive of London's Royal Free Hospital, criticised the computerised medical records system as causing "heartache and hard work".

PAC recommends that the Department of Health should allow health trusts to apply for funding for alternative systems, effectively abandoning the scheme.

## ***Skin Disorders And Type 1 Diabetes***

**DIABETES IS KNOWN** to be associated with skin disorders and one study [Diabetes Care, August 2007] has shown that about two thirds of young people with Type 1 diabetes have skin disorders. These usually develop after the diagnosis and early in the course of the condition but, they can develop before diagnosis and they can be the first sign of Type 1 diabetes.

This study compared the frequency of skin conditions in 212 young people with Type 1 diabetes between the ages of 2 and 22 and 196 healthy volunteers of the same age. The results showed that:

- ◆ 67% of patient with diabetes had at least one skin disorder compared with only 26% of the healthy volunteers.
- ◆ Active skin conditions considered to be associated with diabetes were seen in 38% of the young people with diabetes.
- ◆ Ichthyosis, dry patches of scaly skin, was seen in 22% of those with diabetes compared with 3% of the healthy volunteers.

- ◆ Rubeosis, abnormal growth of blood vessels causing red discolouration, occurred in 7.1% of those with diabetes with none in those without diabetes.

- ◆ Fungal infections were seen in 4.7% of those with diabetes and only 1.5% of those without diabetes.

- ◆ The frequency of skin reactions to insulin was 2.7% which the authors considered to be 'fairly low'.

Based on their findings of the frequency and variety of skin disorders associated with Type 1 diabetes, the authors of the study recommend that a dermatologist is included in the group of doctors who treat people with diabetes. Having this as an automatic facility may well be pie in the sky in our NHS system, where many people can't even see a dietitian, but if you have skin problems this study does support you in asking for a referral to see a dermatologist.

## ***Condolences***

**IT IS WITH SADNESS** that we announce the death of Andrew Mann, aged 67, on February 3rd 2009 at University Hospital, Lewisham. Andrew had Type 1 from childhood. He was one of the very early members of IDDT and always gave IDDT his full support. Our condolences go to his partner and his two children.

## The Balance Of Our Body's Chemistry Is Largely Due To The Work Of Our Kidneys

**KIDNEY DAMAGE [NEPHROPATHY]** can be one of the complications of diabetes and diabetes is the single most common cause of end-stage renal failure in Europe and the US. The key to preventing kidney damage is early detection of the excretion of protein in the urine and early intervention with treatment.

There is strong evidence from research that ACE inhibitors, drugs for lowering blood pressure, also have a protective effect on the kidneys. They are often prescribed for people showing the early signs of kidney problems or as a preventative treatment to try to stop this developing.

### **What do our kidneys do?**

The kidneys are situated just above the waist in your back, are partly protected by the ribs and are about the size of a fist and shaped like beans. You can live a perfectly healthy life with one kidney.

- ◆ They get rid of the body's waste products and excess water as urine. The waste products form from the breakdown of the protein we eat and from normal muscle activity.
- ◆ They also produce hormones that help in the production of red blood cells, build strong bones and help to keep blood pressure under control.

Inside each kidney there are about one million tiny units called nephrons that filter and remove excess fluid and waste products from the blood. The entire body's blood supply circulates through the kidneys every two minutes. The waste products and the fluid that are filtered out are excreted as urine. The urine travels through tubes, the ureters, into the bladder where it is stored until it passes out of the body through another tube called the urethra.

### **What happens if the kidneys don't function properly?**

The harmful waste products build up in the blood, called uremia,

and you feel ill. Some of the signs and symptoms of kidney failure are extreme tiredness, nausea, shortness of breath, difficulty sleeping, swelling of the hands feet and face, high blood pressure, itchiness and loss of appetite. The causes can be:

- ◆ Diabetes.
- ◆ High blood pressure.
- ◆ Chronic kidney infections.
- ◆ Severe injury or birth defects.
- ◆ Certain drugs and other kidney disease.

### **Research investigate Vitamin B1 and kidney damage**

A study at Warwick University [Diabetologia, December 2008] tested the effect of vitamin B1 [thiamine] supplements on 40 patients with Type 2 diabetes to see if it would reverse early kidney damage. [Thiamine is found in meat, yeast and grain.] They found that it stopped the loss of a key protein in the urine.

A third of the patients in the study had a return to normal urinary albumin excretion after being treated with high dose (300mg) thiamine taken orally each day for 3 months. The researchers say thiamine works by helping protect cells against the harmful effects of high blood sugar levels.

This work builds on earlier research at Warwick which showed that between 70% and 90% of people with diabetes are vitamin B1 [thiamine] deficient. According to the researchers, this cheap and readily available supplement could benefit most people with both Type 1 and Type 2 diabetes. More work is planned to confirm these findings.

IDDT has a leaflet 'Kidneys and Diabetes'. If you would like a copy, then you can ring IDDT on 01604 622837, e-mail: [enquiries@iddtinternational.org](mailto:enquiries@iddtinternational.org) or write to IDDT, PO Box 294, Northampton NN1 4XS.

## Lowering Cholesterol Without Medication

**THE ARTICLE IN OUR** January 2009 Newsletter, 'Why do people stop taking statins' was highlighted by many local newspapers and large numbers of people with both Type 1 and Type 2 diabetes contacted IDDT for the Newsletter and with questions about statins. People fitted into three main categories:

- ◆ People already taking statins and having adverse reactions.
- ◆ People with normal cholesterol levels who were being advised to take statins.
- ◆ People who simply did not want to take them.

As we have reported, the government recommends low dose statins for all people over 50 to prevent heart attacks and stroke. It is also recommended that all people with diabetes should take statins, again, as a preventative medicine. So what can people do to try to lower their cholesterol if they don't want to take statins or if they have adverse reactions? The first thing is to discuss this with your doctor because there are other cholesterol-lowering drugs however, there are other things you can do as well:

1. **Go for a daily walk.** Try to increase your speed and distance over several weeks. Exercise can lower cholesterol and triglyceride levels.
2. **Eat fish** such as salmon and herring. They contain omega-3 fats which are good at reducing triglycerides. If you don't like fish, you can buy fish oil supplements which are rich in omega-3. The US,

Food and Drugs Administration [FDA] has recently approved their use in people with high triglyceride levels and an article in the Lancet [March 2007] found that fish oil supplements cut the risk of heart attacks by almost a fifth.

3. **Use olive oil.** It is rich in monounsaturated fat and can lower cholesterol levels and reduce the risk of blood clots. If you steam vegetables or eat salads, you can drizzle on extra-virgin oil for its health benefits and to add flavour. Instead of deep fried fish, you can pan-fry in olive oil.
4. **Avoid eating trans fats.** These are found in hydrogenated vegetable oils and shortening so you should avoid deep fried foods and read food labels carefully.
5. **Eat nuts.** Eating a handful of nuts can lower cholesterol and triglycerides. Almonds, pecans and pistachios are the best for you.
6. **Eat an avocado a day.** They are high in 'good' fat and also high in fibre, vitamins and minerals.
7. **Eat oats.** Oats are rich in a fibre called beta-glucan which is said to lower cholesterol levels.
8. **Use supplements of phytosterols.** These are supplements made from plants and there are many studies that show they lower the 'bad' low-density lipoprotein [LDL] cholesterol. Sometimes they are added to margarines or yogurts.

## ***We Can't Be Perfect All Of The Time!***

**DO YOU KNOW THE FEELING** of a slap on the wrists for blood sugars not being what they should be? No matter what age, many of us have experienced a clinic visit where we feel as if we are being given a slap on the wrists for our test results and we are made to feel as if it's our own fault! We can have been trying really hard but we just can't achieve the targets set by the clinic blood sugars but the slap on the wrist doesn't do any good. It makes us feel angry, fed up, intimidated and sometimes, that there is no point in trying any more.

What is even worse is that we may already expect that our HbA1c results are going to be 'too high'. We already know the reasons – we had 'flu for a month with blood sugars that were all over the place, we've been on holiday and relaxed control more than we intended, we've had the stresses of moving house, changing schools or any of the many stresses that happen in life to everyone, with or without diabetes. The slap on the wrist becomes even more upsetting or annoying, if your explanation of why your, or your child's, HbA1cs are 'too high' is not listened to.

A letter from Mrs M.J. in IDDT's January 2009 Newsletter very clearly made the point that 'we must be allowed to take into account life's stresses'. It was a plea for better understanding not only of what living with diabetes is really like but also for recognition that diabetes does not exclude us from having the stresses, the worries, the temporary illnesses or the enjoyable times that people without diabetes have. As Mrs M.J. says, *'We're all individuals, we're not automatons'*. We can't be perfect all the time!

### ***And it's not just at diagnosis***

There is plenty written about the understanding people need at diagnosis, especially for parents. An article in Nursing in Practice [Jan /Feb 2008] acknowledges the needs of parents at diagnosis: *"Parents experience a range of emotions when their child*

*is diagnosed with diabetes. Nurses need an understanding of their grief to be able to support these families as they try to adapt to their 'new' lives."*

Yes, diagnosis is a very difficult time whatever age you are, but it is not just at diagnosis that support and understanding is needed – it is throughout life, sometimes more so than others. There are different issues that need understanding and support and this has a far better chance of working than a slap on the wrists!

One of IDDT's first members who was 84, was diagnosed with Type 1 diabetes when he was 11 years old and he said that after even 73 years, there were still occasions when he sat with his injection ready but it took him 5 or 10 minutes to actually do it. Every now and then he had just had enough of having diabetes – he was just fed up of it. By his own admittance, at these times he was less than enthusiastic about his diabetes control. Receiving a slap on the wrist for his HbA1c being 'too high' was certainly not what he needed – he needed understanding and support.

### ***Expectations***

Living with diabetes seems to be full of expectations. Health professionals can provide information but this doesn't necessarily mean we can achieve the desired blood sugars as there are many other factors involved. We also have expectations of ourselves – we do everything according to instructions from the clinic and yet blood sugars may still be too high or too low. So we blame ourselves and feel frustrated, angry or upset and sometimes all three! But we are whole people with many things going on in our lives that either affect our glucose levels or affect our ability to manage our diabetes. This is when we need help, support and understanding not what feels like a slap on the wrist. A bit of praise for what we do manage to achieve would also go a long way!

## ***Another Reminder – Little Boy Given The Wrong Insulin***

**IN JANUARY 2009 IDDT** was interviewed on television to give a response to a situation where a pharmacy had given the wrong insulin to a mother of a little boy with diabetes. Luckily, the mum noticed the mistake before she gave her son the insulin because the insulin she had been given was milky, not the clear insulin her son normally has.

Obviously, the mother reported the chemist for the mistake and went to the press to warn other people with diabetes to always check their insulin. IDDT reiterated this on TV with our standard advice that you should always check your insulin BEFORE leaving the pharmacy.

Until the introduction of clear, long-acting insulin analogues, long-acting insulins had always been milky in appearance so there was less chance of confusion. Here is a table to help avoid confusion.

Type of insulin	Clear	Milky
Rapid-acting analogue insulin	Yes	
Short-acting human, pork and beef insulins	Yes	
Long [intermediate] human, pork and beef insulins		Yes
Long-acting analogue insulins	Yes	
Pre-mixed insulins		Yes

In the interview, we also took the opportunity to highlight that mistakes can easily happen because many of the names are so similar. For instance, the name of Lilly's Humulin is very similar to Humalog and Novo Nordisk's NovoRapid is very similar to NovoMix. Undoubtedly, the pharmacy was wrong and careless but the naming of insulins and the packaging should be much clearer, especially now that most of the insulins are all clear.

**Note:** The US drug regulatory authority [FDA] estimate that 10 to 15% of all medication errors are due to drug name confusion and the US Pharmacopeia has error reports of 3,170 pairs of generic and brand named drugs.

# Published Study Adds The Safety Of Ins

***IDDT is well aware that any concern raised about the long-term safety of insulin analogues is always debated whether or not this is a topic for discussion in the Newsletter. However, the study makes informed choices of insulin treatment and readers who are health professionals should be able to***

## WHAT ARE INSULIN ANALOGUES?

Surprisingly, IDDT finds that considerable numbers of people are unaware of what type of insulin they are taking and what insulin analogues are. So at the outset, let us be clear about this.

Insulin analogues are biotechnology products [artificial insulins] made by genetically modifying synthetic 'human' insulin, also made by genetic engineering. They are designed to have different absorption profiles compared to other insulins. As they are biotech products, they are likely to have different patterns of toxicity with unknown consequences. Their long-term effects and safety have not been established.

The clinical benefits of insulin analogues have been extensively studied. While there are studies showing there is less hypoglycaemia with insulin analogues, overall reviews have shown negligible benefit. The biological effects have not been systematically studied despite the scientific community's concerns about their carcinogenic potential due to their similarity to insulin-like growth factor 1 [IGF-1].

***Let us be clear, this does not mean that they cause cancer but they could and it is not known if they do.***

**Some people may consider even a minimal carcinogenic risk with insulin analogues is unacceptable when there is little or no benefit in day to day blood glucose control. This is what having an informed choice is about.**

## WHICH INSULINS ARE ANALOGUES?

Short-acting insulin analogues	Long-acting insulin analogues
Apidra [glulisine]	Lantus [glargine]
Humalog [lispro]	Levemir [determir]
NovoRapid [aspart]	

**Insulin analogues display IGF-1 like mitogenic and anti-apoptotic activities in cultured cancer cells.** Diabetes/Metabolism Research and Reviews, 2009; 25: 41- 49

## AIMS OF THE STUDY

This study aimed to investigate whether Lantus, Levemir, Humalog and NovoRapid exhibit IGF-1-like activities on various cultured cancer cells in comparison with IGF-1 and regular human insulin in vitro. The cell lines used were colorectal cancer, prostate cancer and breast cancer all of which were treated with insulin, IGF-1 or insulin analogues and human insulin.

## RESULTS

- ◆ Lantus, Levemir and Humalog all had proliferative [mitogenic] effects that resemble IGF-1 action but ordinary insulin did not.
- ◆ Lantus and Levemir displayed an IGF-1-like anti-apoptotic activity which means that they stopped the normal self-induced termination of a cell's life, to become replaced by a new one. This again leads to an increase in the numbers of cells.

Firstly, the title is confusing enough, so here are a few definitions to help us understand:

**Apoptosis** – normal self-induced termination of a cell's life, to become replaced by a new one, so anti-apoptotic means that this normal action is stopped or reduced.

**Carcinogenic** – a substance that has cancer forming properties.

**IGF-1 or insulin-like growth factor -1** – a hormone which has a broad range of effects including promotion of cell survival, cell proliferation, inhibition of apoptosis, stimulation of metabolism. It is a growth factor involved in cancer initiation and progression.

**Insulin receptors** – insulin receptors are the chemical structures on cells, where insulin binds to the cell and where insulin can get its messages inside the cell.

**In-vitro testing** – refers to research that takes place in a controlled environment outside the body. It is better suited for deducing the mechanisms of action.

**Mitogenic** – promotion of the division and proliferation of any cell, including malignant and non-malignant tumour cells.

# Answers To Concerns About Insulin Analogues

*Insulin analogues is likely to cause concern or fears amongst readers. For this reason, we have however, the alternative of not publishing the information, means that readers are unable to discuss with their professionals are unable have informed discussions with their patients – us.*

## CONCLUSIONS

Lantus, Levemir and Humalog show in vitro proliferative and anti-apoptotic activities in several cancer cells lines and these actions resemble some of the effects of IGF-1 which is a growth factor involved in cancer initiation and progression.

## COMMENTARY

(Diabetes/Metabolism Research and Reviews, 2009; 25: 50 – 51)

There is a commentary on this study by authors from the University of Genova, Italy. The commentary makes several interesting points.

- ◆ Doctors prescribe analogues because they *believe* them to be better and on the findings of *several* clinical trials.
- ◆ The proliferative effect of the analogues is an important finding that 'sustains the idea of a potential link between insulin analogues and increased risk of cancer and teratogenic effects' [birth defects]. These findings could influence the guidelines for the use of insulin analogues.
- ◆ As yet no studies have reported any carcinogenic effects of insulin analogues in animals or in humans but there has been relatively short follow up periods in all studies. [ie not long enough to show whether cancers develop.] There needs to be more studies of better design and longer duration before reaching definitive conclusions about the long-term safety of analogues.
- ◆ The studies designed before the introduction of insulin analogues were designed to look at the effects on blood glucose control and short-term safety on a 'modest' number of patients. This prevented firm conclusions about the carcinogenic or teratogenic effects.

## WHAT DOES THE COMMENTARY RECOMMEND?

- ◆ Doctors should prescribe the insulin that gives the best glycaemic control for non-pregnant patients but also recognise that these new analogue insulins may have adverse effects that only appear many years later.
- ◆ Given the uncertainties, the potential for harm and the relatively modest benefits of the new analogues, all use of insulin analogues should be avoided until much more extensive data are available for analysis by experts in the field.

## IDDT COMMENTS

This study was funded by a research grant from IDDT. As highlighted by the authors of the Commentary, there are unanswered questions about the safety and long-term adverse effects of insulin analogues. As they are now being widely prescribed as first line treatment, IDDT sees it as vital for the health and safety of adults and children with diabetes that research addresses these unknowns. In the light of this, IDDT has just awarded a further grant to the University of Tel Aviv to continue their investigations in this area. Our further concern is that Novo Nordisk have made a public announcement that they intend removing all other insulins to have an insulin analogue only portfolio – a worrying prospect in the absence of evidence of long-term safety.

**If you would like a free copy of a report by Prof. Dr. med. Ernst Chantelau and Jenny Hirst, 'The Safety of Insulin Analogues – should patients be concerned', don't hesitate to contact IDDT on 01604 622837, e-mail enquiries@iddtinternational.org or write to IDDT, PO Box 294, Northampton NN1 4XS**

**IF YOU WISH TO CONTACT IDDT  
YOU CAN DO SO BY  
Telephoning 01604 622837  
or Faxing us on 01604 622838**

Continued from P9

**The recommendations for use of insulin analogues in children and pregnant women in the approved Summary of Product Characteristics documents**

Type of Insulin Apidra [Glulisine]	children Insufficient evidence for use in children under 6 years.	in pregnancy No adequate data for use in pregnancy
Humalog [Lispro]	Should only be used in children in preference to soluble insulin when a fast action of insulin might be beneficial.	Information on large numbers of pregnancies do not indicate any adverse effect on pregnancy or the foetus.
NovoRapid [Aspart]	Should only be used in children in preference to soluble human insulin when a rapid onset of action might be beneficial. No studies have been performed in children under the age of 2 years.	There is limited clinical experience with in pregnancy. There have been two studies which do not indicate any adverse reactions during pregnancy.
Lantus [Glargine]	Safety and efficacy has been established in adolescents and children of 6 years and above. But its efficacy and safety has only been assessed when given in the evening.	No clinical data on exposed pregnancies are available. Data are insufficient to exclude risk.
Levemir [Determir]	The efficacy and safety has been studied in children between the age of 6 and 17years in studies of 6 months duration. It has not been studied in children under 6 years.	There is no clinical experience of use during pregnancy. Caution should be exercised when prescribing to pregnant women.

## *Services For Children With Diabetes Are Lacking And Targets Are Not Being Met*

**ACCORDING TO A REPORT** from Diabetes UK [February 2009], in 2008 some Primary Care Trusts [PCTs] were inadequately staffed to look after children with diabetes. Some paediatric diabetes specialist nurses [PDSNs] were overstretched as they were looking after 150 children when the recommended number is 70, so they were unable to spend the necessary time to give the children individual advice and support.

Douglas Smallwood, the CEO of Diabetes UK, pointed out that the poor staffing levels were responsible for 80% of children with diabetes not achieving the target blood glucose levels so putting children at risk of the long-term complications. He called upon the government to fulfil the promise made 6 years ago, to improve specialist services for children with diabetes.

It is IDDT's experience that when questioning government about services, or the lack of them, the answer is always the same – it is the local PCTs' responsibility to provide the necessary services for the needs in their area. So if you don't think the diabetes services for your child are adequate, write to the head of your PCT pointing this out and asking when they intend to improve the services. Better still, if you belong to a local group of parents, write as a group.

***However did we manage in the past?***

Many of our members are fit and healthy adults who have grown up with Type 1 diabetes from a young age, or are parents whose children with diabetes are now grown up. Paediatric diabetes

nurse specialists simply did not exist. Could the results have been worse than 80% of children not reaching target blood glucose levels? How did parents and children manage then?

- ◆ Type 1 diabetes meant a more regimented lifestyle – meals at regular times.
- ◆ Carbohydrates were counted and restricted to roughly the same amount for the same meal each day.
- ◆ When there was the odd high blood sugar, the use of exercise was encouraged rather than automatically giving extra insulin to lower blood sugars which can affect the blood sugars for the rest of the day.
- ◆ Insulin regimes were less complex and easier to understand. There were more insulins to choose from to suit individual needs. Admittedly rapid-acting insulins were not available but short-acting insulins were used and they last longer so there was rarely a need to inject at school.
- ◆ Hypos were still the main day to day concern but it was almost unheard of for a child not to have good hypo warnings.
- ◆ There were no targets to achieve, or to fail by! The aim was for the best possible blood glucose levels while trying to avoid hypos – so less risk of feeling a failure.

This is not to suggest that the old days were the best – just different. There were a lot of drawbacks too – needles the size of poker, lack of disposable syringes are just two examples but we managed . . .

## Here's What You Have Done To Help Adults And Children With Diabetes In Developing Countries

**AS THE UK ARM** of 'Insulin for Life', during 2008 IDDT collected more supplies to help people in developing countries than in any previous years. It is thanks to you that we have been able to help people who are unable to afford insulin and syringes, not to mention blood glucose test strips. Our joint efforts helped saved lives as we sent:

- ◆ 26,390 mls of insulin – over 26 million units of insulin.
- ◆ 8,037 blood glucose test strips.
- ◆ 7,295 syringes.
- ◆ 19,000 lancets.
- ◆ 11,800 pen needles.

So huge thanks for all you are doing to help people who cannot afford the very basic essentials for the treatment of their diabetes. If you can help, just send any unwanted, in-date, unopened insulin and other supplies to: IDDT, PO Box 294, Northampton NN1 4XS

***But there are people in developed countries who need help . . .***

IDDT has significant numbers of members in countries around the world and many of them need animal insulins because they cannot tolerate human or analogue insulins.

With the invaluable help from members, IDDT fought a long, hard battle to ensure that the UK Dept of Health acknowledged that some people are better suited to animal insulins and they should continue to be available [Minister of Health, 2005]. But in most other countries, such as the US, animal insulins disappeared from the market. This happened despite a lack of evidence that human insulins are better than animal insulins and that much of the research was methodologically poor [Cochrane Review, July 2002]. In the studies there were too few participants, the duration of the studies was too short and there were no comparisons made of complication and mortality rates or quality of life between the two insulins.

Interestingly, Professor Sir Michael Rawlins, chairman of the National Institute for Health and Clinical Excellence [NICE], in a lecture to the Royal College of Physicians, October 2008 made comments about research methods that apply to the trials for human insulin: *"The 'gold standard' is the randomised controlled trial, where patients are assigned to receive either a real treatment or a dummy, but they are expensive, are often too small, do not last long enough and may not detect harmful side effects."*

**Yet on this basis, people are being denied the animal insulin they need. Here's a reminder of what this means for IDDT member, Larrane Ingram in Australia . . .**

*"In 1991 I was advised that the genetically engineered "Human Insulin" was the next progression in treatment and enthusiastically made the change. Almost immediately I had severe hypos with no warning signs, along with erratic and uncontrollable readings from very high to very low which could occur within minutes of each other. I felt constantly unwell, had no energy, unknown viral attacks, two bouts of hospitalisation with septicemia and the indescribable frightening hypos which rendered me unable to give myself the most basic help needed and made me incapable of speech or*

*movement. This culminated in me giving up work for 6 months. Prior to the change of insulins I had none of these problems.*

*I persisted with the insulin as the doctors advised that "Human Insulin" could not be the cause and I was hospitalised several times to try all the "Human Insulins", but they were not successful.*

*I have always maintained a strict regime to maintain my blood sugar levels but whilst on Human Insulin, I became even more regimented and eventually my specialist and GP agreed that it was indeed the synthetic insulin.*

*Within days of being given animal insulin, my hypo warnings returned and a definable and definite improvement in my wellbeing was evident. This allowed me to return to work and I have not had any problems since. Today if a hypo occurs I can deal with it myself, I am not dependent on my partner or others, nor do I have to endure the loss of independence by not being able to drive. In short, I have my life back but for this, I need animal insulin."*

***Imagine how you would feel if the insulin you use was removed from you.***

Most countries allow personal importation to enable people to import pork or beef insulins from the UK, assuming they can convince a doctor that animal insulin is a necessity for them! But it is expensive and recently the costs have become even greater – £100 handling fee and £100 courier charges before you start on the cost of the insulin. There are limits on how much insulin can be imported at any one time, so these costs are incurred several times a year.

This last price increase has resulted in more and more desperate people contacting IDDT from outside the UK – these increases have made it unaffordable for many. Here in the UK and the comfort zone of free prescriptions and all types of insulin being available, you might say, you would pay anything for the life-saving insulin you need, but imagine just about managing to pay the mortgage and the bills, then the cost of importing your insulin goes up by £200! Imagine too, being forced to use a type of insulin that causes you serious adverse effects – this is the future for people like Larrane.

***Where does the responsibility lie?***

Animal insulins have been withdrawn for commercial reasons, so pharmaceutical companies carry the main responsibility. But others must take responsibility too – for assuming that human insulin was better than animal insulin without requiring evidence, for not acting upon the reported adverse effects to human insulin and for the hasty marketing approval granted to human insulin, the first ever genetically engineered drug to be used in man.

That's responsibility for the past but who is going to take responsibility for the future, for the health and even the lives of people who cannot afford the insulin they need? Or will the effects on their health and lives simply be swept under the carpet?

# FROM OUR OWN CORRESPONDENTS . . .

**Here is a selection from the many letters we have received and which the writers have kindly allowed us to reproduce:**

## I STOOD MY GROUND!

Dear Jenny,

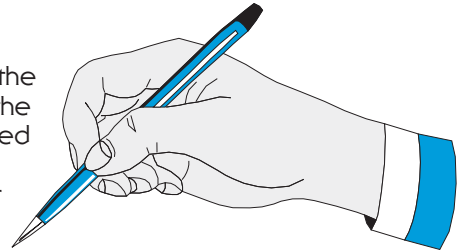
How I agree with Mr S.G.'s letter! [January 2009, Newsletter] Every time I go to the clinic they try to push me on to analogues. I am on two injections a day, and the diabetes nurse always makes some sarcastic comment about how old fashioned my regime is, and how I should be on at least 4 a day.

I was on 4 a day for my first pregnancy 10 years ago and could not wait to get off this regime. Having had diabetes since I was almost 3, I had already had lots of injections, so to double the quantity, was believed to be a necessity for a healthy pregnancy.

My second pregnancy 10 years later was on two injections a day. The care team tried to get me on to analogues, but I stood my ground and had a successful pregnancy and gave birth in June 2008.

Why are people automatically tarred with the same brush? Why can't medical teams treat people as individuals and respect their choice of regime? Why am I deemed as "old fashioned" because I am happy to continue with the regime that I have been happy with for years? The old saying goes, "If it isn't broke, don't fix it" so why don't medical teams respect this?

Thanks IDDT, for helping me to make my own decisions and stand my ground!



*R.N., By e-mail*

## HAS HUMAN INSULIN LEFT AN INSIDIOUS FOOTPRINT?

Dear Jenny,

I had been on Lantus since its inception and wrote to you then extolling its virtues. My blood sugars were in the range of 7 to 20 and I wasn't too unhappy with that as my HbA1c was below 8.5 which, for me with my relaxed lifestyle, was not unreasonable.

Then about 2 years ago the readings began to increase and 18 months ago my HbA1c was over 10 and the medics shifted up a gear "you're not controlling your regime well enough" they said and put me in detention. After 60 years of Type 1 diabetes and going it alone I was not enamoured with this.

During this detention my diabetes specialist nurse suggested a change to Levemir which I complied with and at first, thought it was less aggressive. I found that my blood sugars were less erratic by reducing the dosage but they were between 16 and 27, I could not get below 16. You can imagine no-one was happy but I was in a situation where I had lost all control.

I took your advice and requested trying a change to porcine insulin and my nurse was no problem at all, the request was granted. I continued with my basal/bolus regime and continued with counting carbohydrates, as I have always done. After a month, I felt better and apparently I was better tempered. Now after 4 months, I have regained control of my blood sugar levels.

Unfortunately over the last 25 years, the human insulins have robbed me of warning symptoms except at night when hypo's wake me up, but there is no sweating etc so I doubt whether it is a hypo and have to test. During the day I can get vague warnings but generally I do not recognise them.

At the moment, I would agree with your previous Newsletters that the animal insulins "do what they say on the tin". What is interesting though is that it doesn't happen overnight. I reckon that it was exactly a week before the changes started and then after a month there was another dramatic change when control got even better and now after 4 months things are becoming somewhat predictable.

So, "human" insulins have well and truly messed up my life. From 1948 to 1983 I had good control on animal insulins (and I've tried 'em all), my HbA1c's in 1984 were almost in the "non-diabetic" range. The problems started when I was put on to human insulin so that I could vary the time I had lunch and the amount of carbs I ate.

My latest retinopathy photos show that the first signs of retinopathy have appeared. I gather this is rare after 61 years of diabetes – perhaps if it wasn't for these latest problems, I would still be free of retinopathy.

In my humble opinion, in some people the body can react, either quickly or slowly, in a bad way to human insulins. Possibly this slow reaction is the worst because its insidious effects are not noticed for what they are. The important point that I am trying to make is that it seems that the "human" insulins left some sort of insidious "footprint" which has taken all this time to disappear. Thank you for the advice.

*Mr T.D., By e-mail*

## CHOICE OF INSULIN STILL NECESSARY AT 84 YEARS OLD

Dear Jenny,

I thought you would be interested to hear what happened to me when I was put on insulin in June 2008. Over the years I have been treated with metformin of both types which gave me violent diarrhoea and when the glicazide began to fail, it was decided that I should go on to insulin.

The nurse gave me the 'wonder' analogue on July 4th and by the beginning of September I was suffering all the side effects your literature lists – hypos most mornings and rocketing recoils at night of 25 mmols/l plus! When violent diarrhoea kicked in plus a zombie trance and anal bleeding, I demanded immediate transfer to pork insulin. Within days of changing my blood glucose levels had settled. Now my levels have settled and my January HbA1c was 8.3%. At aged 84 and 9.5 stones, I consider this is fine and I am loathed to upset what seems a fair level. You will be delighted to hear that the local diabetes centre has a large notice in its corridor stating you CAN have porcine insulin! Thank you again for all the useful papers, they alerted me to very dangerous side effects.

*Mr S.C., South West*

## COMMENTS ON DEPRESSION

Hi Jenny

I was interested to read your article in the last IDDT newsletter (Jan 2009) on depression and diabetes in which you draw attention to the work published by Kirsch. In my view, he is not without some bias against medical model treatments [drugs] and whilst promoting talking treatments as a logical alternative, it should be noted that psychological therapies carried out by inadequately trained personnel have been shown to be harmful.

Since 2002 we have in the UK the NICE guidance for depression [CG 23 first published Dec 2004] which uses much broader sources of information to make its recommendations. There is agreement that at the milder end of depression talking treatments are the preferred option but many PCTs, where most depression is managed, do not have the resources to meet the need so medication does get used at earlier stages in an agreed and patient preferred attempt to 'do something'.

With more severe depression medication is often needed because some of the symptoms of depression (eg poor concentration, lack of motivation, often a high anxiety state) make engaging with talking therapies almost impossible. As recovery takes place adding in a non-drug strategy can be especially helpful – the two aren't in competition.

For anyone on a course of antidepressants it is important to not stop treatment abruptly as this can lead to unpleasant withdrawal symptoms. People reading Kirsch should not abruptly stop their antidepressant even if they conclude for them they do not want to continue. Readers who would like further information about medicines and treatments used in mental health might like to look at an independent website [www.choiceandmedication.org](http://www.choiceandmedication.org)

*Alan Pollard, Chief Pharmacist  
Worcestershire Mental Health Partnership NHS Trust*

## IDDT News



### *The Guy Culverwell Childrens Trust – Swimtrek*

We would like to introduce you to a group with whom we have been working closely with over the last few months – The Guy Culverwell Childrens Trust.

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

The Trust have been very active over the last few months and have raised over £7000 in total but a very special mention has to go to Pam for her outstanding achievement in completing her Egypt Swimtrek. Pam's target was to raise £1500 through donations and sponsorship by swimming a total of 19 kilometres over 5 days in the Red Sea. With a lot of hard work and courage Pam completed her challenge and raised an amazing £3400, including a generous £750 in matched fundraising from Barclays Bank.

We know Pam was very surprised and deeply moved by the amount of support she received but we also think it reflects the courage and strength she has shown by completing this challenge.

Pam kept a log of her swim and it will give you a good idea of what she has achieved. You can read about by going to: [www.guyculverwelltrust.com](http://www.guyculverwelltrust.com) or [www.iddtinternational.org](http://www.iddtinternational.org)

Hats off to Pam – You didn't just do good, you did brilliant!!!

### **e-Bay Weekend**

A big thank you to all the sellers, bidders and buyers who took part in the e-Bay weekend in January. The weekend generated a lot of activity and people donated from 25% up to as much as 100% of their sales to IDDT. By the end of the auctions we raised over £170!

While we are on the subject of e-Bay, we need to say another thank you to Jean from Darlington who continues to list for us on a regular basis and has now listed over 300 items. With Jean's help e-Bay for charity has now raised over £340 for IDDT, so thanks to Jean and all of you who took part in our e-Bay weekend.

Don't forget, you can donate to IDDT on e-bay all year round!

### **Thank You for Recycling**

A big thank you to all of you who have been posting your empty inkjet cartridges and mobile phones, to help raise money for IDDT. At the time of writing, recycle4charity have received 81 mobile phones and over 110 ink cartridges and raised £227.85 for IDDT. So keep recycling and don't forget to put your name and address on the back of the recycle envelope before you post it!

## *‘Understanding Your Diabetes’ IDDT New Booklet*

IDDT HAS PRODUCED A NEW BOOKLET, *Understanding Your Diabetes*, for two main reasons.

- ◆ **Our members with Type 1 diabetes are tired of the lack of clarity between Type 1 and Type 2 diabetes and of being accused of having been overweight at some stage in their lives!**
- ◆ **We are hoping that *Understanding Your Diabetes* will help people with Type 2 diabetes to have a better understanding of their condition.**

Type 1 and Type 2 diabetes are both serious conditions, but they are different in both cause and the categories of people that are affected. *Understanding Your Diabetes* explains the two conditions, their similarities and their differences and it is our intention to use this widely. We will also send a copy to the press, every time they produce an article that talks about ‘diabetes’ and does not clarify which type they are writing about. You may question whether this it is IDDT’s role to be concerned about people with Type 2 diabetes, but we think it is.

IDDT’s full title is the *‘Insulin Dependent Diabetes Trust’* and this name was chosen for a reason – to include people with diabetes who need to use insulin which is those with Type 1 and Type 2 diabetes. We never forget that IDDT formed to support people who experience adverse reactions to the synthetic human insulins and need animal insulin – this applies to people with Type 2 diabetes as well as those with Type 1. Also at the core of IDDT’s beliefs is that people with both types of diabetes should have informed choices which must include lifestyle and quality of life issues, not just insulin and medication.

Things have moved on in the 15 years since IDDT formed and we have broadened our activities, largely in response to the needs of people who contact us and obvious gaps in the information provided to them. Part of this growth means that we are now being contacted more and more by people with Type 2 diabetes, some of whom are taking insulin and some who are not. Bearing in mind that, on average, people with Type 2 diabetes start to have to use insulin within 7 years of diagnosis, we believe that it is important that we welcome

people with Type 2 diabetes into the IDDT fold! There are key messages that they will learn:

- ◆ They should be involved in decisions about the treatment of their diabetes.
- ◆ They should ask about their medicines and their choices.
- ◆ If or when they move to insulin treatment, they will know that they have choices – human, animal or analogues.

They will know that the synthetic human and analogue insulins involve different regimes which often involve more daily injections, so they will be in a position to discuss whether this is something they are able to cope with.

### ***Lack of knowledge***

Sadly, one thing that we have learned from increased contact with people with Type 2 diabetes, especially those not using insulin, is the lack of information they have been given about their condition – often very basic knowledge. *“I was given my medication and told to eat a healthy diet”* is something we hear all too often. The greatest gap in knowledge seems to be about diet but also how diet relates to insulin or medication and to exercise – arguably the most important facts to understand for people with both types of diabetes! We feel that IDDT cannot ignore this situation any longer and that it is in everyone’s interests that we try to help.

### ***Understanding Your Diabetes***

The booklet explains the differences between Type 1 and Type 2 diabetes and the points they have in common in an easy to understand language. It explains the relationship between insulin or medication, diet and exercise. In doing this, it supports people with both types of diabetes by removing some of the harmful myths and misunderstandings. At the same time, we hope that it will help people with Type 2 diabetes to better understand their condition and that it is a booklet that GPs and nurses will find useful to give to their patients.

***Understanding Your Diabetes* is available free of charge by contacting IDDT, PO Box 294, Northampton NN1 4XS, telephone 01604 622837 or if your online by e-mailing [enquiries@iddtinternational.org](mailto:enquiries@iddtinternational.org)**

## *Holidays Will Soon Be Here – Be Prepared*

### ***Diabetic holiday foot syndrome***

Research has shown that there is a greater risk of foot ulceration, which can lead to serious complications, during holidays and especially in people holidaying abroad. This especially applies to people with diabetes and neuropathy, where injuries can go unnoticed due to the lack of nerve sensation in the feet. There are several causes of diabetic holiday foot syndrome.

- ◆ Direct injury.
- ◆ Unaccustomed exercise.
- ◆ Walking barefoot on the beach or in the sea.
- ◆ Burns from walking barefoot on hot pavements.
- ◆ Wearing inappropriate inflexible bathing shoes.

Research has shown that overall 6.5% of all foot ulcers in people with diabetes and neuropathy occurred while on holiday. The ulcers took several months to heal and this has the added risk of poor quality of life and time off work. [Pract Diab Int, May 2008 Vol 25, No.4] So it is important to take precautions against any injuries to the feet while on holiday.

### ***Looking after your insulin***

Going on holiday if you have diabetes means that you have to take a few extra precautions, especially if you are travelling overseas. Here are some tips to help you – ones that we have

learned by experience.

- ◆ Travelling overseas probably means that your insulin will not be kept in a refrigerator for days or even weeks. Exposing insulin to high temperatures can make the insulin weaker and so it will not act as efficiently.
- ◆ If a refrigerator is not available try to store the insulin in a cool dark place.
- ◆ Carry your insulin in a polystyrene container or a small wide necked vacuum flask.
- ◆ FRIO wallets can be purchased and they will keep insulin cool and safe for up to 45 hours. They are simple to use – the wallet is immersed in cold water for as little as 4 minutes. The crystals in the side panels of the wallet then expand into a gel which remains cool for several days. FRIO wallets can be ordered over the internet by visiting [www.friouk.com](http://www.friouk.com) or FRIO can be contacted by phone, 01437 741 700 or by writing to PO Box 10, Haverfordwest SA62 5YG

### ***Travel insurance***

Travel insurance sold by insurers and brokers is regulated by the Financial Services Authority [FSA] but insurance bought with a holiday package is not. The lack of regulation for travel insurance through travel agents could mean that you are not receiving the required protection. Always check the small print

of a policy to make sure that you and your diabetes are adequately covered. If you are not asked very detailed questions about your health, you should ask whether any of the conditions you have will affect the cover.

Diabetes is a pre-existing medical condition which must be declared otherwise if a claim is made the insurer will not pay up. Each insurance company has its own criteria for judging medical conditions and diabetes can attract a higher premium.

#### **European Health Insurance Card**

If you are travelling to EU countries and Switzerland you should obtain an EHIC card from any post office. This entitles you to reduced or free essential medical care and covers chronic conditions such as diabetes. However, it is advisable to have additional travel insurance.

#### **Precautions when travelling by air**

- ◆ Make sure that your insulin is in your hand luggage in the cabin with you. The luggage hold of the aircraft will go below

freezing point due to the high altitude and this will destroy or damage your insulin.

- ◆ As a result of security controls, you require a letter from your doctor to state that you have diabetes and need to carry syringes/pens and lancets with you on the flight.
- ◆ Always carry a card to say that you have diabetes.
- ◆ Carry two lots of insulin, testing equipment and syringes/pens and distribute them between two different hand luggage bags – luggage does get lost!
- ◆ Always take sufficient insulin with you because you may not be able to obtain your type of insulin in the country you are visiting.
- ◆ On your return, it is sensible to throw away any unused insulin that has travelled with you as it has been exposed to heat, bright light and to vibrations, all of which can damage insulin and make it less effective.

With all this in mind, have a good holiday!

## **Type 2 Diabetes One Of The Longest Clinical Trials In Medical History**

**THE UNDERSTANDING AND TREATMENT** of Type 2 diabetes today is largely as a result of one of the longest clinical trials in medical history – the United Kingdom Prospective Diabetes Study [UKPDS]. The trial lasted from 1977 to 1997 and then there was a further 10 years of follow up of the patients who took part in the study, so 30 years in all. It was headed by the late Robert Turner and Rury Holman in Oxford and involved 5102 people with newly diagnosed Type 2 diabetes in 23 centres across the UK.

It is hard to imagine how little was known about Type 2 diabetes in 1977 – this was a time before home blood glucose monitoring and the HbA1c test existed.

#### **What did the UKPDS show?**

- ◆ From diagnosis only 16% of patients achieved blood glucose levels within the target of 6.0mmol/l within 3 months. The presence of obesity, or not, did not determine the response to diet but the fall in glucose levels did match up with weight loss and energy restriction. The higher the glucose levels at diagnosis, the more weight had to be lost to achieve target glucose levels of 6 – 8mmols/l.
- ◆ It showed that Type 2 diabetes is progressive. After the initial lowering of blood glucose levels due to weight loss, HbA1cs and fasting glucose levels rise and continue to rise due to the progressive loss of beta cell function [the insulin-producing cells].
- ◆ Treatment with insulin or sulfonylureas was equally effective at lowering glucose levels for 6 years, with similar weight gain but there was more severe hypoglycaemia in those treated with insulin. Metformin was equally effective but without weight gain or hypoglycaemia. Sulfonylureas reduce the risk of cardiovascular complications to the same extent as insulin and metformin achieved the same benefits to glucose control but with a greater risk reduction. [Press reports that more people with Type 2 diabetes should be treated with insulin was not what the UKPDS showed.]
- ◆ Insulin should be a routine part of treatment when blood

glucose levels rise cannot be controlled with oral drugs. The evidence suggests that there is no particular benefit from a regime of basal [long-acting] insulin over mealtime insulin or pre-mixed insulins.

- ◆ The UKPDS also gave some difficult messages – that in 50% of people there were evidence of complications at diagnosis; that within 9 years of the start of the study [and therefore diagnosis] 20% of patients had a macrovascular complication [heart damage, stroke or angina].

#### **Unexpected findings**

One of the unexpected findings of the UKPDS was that glucose control was only a part of the risk for these macrovascular complications and that hypertension [high blood pressure] played almost as big a part as high glucose levels. This also applied to the development of microvascular complications [retinopathy and nephropathy]. However, a follow up study published in 2008 [New England Journal of Medicine, Sept 10, 2008] which looked at the same patients after 30 years showed a marked difference in the risks of macrovascular complications in the group that received intensive treatment [tight control] compared to those on conventional treatment. The risk of heart attack was reduced by 33% while the risk of death was reduced by 27%. This suggests that the benefits of tight blood glucose control on macrovascular complications in Type 2 diabetes may only show up over time.

#### **In summary**

The UKPDS showed that aggressive treatment of blood glucose levels must be followed to reduce the risks of complications and that treatment must be increased with the progressive loss of beta cell function. Above all, it showed that control of blood pressure is central to the prevention of cardiovascular complications.

So the UKPDS set the standards for today's treatment of Type 2 diabetes and perhaps this brief explanation of a 30 year study offers an explanation of the treatment people with Type 2 receive.

## **Is Lettuce The Answer For Type 1 Diabetes?**

**PROFESSOR HENRY DANIELL**, University of Central Florida, has come up with a way to train the body's immune system to make its own insulin using genetically engineered lettuce that includes the insulin gene. Instead of injections, Prof Daniell uses dried lettuce in powder or capsule form and the lettuce cells protect the insulin as it goes through the digestive system. Once in the intestines, the lettuce cells break down and the insulin triggers

an immune response that results in the body making its own insulin cells.

It has worked in diabetic mice and they have shown normal blood and urine sugar levels after 8 weeks.

This research was funded by a \$2 million National Institutes of Health grant and the JDRF, but Prof Daniell hasn't been able to raise the \$20 million to go to the next step – trials in humans.

# SNIPPETS . . .

## **Diabetes UK new Chairman announced**

Professor Sir George Alberti, the government's tsar of emergency care is to be the next chairman of Diabetes UK. He has been involved with the charity since 1974 and became a vice president in 1999.

## **The American Diabetes Association cuts jobs**

In December 2008 the American Diabetes Association [ADA] cut 86 jobs, about 10% of its workforce. This was to address cuts in research funding and expected reductions in fundraising in the present economic climate.

## **Bayer to pay \$97.5 million to settle US government allegations**

The US Justice Department alleged that pharmaceutical company Bayer paid Liberty Medical supply Inc, one of the largest suppliers of diabetes equipment in the US, about \$2.5 million to convert patients from competitors to Bayer supplies between 1998 and 2002. \$375,000 was also paid to 10 other diabetes equipment companies. All 11 companies received government payments for providing equipment to patients enrolled in Medicare, the US federal healthcare plan for senior citizens between 1998 and 2007. Not admitting or denying any wrongdoing, Bayer has agreed to pay \$97.5 million and agreed to a corporate integrity agreement in settlement. Just goes to show what really goes on!

## **Coco Cola and Pepsi have a new sweetener**

In the US, the FDA [food and drugs regulatory body] has approved two versions of a new zero-calories sweetener, one developed by Coca Cola, marketed as Truvia, and the other by PepsiCo marketed as PureVia. Both products use rebiana which is an extract from the stevia plant. For both products, the FDA has stated that it has no objection and they can be 'generally recognised as safe'. Interesting turn of phrase and a bit like standing on the fence!

## **Putting healthy snacks in a McDonald's Bag!**

According to US research, pre-school children consistently preferred the taste of food from a McDonalds bag even if it was not a McDonald's meal. A study of 63 children between the ages of 3 and 5, asked the children to point to which food they preferred out of two choices – one presented in a McDonalds bag and the same food presented in a plain bag. The majority of times they pointed to the McDonald's bag and this even extended to raw carrots and milk when in a McDonald's bag. This just shows the power of advertising and why food and beverage companies spend more than ten billion dollars yearly on advertising!

## **White or Red wine?**

It has been said for some time that red wine, in moderation, is good for your heart but a new study in rats has shown that white wine may have the same protective effect on the heart. [J Agric Food Chem, 2008;56]

## **Omega-3 proved to be beneficial**

There is now convincing evidence that supplements of omega-3 are safe and reduce the risk of first or second heart attacks by 20%. They can also reduce the risk of having to undergo hospital treatment for recurring heart problems. [Lancet 2008;372]

## **Mercury contaminated fish doesn't do us much harm**

We have been warned about eating fish that are high in mercury from polluted seas. However, a new study involving 6410 Finnish fisherman and their families who eat more fish than most people, has shown that they all live longer than non-fishermen, have less heart disease and lower cancer rates than the general population. So it appears that fish is safe to eat but not to catch as fisherman are eight times more likely to die in accidents at sea! [Int J Epidemiology, 2008;37]

**If you would like to join IDDT, or know of someone who would, please fill in the form opposite (block letters) and return it to: IDDT, PO Box 294, Northampton, NN1 4XS.**

Name: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_

Postcode: \_\_\_\_\_

Tel No: \_\_\_\_\_

## **From Your Editor – Jenny Hirst**

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