



# Insulin Dependent Diabetes Trust

January 2009 Newsletter



## Another New Year

### We send Best Wishes to all ourMembers and Readers for 2009

It is a year that IDDT should mark too – it is 15 years since IDDT formed. In 1994 literally a handful of people got together to form a new organisation for people with diabetes. It had no name and no money but between us we had years of experience of living with diabetes and huge commitment! But we had some very clear aims and goals and a determination to remain financially independent of the pharmaceutical industry.

We found a name, we managed to raise some money and no one has challenged our claim that IDDT is the only international diabetes organisation for people with diabetes and their families which is

totally independent and therefore uninfluenced by the pharmaceutical industry. Our only masters are our members and their needs and wishes.

15 years ago our goals were to maintain supplies of animal insulins for the people who need them and so far this has been achieved – the UK is the only country where pork and beef insulins are easily available through the normal health system. In 2009 and the coming years, it is IDDT's intention to make sure that this remains the case. With today's government policy of patients being equal partners involved in decisions about their treatment, it is our hope that 2009 sees this truly applied to people with diabetes so IDDT no longer receives calls from people who say that their healthcare team will not let them change their insulin. We hope too that the informed choice of treatment to which we are entitled will be based on good quality evidence of benefit to patients.

When other diabetes charities have been around many years, 15 years is not very long and when other charities employ 150 or more staff, IDDT's staff, although very committed, is small. We did not set out to form a monolithic organisation but one that grows steadily and never loses sight of what is important – the needs and welfare of children and adults with diabetes. As a small organisation, we have the advantage of getting to know our members and they get to know us. We always try to be sensitive to their needs and their feelings.

We try to raise awareness of diabetes and some of the difficulties of living with it but first and foremost our awareness or advertising campaigns are always sensitive to the needs of people living with diabetes. Shock and hard hitting advertising may advance the profile of a charity and may raise funds, but at what cost? Hard-hitting advertising can hurt the very people the advertising is purporting to help – children and adults with diabetes and their families.

As a charity for people living with diabetes, in 2009 IDDT will not waiver from our commitment to continue to offer help, support and information and in all our activities, the needs, feelings and wishes of adults and children with diabetes and their families will be our priority.

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## NHS News

### NHS charges to be dropped

- Patients with long-term illnesses such as cancer will not have to pay prescription charges. Cancer patients will not have to pay any prescription charges from 2009 and patients with other long term conditions will see charges abolished over the next few years.
- Patients with long-term illnesses will get their own care plans for

the first time.

- From April 2009 there will be free universal check ups for everyone over 40.
- £15 billion invested in research will be “directed to turning the major advances of the last few years into actual treatments and cures for NHS patients”.

### New drug pricing scheme for the NHS

The government has announced a new deal with the pharmaceutical industry which includes a 3.9% reduction in the cost of drugs sold to the NHS and a further 1.9% reduction in January 2010. It introduces a more flexible pricing system whereby initially new drugs will be available at lower prices with the option for the pharmaceutical companies to increase the prices if the drugs are proven to be effective.

This certainly sounds a more business-like approach than in the past. If pharmaceutical companies are convinced of the value and effectiveness of their new drugs, they should have nothing to fear by this new system. It will also enable the National Institute for Health and Clinical Excellence [NICE] to recommend more new drugs eg for cancer, for use in the NHS that have previously been hugely expensive.

### No real benefits for patients from government reforms

A report by the King's Fund [20.11.08] claims that patients have failed to see any real benefits from government health reforms despite GPs being paid almost £100 million in incentives to deliver the scheme of practice based commissioning of services. It also reports that it has not delivered any financial savings to the NHS.

The policy was introduced in 2005 and allowed GPs to run local budgets and buy in services such as hospital and community care. This included diabetic care, diagnostic testing and dermatology. The intention was to provide more patient care in the community so cutting

costs and the number of referrals to hospitals. However, the report says that the implementation has been 'painfully slow' and in some areas has halted altogether with very few GPs using the scheme to commission new services.

### **More 'pacesetters launched to help health inequalities, including diabetes**

In November 2008 the government announced the second wave of 'pacesetters' in which 18 new projects will have access to £5.5 million to develop new ways of helping people from deprived communities in the UK to manage diabetes, cancer and cardiovascular disease. The projects will look into how to support families living with these conditions and provide case studies to help other trusts to address similar health inequalities.

### **Undercover pharmacy survey**

The consumer organisation, Which? has warned that unsuitable and potentially dangerous advice is being given by poorly trained staff in some pharmacies across the UK. Which? carried out an undercover survey of 101 pharmacies and found that a third of visits resulted in the provision of unsatisfactory advice. This appeared to be particularly noticeable in independent pharmacies which gave 'bad' advice on around half the visits. Potentially dangerous omissions were made in providing advice on drugs that should only be sold by a qualified pharmacist. The survey did find some improvement since the last one in 2004 eg more pharmacists now offer a private area to discuss sensitive issues. Which? commented that with plans to expand the role of pharmacists, it is vital that training of sales assistants improves so that pharmacies can be relied upon to give trustworthy advice. The Royal Pharmaceutical Society of Great Britain agreed that more needs to be done.

## **Anti-Obesity Drug Acomplia Is Suspended**

The European Medicines Agency [EMA] has concluded that the benefits of Acomplia no longer outweigh the risks and the marketing authorisation across Europe has been suspended. Acomplia [rimonabant] was licensed in 2006 as weight loss drug in people who are obese with an additional risk factor, such as Type 2 diabetes. Warnings about psychiatric side effects have been included since it was first licensed and people with severe depression or taking antidepressants were advised not to take it. In the July 2008 Newsletter we reported that in the UK NICE had approved the use of Acomplia in the treatment of overweight and obesity as an addition to diet and exercise in people who cannot tolerate the other two anti-obesity drugs, orlistat and sibutramine.

Readers will know that IDDT's Newsletters have been regularly reporting on Acomplia one of the concerns being that Acomplia has never received marketing approval in the US because of the psychiatric risks. If it was not OK for people in the US, was it really OK for people in Europe? Obviously not! The EMA is now recommending that health professionals stop prescribing Acomplia and anyone who is presently taking it should consult their GP as soon as possible.



## **Research News**

### **Type 1 diabetes may not be caused by bad genes but good genes behaving badly**

Researchers at Stanford University looking for the genetic variant responsible for triggering Type 1 diabetes have found that what triggers the immune system to attack the insulin-producing cells is more to do with how the behaviour of genes may differ in people with diabetes than having a distinct set of gene variants. It has been known for a long time that gene variants make people susceptible to Type



1 diabetes and many people have those genes but only a fraction of them develop the condition. In identical twins both have exactly the same genes but about half the time only one twin gets Type 1 diabetes. So the researchers looked for genes in the diabetic twin that act differently from the same genes in the twin without diabetes. The finding that it is the behaviour of the genes rather than the genes themselves may provide an early warning for pre-diabetes but there is still the major question of why a diabetic identical twin's genes began to act differently in the first place! [Clinical Immunology, Nov 2008]

### **Cancer drugs may have a role in preventing Type 1 diabetes**

Researchers in California have used two common cancer drugs to block and reverse Type 1 diabetes in mice. They used Imatinib [Gleevec] and Sunitinib [Sutent] to treat mice that had been genetically engineered to be susceptible to developing Type 1 diabetes. These drugs act by blocking a group of enzymes called tyrosine kinases which are thought to play an important role in several diseases from cancer to autoimmune diseases such as Type 1 diabetes. The researchers believe that tyrosine kinases may regulate the immune system and have a role in destroying the insulin producing cells in the pancreas. When susceptible mice were treated with the drugs before they had developed diabetes, the onset of diabetes was prevented beyond the 7 week course of treatment. They gave the drugs to mice that had already developed diabetes and after 2 months 80% of the mice no longer had diabetes. This is interesting research and new drugs may hold promise but there is still a long way to go. ['The Proceedings of the National Academy of Science,' Nov 2008]

### **Hygiene theory again**

Research has shown that a lack of exposure to bacteria and viruses during childhood may lead to an increased chance of high blood sugar and related diseases. It warns that children brought up in extremely clean houses could be at greater risk of developing Type 1 diabetes later, supporting what is known as the hygiene hypothesis. The researchers suggest that a lack of exposure to bacteria and viruses during childhood may explain the large rise in children under 5 years old being diagnosed with Type 1 diabetes. They suggest that

exposure to some forms of 'friendly' bacteria prevents the onset of Type 1 diabetes. The research used genetically modified mice that lacked the part of the immune system which responds to bacteria. 80% of the mice raised in a completely germ-free environment and therefore lacking 'friendly' gut bacteria developed Type 1 diabetes. However, when they gave the mice a cocktail of the usual bacteria found in the gut, the incidence of diabetes fell dramatically. If there is a better understanding of which bacteria are having this effect and why, then it may be possible to stop the development of Type 1 diabetes. [Nature, September 2008]

### **Honey for healing**

IDDT is funding research in Fiji that is looking into locally produced honey to find out if it can be successfully used to help healing of leg ulcers – a complication of diabetes. This is not as silly as it might sound. A recent study in Canada has shown that ordinary honey kills bacteria that cause sinus infections and in most cases it does it better than antibiotics. The early tests were carried out in laboratory dishes, not live people. So far the researchers have tested manuka honey from New Zealand and sidr honey from Yemen. These two types of honey killed off all floating bacteria in liquid and 63-91% of biofilms whereas the most effective antibiotic, rifampin, only killed 18% of the biofilm samples! Biofilms are micro-organisms which sometimes form a layer in sinuses, urinary tracts and heart valves which protect the bacteria from normal drug treatments and this often leads to chronic infections. Interestingly not all honeys have this same effect – Canada's clover and buckwheat honey did not work at all.

### **How alcohol lowers blood sugar – sorry this is a bit late for the festive season!**

Researchers in Sweden have found that the reason alcohol lowers blood sugar levels is that it redirects blood within the pancreas and sends large amounts to the insulin-producing islet cells. This then spurs insulin production which lowers the glucose levels. Presumably this does not apply to people with Type 1 diabetes where the pancreatic cells do not produce insulin, but it was also found that alcohol causes changes in the blood flow by affecting nitric oxide

which is instrumental in glucose transport and the actions of insulin. Hopefully we are all aware that in people with diabetes alcohol lowers blood glucose levels and this effect can occur for over 24 hours after significant alcohol consumption. [Endocrinology, January 2008]

### **Diabetes and psoriasis linked**

Results from a large case controlled study carried out in Israel show that there is a clear association between psoriasis and diabetes. Analysis of information on 16,851 people with psoriasis and 74,978 controls found that 13.8% of people with psoriasis had diabetes compared with 5.4% of those who did not have it. This association only applied to people over 35 years of age. The researchers recommend that people with psoriasis should be advised about additional risk factors such as smoking and obesity. [Journal of the European Academy of Dermatology and Venerology, March 2008]

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## **Following on from Oct 2008 Newsletter**

There have been developments or research published on some of the topics discussed in IDDT's October Newsletter, so here is an update.

### **Continuous glucose monitoring**

In the October 2008 Newsletter, we gave some comments from a user of the continuous glucose monitoring systems [CGM]. We also looked at what the research told us – that current evidence suggests that continuous glucose monitoring cannot be recommended to improve control in every patient but it might in some people, especially those without hypo warnings. However, before our October Newsletter landed on your door steps the results of another study were published [ref 1]. It supported some of the evidence we quoted – that greater use of Medtronic CGM resulted in improvements in HbA1cs in adults with Type 1 diabetes.

The multi-centre study, funded by the Juvenile Diabetes Research Foundation, involved 322 adults with Type 1 diabetes and the results showed:

- after 6 months adults using CGM there was a statistically significant 0.53% reduction in HbA1c compared to the control group. Importantly, these improvements occurred without an increase in severe hypoglycaemia.
- Younger people did not see a statistically significant reduction in their HbA1c but they used CGM less often than prescribed, 50% of the time or less.
- The most compliant study group – adults 25 to 72 years old – used the device more than 85% of the time and subsequently saw the greatest improvement in A1c.
- When CGM was used at least six days a week all patients in the study regardless of age, experienced reductions in HbA1c levels ranging from 0.5 to 0.7%.

These findings raise the question of why younger people in the study were 'non-compliant' and didn't use the continuous glucose monitoring system as prescribed? Was it just a question of personal choice or are there other reasons why young people did not want to use CGM? These questions need addressing before CGM becomes classed as 'normal' treatment for people with Type 1 diabetes.

### **Continuous glucose monitoring and pregnancy**

A UK randomized control trial, looked at continuous glucose monitoring [CGM] in 71 pregnant women with Type 1 and Type 2 diabetes [ref 2] Evidence suggests that measuring glucose more often improves pregnancy outcomes but the optimum frequency of blood testing is not known. The results showed that continuous glucose monitoring as part of antenatal care improves maternal blood glucose control, lowers birth weight and the risk of macrosomia [large babies]. However, the authors state that the rates of macrosomia were still 3.5 times higher than in the general maternity population so there is still a need for novel educational and technological developments especially in women with long duration of Type 1 diabetes.

Ref 1: Continuous Glucose Monitoring and Intensive Treatment of Type 1 Diabetes, published at [www.nejm.org](http://www.nejm.org) September 8, 2008 (10.1056/NEJMoa0805017)

Ref 2: British Medical Journal 26.9.08

### **More about aspirin**

In IDDT's July 2008 Newsletter we reported on a study that suggested that aspirin may be less effective at preventing blood clots in the arteries in people with diabetes than in people without diabetes. This was followed by a letter in the October 2008 Newsletter from a member whose eye specialist advised her against taking aspirin and within weeks her retinal bleeds stopped. One of the known side effects of aspirin is that it can cause stomach bleeds.

On 14th October 2008, the British Medical Journal online published a study carried at Dundee University that concluded that doctors should not routinely prescribe regular aspirin to people with diabetes to help guard against a heart attack or stroke as it offered no benefits. However, it was effective for those who had already developed heart disease or suffered a stroke – aspirin has been shown to reduce risks of future heart attacks or stroke by about 25%.

The study included details on 1,276 men and women who had never had a heart attack or stroke but were at high risk because they had Type 1 or Type 2 diabetes or peripheral arterial disease. The researchers gave some people either aspirin or a placebo and others an antioxidant or placebo. They found that after 8 years the number of heart attacks and strokes was about the same.

The findings that only patients with a history of clinical or symptomatic heart disease or stroke benefit from taking aspirin contradicts many guidelines which advocate all people with diabetes should use aspirin to prevent heart attack and stroke. It is important to be aware that there are key high risk groups who still need to take aspirin – those who have already had a heart attack or stroke.

Note: there is no panic and people should not stop taking aspirin before talking to their doctor.

### **More about Carers**

Readers will remember that in our October Newsletter we highlighted the needs of carers and gave news of increased government funding to address these needs. Sometimes it is good to chat to other people who are carers to share experiences or even to vent some of the frustrations of dealing with authorities. For those who have internet access there is a website set up for just this purpose where people can chat from their own homes. At [www.carersfriends.co.uk](http://www.carersfriends.co.uk) you can decide how far you want to go from an occasional email to a full-blown friendship.

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## **Recycle For IDDT**

Members will remember that in our November letter we asked you, your friends and your work colleagues to start collecting old mobile phones and empty inkjet cartridges to raise £££s for IDDT. With this Newsletter we are now sending an addressed FREEPOST bag for you to send these to recycle4charity.

- Up to £1 is donated to IDDT for every empty inkjet cartridge.
- Up to £30 is donated to IDDT for every mobile phone.

Please collect and send any type of mobile phone and Dell, Canon, Lexmark and Hewlett-Packard inkjets but NOT Epsom inks or laser 'toner cartridges. For a full list of wanted inkjets visit [www.recycle4charity.co.uk](http://www.recycle4charity.co.uk)

Please put your name and address on the back of the envelope to receive another FREEPOST bag to continue collecting. If you collect at work and would like a free recycling box, please tick the box on the back of the enclosed bag.

## Cost of Type 2 Drugs in the USA Doubles Over 6 Years

An expert panel in the US issued recommendations that doctors should use older, cheaper drugs first to treat Type 2 diabetes. A week later, there were several studies published in the Archives of Internal Medicine [Nov 3, 2008], the first of which shows that the cost of diabetes drugs, both tablets and insulin, prescribed by doctors in the US is now \$12.5 million a year, a doubling over a six year period. The number of people with Type 2 diabetes is increasing but more patients on newer drugs are receiving multiple prescriptions. Researchers said that newer more costly drugs are driving the increased costs despite a lack of strong evidence that these new drugs have greater benefits and safety.

A second study in the same journal adds weight to this view by showing that metformin, an inexpensive generic drug for Type 2 diabetes, has proved its reliability over decades and it may prevent heart disease but the newer more expensive Avandia did not show that benefit. This was confirmed by a third study at John Hopkins University which analysed the findings of 40 published trials of Type 2 tablets that measured heart risks. Compared to other diabetes drugs or a placebo, metformin was linked to a lower risk of deaths from heart disease.

An editorial in the same journal by Dr David Nathan stated *“We need to pay attention to this. If you can achieve the same glucose control at lower cost and lower side effects, that’s what you want to do.”*

### Is this applicable to the UK?

IDDT does not know the total drugs bill for Type 1 or Type 2 diabetes but costs do matter. We are constantly being told that the cost of diabetes to our NHS is huge. If more expensive drugs and insulin have a lack of evidence of benefit and little evidence of long-term safety compared to cheaper drugs or insulin with a proven long history of safety, then not only would patients benefit but so would the NHS.

Perhaps more benefit would be gained by spending the money on better education for people with diabetes or on more trained staff.

### Old or new drugs – making choices

After decades and many new drugs, evidence suggests that metformin is still the best treatment for Type 2 diabetes so it is appropriate to quote from a little book by Alan Cassels [ref 1]. He warns about the medicalisation of conditions that are normal and those that will go away of their own accord yet the pharmaceutical industry produces pills for all ills, even those that aren’t. He calls this ‘disease mongering’ for which his recommended treatment is a healthy dose of scepticism!

Cassels recommends that we should ask questions if a particular treatment is recommended, one of these is ‘How old is the treatment?’ This seems an appropriate question for Type 2 diabetes! Cassels says:

*“If you are given the choice between a drug that has been around for 40 years and one that came on the market last week, ask for the older one first. Physicians know more about older drugs, including what kinds of adverse reactions one might expect and ways to deal with the side effects. Older treatments and drugs come with much more acquired wisdom about how to use them, so you have more knowledge about what you’re getting. You must assume that with any new drug the benefits of it could very well be exaggerated and the risks are likely to be either unknown, understated or concealed.”*

Ref 1 The ABCs of Disease Mongering: an epidemic in 26 letters, Alan Cassels. ISBN 978-0-9780182-3-8

### And while talking big money, this is worth a note

A report from York University in Toronto [ref 1] says the pharmaceutical industry spends about twice as much on promoting its drugs as it does on trying to develop them. The latest published figures show that US drug companies spent \$57.5bn ( 39bn) on promotion in 2004 which includes free samples, visits from drug reps, direct to consumer advertising of drugs, meetings with doctors, e-mail promotions, direct mail, and clinical trials designed to promote the prescribing of new drugs rather than to generate scientific data [‘seeding trials’]. There are

additional promotional costs not included this total, such as the ghost-writing of articles in medical journals by drug company employees and the off-label promotion of drugs.

### **Here's just one example of advertising costs and how we can be deceived!**

Back in February 2008, Pfizer ran an advert in the US for its anticholesterol, Lipitor. In the adverts, a well-known US scientist Robert Jarvik who invented the artificial heart, endorsed Lipitor. Wearing a white coat, Jarvik tells viewers that Lipitor can lower "bad" types of cholesterol by between 39% and 60% and goes on to say "I'm glad I take Lipitor, as a doctor and as a dad". The final shot shows him rowing in healthy, muscular fashion across a sun-kissed mountain lake. Nothing wrong with this you may think. But Jarvik, 61, isn't qualified to practise medicine and he has admitted that he wasn't actually taking Lipitor at the time the adverts were filmed. Finally, he doesn't know one end of a boat from another so the advertising agency used a stunt double with an impressive late middle-age physique. Dr. Jarvik was paid 1.35 million dollars!

Ref 1 The Cost of Pushing Pills: A New Estimate of Pharmaceutical Promotion Expenditures in the United States" published in PLoS Medicine in January 2008

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## **Report Says Government Targets Drive a Wedge Between Doctors and Patients**

In November 2008 a report by Civitas, 'Checking-up on doctors', found that the government's target culture is undermining the relationship of trust and integrity between patients and GPs. It maintains that the quality and outcomes framework [QOF] offers inappropriate financial incentives which distract GPs from providing high quality personalised care for patients by linking a third of general practice income to performance in only a few key measurements or indicators. The focus is almost solely on clinical performance eg blood pressure

measurements, which may not be the priorities for patients who visit their GP.

The report acknowledges that QOF has delivered benefits in improving clinical quality for chronic disease management [presumably this include diabetes] and that health inequalities have been reduced. However, the improvements have not been as good as expected and where conditions have not been covered by QOF targets, some patients can be worse off as a result of financial incentives directing doctor's attentions elsewhere. The report recommends that the QOF targets be downsized to enable GPs to give greater priority to patient need and doctors' professional judgement.

A British Medical Association spokesman responded by defending QOF and said that the assertions in the report are 'based on anecdotes that are without evidence'. Perhaps readers will have a view on this – if so, write to: Jenny Hirst, IDDT, PO Box 294, Northampton, NN1 4XS , or e-mail: [jenny@iddtinternational.org](mailto:jenny@iddtinternational.org)

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## **NHS Choices Website Updated**

**By Martin Hirst**

The NHS National Centre for Involment (NCI) recently publicised updates and improvements to the NHS Choices website. The NHS Choices website is a "service designed to help people make the most of their own health and get the best out of the NHS".

The website has a dedicated diabetes "pathway" that allows people, including healthcare professionals, to access information about many aspects of diabetes and then to print an individualised "Information Prescription" containing the information about diabetes that they need.

From 2009 everyone with a long-term condition is entitled to be given an 'Information Prescription' by their GP so we have had a good look at the information contained in the 'Information Prescription'. We

were surprised and worried at what we read. The information is often confused, unclear and in some cases dangerously incorrect. Here are some examples:

- *“If you have type 1 diabetes, it is likely that you will need to have regular insulin injections, to keep your glucose levels normal.”* IDDT comment – this is incorrect and dangerous. It is not simply ‘likely that you will need regular injections of insulin’ – without insulin those with Type 1 diabetes will die.
- *“There are six main types of insulin.”* IDDT comment – there are 4 species of insulin – analogue, human, pork and beef insulins and within these species there are different types of insulin with different time actions and activity profiles. An alternative would be to give the number of insulins by their time action but even then, there would only be five – rapid, short, intermediate, long and biphasic.
- *“Over 2 million people in England are living with diabetes. Many more have the condition but don’t know it. Type 1 and type 2 are the most common forms.”* IDDT comment – ‘Many more have the condition but don’t know it’ only applies to Type 2 diabetes, not Type 1 and this should be clarified.
- *“Some recent studies have concluded that selfmonitoring of blood glucose may not be beneficial and may increase some people’s anxiety around their diabetes.”* IDDT comment – apart from the fact that these studies have been criticised as flawed, this statement fails to state that they were carried out in people with Type 2 diabetes, not Type 1 diabetes. Thus it is incorrect and misleading, especially as self-monitoring in Type 1 diabetes is an essential part of achieving recommended treatment targets while at the same time reducing the risks of hypoglycaemia.

**In addition:**

- The ‘Information Prescription’ can only be printed in a font size 6 which is hard for the general population to read with normal visual acuity but many people with diabetes have visual difficulties and for them, this font size makes the information inaccessible.
- The information presented repeatedly fails to acknowledge that Type 1 and Type 2 diabetes are different conditions and many of

the statements contained only apply to Type 2 diabetes which has a very real potential to dangerously mislead people with Type 1 diabetes.

In response to this IDDT has written to Ian Maidment, National Co-ordinator for Information Prescriptions pointing out these inaccuracies, inconsistencies and misrepresentations. We have requested that they be rectified at the earliest possible opportunity. We have also requested that separate information prescriptions be made available for people with Type 1 and Type 2 diabetes. IDDT believes that this will reflect the fact that Type 1 and Type 2 diabetes are two separate conditions and should always be regarded as such.

Mr Maidment has thanked us for our comments and has kindly agreed to provide a formal response in due course.

Note: From November 12th 2008 NHS Choices and NHS Direct joined forces to provide one website so the public have all the health information they need in one place – NHS Choices [www.nhs.uk](http://www.nhs.uk) At the time of writing, NHS Direct still has a website [www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk) and of course their phone line continues to offer help and advice and this is 0845 4647.



## Testing For Creatinine

A creatinine test is another test that people with diabetes may have to have but many do not know what it is. So here is some information.

### What is creatinine?

Creatine is a compound that is made primarily in the liver and then transported to your muscles to be used as an energy source for muscle activity. Once in the muscle, some of the creatine is spontaneously converted to creatinine. The amount of both creatine and creatinine depend on muscle mass, so men usually have higher

levels than women.

### **Why test creatinine levels?**

The test can be used as a measure of kidney function.

### **What are 'normal' creatinine levels?**

In Canada and Europe creatinine levels are usually measured in mmol/litre but in the US they are usually reported in mg/dL. [88.4 mmol/L of creatinine is the same as 1 mg/dL] The typical ranges of creatinine levels for women are about 45-90mmol/L for women and 60-110 mmol/L for men. However, they will vary in individual people - for instance creatinine of 150mmol/L may indicate normal kidney function in a body builder who uses his muscles a lot but 60mmol/L could indicate significant kidney disease in a frail old lady.

### **Other causes of raised creatinine**

- One of the adverse effects of statins is inflammation and damage to muscles which results in muscle pain, tenderness or weakness. This inflammation and damage may cause raised creatinine levels called creatinine phosphokinase (CPK). If you report these adverse effects to your doctor he/she may carry out a creatinine test and usually if the creatinine levels are high, then your doctor may advise you to reduce the dose or stop taking statins. Your creatinine levels should then return to normal.
- ACE inhibitors [ACEI] and angio-II receptor blockers [ARBs] are used to treat chronic heart failure and they may increase creatinine levels by more than 30%. Using both ACE inhibitors and ARBs together will increase creatinine levels to a higher level than either of the two drugs individually.
- Creatine is available as a dietary supplement and your creatinine levels may be higher when you take the supplement than when you don't. You should tell your doctor if you are taking dietary supplements.

## **Sharing My Experiences Is Important**

A message for other people using insulin and for health professionals from Sandra Den-Braber to IDDT.

Could you please publish this letter in your Newsletter. I had problems with Lantus [insulin glargine] and I want other people to know to see if they are having similar problems but don't realise that it could be Lantus that is causing them.

One Saturday morning in December 2007, the IDDT Newsletter arrived in my mail and thank goodness it was sent to me. I read a section about the safety of Lantus and other analogues being unknown and that they could have the potential to cause tumours, either benign or malignant. I had been taking Lantus since December 2006 and as I had a family history of cancer, I decided I could not stay on it.

My sugar levels had been very good on Lantus but during the time I was using it I started to have very bad pains in my neck and left shoulder. My health became worse and I went to a specialist because my GP did not know what was wrong. I was sent to a physiotherapist and an occupational therapist but as time went on my hands became very painful and lumps developed in both palms and my fingers were being pulled over. The pain became so severe that I could not sleep and I was fitted with splints for my hands and eventually at night for my arms. As a result of IDDT's Newsletter I came off Lantus and went on Hypurin Porcine insulin. I put on weight but my sugar levels and health were fine and as the weeks went by my symptoms disappeared. I am still left with small lumps in my palms but my fingers are straight again. However, I was then put on Humalog Mix insulin, another analogue, and all my problems started again so I am going back on to pork insulin again.

I would like anyone having similar problems to me, and health specialists, to take note that this did happen to me and the problems disappeared when I changed to pork insulin. I would recommend

that anyone having similar problems to me on Lantus calls Jenny at IDDT on 01604 622837 or by e-mail enquiries@iddtinternational.org If anyone would like to talk to me, give me a call: Sandra Den-Braber on 01928 790067 or email sandra.denbraber@yahoo.co.uk

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## Reporting adverse reactions

It is important for Sandra to report these adverse reactions through the Yellow Card Scheme which is one of the methods of monitoring the safety of medicines. Adverse reactions may not be picked up during the relatively small pre-licensing trials but can appear once a new drug is used in the wider population. Adverse reactions can be reported online [www.yellowcard.gov.uk](http://www.yellowcard.gov.uk) or on a paper Yellow Card which can be obtained from your GP, Pharmacist, by telephoning the MHRA on 0207 084 2000 or you can also contact them by e-mailing [patientreporting@mhra.gsi.gov.uk](mailto:patientreporting@mhra.gsi.gov.uk)

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## Why Do People With Diabetes Stop Taking Statins?

Of course not everyone does stop taking their statins but it seems that a lot of people do. Statins are prescribed to lower cholesterol levels and in people without high cholesterol levels, low dose statins are recommended as a prevention heart disease.

Researchers at Dundee University have looked at why people with diabetes do not follow the advice to take statins regularly and long-term. They found that poor long-term adherence was greater in people who:

- were of younger age,

- had higher HbA1cs,
- no history of smoking,
- no cardiovascular problems when they started statins and
- the development of cardiovascular disease after starting statins.

The researchers found that not taking statins tends to start early in treatment and in general long-term adherence to statin in people with diabetes is poor, especially in those with few other risks of cardiovascular disease. [Diabetes Medicine, July 2008]

IDDT receives a considerable number of calls from people who have adverse effects when taking statins, sometimes just feeling unwell, so perhaps this is one reason why people stop taking them.

### Low dose statins preferable

A study in the Journal of the American College of Cardiology, [April 2008] examined the results of 23 large clinical trials of statin use for patterns of liver damage. They found that highdose statins caused 2.4 times as many cases of liver damage as low-dose statins. When the researchers looked at individual statin drugs, they found that these effects in Zocor (simvastatin) were 1.6 times worse in high doses than low doses and in Lipitor (atorvastatin) 4.0 times worse in high doses. This supports previous studies such as one in the New England Journal of Medicine which found a 5.5 higher risk of liverdamage from maximum-dose Lipitor relative to a lower dose. Most cases of liver damage from statins are minor and reversible, but some can be severe or even potentially fatal. The researchers suggest that it may be wise to prescribe a low dose statin in preference to high dose except in cases where specific LDL [bad] cholesterol levels have to be achieved.

### Statins and pregnancy

Pregnancy is a case where statins must be stopped. Cholesterol is essential for the developing baby and studies have shown a high proportion of foetus malformations in women taking statins during the first trimester. NICE recommends that 'Statins should be discontinued before pregnancy or as soon as pregnancy is confirmed.' Increasing

numbers of women with diabetes of childbearing age are likely to have followed the guideline of taking statins for prevention purposes, so it is important that doctors make them aware of these risks in case of unplanned pregnancies.

### **While talking about cholesterol levels, did you know?**

In people with an under-active thyroid [hypothyroidism] cholesterol levels are usually higher than normal. This is because the cholesterol in the blood is influenced by the amount of thyroid hormones secreted by the thyroid glands. Once hypothyroidism is treated with thyroxin and maintained within the 'normal' range, cholesterol levels should go back to their previous levels.



## **WHO IS THIS?**

This is the new member of the IDDT team! We are proud to introduce our new mascot and we hope that he will be able to help IDDT to support and educate both children with diabetes and children without diabetes. IDDT introduced our mascot at Cedar Road Primary School in Northampton where the class of 9 to 10 year olds joined in a discussion to help them to grow up with a better understanding of diabetes.

There are many children in the UK that have Type 1 diabetes and through no fault of their own. They have to deal with multiple daily injections and blood tests in order to control their condition.

We believe that these children and their brothers and sisters need a reward for coping so well with difficult and life changing situations. So we are giving children with diabetes and their siblings a free 'Goodie Bag'.

We also want to acknowledge the children's achievements by giving certificates. We have opened a Hall of Fame on our website where parents, relatives, friends and teachers can nominate children for their achievements eg their first injection, first blood test, dealing with their diagnosis or their their first day at a new school. Take a look at Alex, our first nominee by visiting [http://www.iddtinternational.org/Hall\\_of\\_fame/index.htm](http://www.iddtinternational.org/Hall_of_fame/index.htm)

So to parents we say: no matter how big or small the achievement, we want to hear about it and let your children know how proud we all are of them. We also don't want to forget brothers and sisters as well – they have a lot to deal with too and they deserve a shout out as well. The 'Goodie Bags' are supplied with IDDT Parents Bulletins which is produced every quarter to give parents tips and basic information about diabetes in childhood. IDDT hopes to make the whole family's life a little easier.

The next event is to name the mascot and details of this competition will be in the February 2009 Parents' Bulletin so join now!

For your free 'Goodie Bag' and membership contact: Bev at IDDT on 01604 622837, e-mail [bev@iddtinternational.org](mailto:bev@iddtinternational.org) or write to IDDT. PO Box 294, Northampton, NN1 4XS.



## **RECYCLE FOR IDDT**

Members will remember that in our November letter we asked you, your friends and your work colleagues to start collecting old mobile phones and empty inkjet cartridges to raise £££s for IDDT. With this Newsletter we are now sending an addressed FREEPOST bag for you to send these to recycle4charity.

- Up to £1 is donated to IDDT for every empty inkjetcartridge.
- Up to £30 is donated to IDDT for every mobile phone.

Please collect and send any type of mobile phone and Dell, Canon, Lexmark and Hewlett-Packard inkjets but NOT Epsom inks or laser toner cartridges. For a full list of wanted inkjets visit [www.recycle4charity.co.uk](http://www.recycle4charity.co.uk)

Please put your name and address on the back of the envelope to receive another FREEPOST bag to continue collecting. If you can collect at work and would like a free recycling box, please tick the box on the back of the enclosed bag

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## A Will for Free

In the spring of 2009, IDDT will be launching a new legacy campaign to raise funds from the general public. In the campaign we are offering to pay the cost of a standard Will for anybody who is over the age of 50. All we will be asking in return is that people give consideration to making a gift to IDDT if they take up our offer.

As a thank-you for your support over the years, we are making this offer to ALL our members and supporters, regardless of age. So if you are thinking about making or updating your Will, then look out for the Will for Free Leaflet that will accompany your April 2009 Newsletter.

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## Christmas Cards

We would like to say a big thank you to all the people who bought IDDT Christmas cards. As ever, we are very grateful for your help and support.

## IDDT Funded Research – do you want to take part?

### Patient Choice in the Treatment of Diabetes – the role of information provision.

This study is being carried out over 8 months by researchers based in the University of Warwick, using focus group discussions with people living with diabetes to explore issues relating to information provision and treatment choice. At least one focus group will be conducted in the University of Warwick and one in central London with some attendance expenses for participants. A questionnaire for use in a larger collaborative study on the same topics will subsequently be developed and tried out in a pilot.

If you might like to take part in a focus group discussion, or to complete and comment on a piloted questionnaire about treatment choice and information provision in the care of diabetes, please contact Dr Natasha Posner on [natasha.posner@warwick.ac.uk](mailto:natasha.posner@warwick.ac.uk) or 07921 481376, or RCN Research Institute, School of Health & Social Studies, University of Warwick, Coventry CV4 7AL. Alternatively you can contact Jenny on 01604 622837, [jenny@iddtinternational.org](mailto:jenny@iddtinternational.org) or at IDDT, PO Box 294, Northampton NN1 4 XS

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## Pharmaceutical Industry News

### Inhaled insulin – not quite over yet!

Studies are continuing into the last remaining inhaled insulin and Mannkind, the manufacturers of Technosphere Insulin System, have released the results of phase 3 trials. These compared the safety and efficacy of Technosphere Insulin inhaled after meals with meal time subcutaneous injections of NovoRapid in people with Type 1 diabetes over 12 months. Both groups also received daily injections

of the basal insulin Lantus [glargine]. The decrease in HbA1cs was the same in both treatment groups but there was weight loss and less hypoglycaemia in those using inhaled insulin compared to those using injected insulin.

Note: a small number of people using the now discontinued inhaled insulin, Exubera, have a medical need for inhaled insulin, so Pfizer and Mannkind have teamed up to transfer these patients to Technosphere insulin.

### **Novo Nordisk invests 400 million US dollars in insulin plant in China**

In November 2008 Novo Nordisk announced that it is to invest nearly 400 million US dollars in a new insulin producing plant in Tianjin, China. This is the largest investment in the history of the company. The new plant, expected to be operational by 2012, will supply insulin to both China and export markets. The insulins produced will be NovoMix 30, NovoRapid and Levemir. It is estimated that nearly 40 million people in China have diabetes, the second-highest number after India. In addition, 64 million people have glucose intolerance [pre-diabetes] so the number of people with diabetes is likely to increase, as is the market for insulin.

### **Stem cell research agreement**

Novo Nordisk, Cellartis AB, stem cell biotechnology company, and Lund University Stem Cell Center have signed a collaborative research agreement for the development of insulin-producing cells from human stem cells. The collaboration aims to develop a cell therapy for the treatment of insulin-dependent diabetes and, in the longer term, a cure for diabetes. Novo Nordisk acquires the exclusive rights to further develop and commercialise potential products for the treatment of diabetes, while Cellartis acquires the exclusive rights to further develop and commercialise certain other products resulting from the technologies developed under the collaboration. Early stages for new generation of insulins Novo Nordisk has achieved clinical proof of concept with a new generation of insulins, NN5401 and NN1250 and intends to start phase 3 clinical development in the second half of 2009.

### **Tamiflu [oseltamivir]**

This is an antiviral drug used to treat and prevent influenza Virus A and Virus B approved for the use of adults and children over one year of age. Now both the FDA in the US and Roche the manufacturers are warning of possible psychiatric side effects which include delirium, other abnormal behaviour and death in some cases. The FDA is updating the Tamiflu label to warn that “patients with influenza should be closely monitored for signs of abnormal behaviour.” Since its approval in 1999, Tamiflu has been given to 20 million children.



## **New Study Sheds Light On When To Test**

People who remember the introduction of rapid-acting insulin analogues, Humalog [Lilly] followed by NovoRapid [NovoNordisk], will also remember that their big selling point was that they lowered the after-meal [post-prandial blood] glucose levels. It was thought that this would lower HbA1cs and in turn, lower the risks of complications although there was no evidence for this. Indeed, Lilly’s approval documents actually said that the effect of lowering post-prandial blood glucose levels was unknown.

The evidence for this is still debatable although people are being advised to measure their blood glucose levels a couple or so hours after eating and making insulin adjustments on these results as a more reliable way of achieving ‘good’ HbA1cs. Some people have found the logic of this difficult to understand as the pre-meal [pre-prandial] tests are the ones that they feel they need. It now seems that there view may be correct!

In September 2008 a study [ref 1] presented to the European Association for the Study of Diabetes conference showed that in people with Type 1 and Type 2 diabetes before meal [preprandial] glucose levels are generally more closely associated with long-term HbA1c levels than after meal [post-prandial] glucose levels.

Researcher Dr. Rikke Borg from the Steno Diabetes Center, Denmark reported: *“Our study shows that pre-prandial glucose values have a larger impact on HbA1c levels, presumably because they resemble the 24-hour, and thus the long-term, glucose levels more closely”*.

In the study blood glucose measurements were obtained pre and post-meal for approximately 10 full days during the 3-month study for each of 273 people with Type 1 and 168 people with Type 2 diabetes.

The researchers found that:

- Self-monitoring blood glucose at particular times of the day were stronger predictors of HbA1c than others.
- The relationship was different for Type 1 diabetes and Type 2 diabetes.
- For Type 1 diabetes, pre-breakfast, pre-lunch, and post-lunch values predicted HbA1c the best.
- For Type 2 diabetes [both non-insulin and insulin-treated], the pre-breakfast and post-lunch, and pre-dinner values provided the best prediction of HbA1cs.

### **What does this mean for people with diabetes?**

This research has identified the tests that are important to try to achieve the best possible long-term blood glucose results as measured by the HbA1cs. Assuming that ‘good’ HbA1cs reduce the risk of long-term complications, the above tests are the ones to carry out for people with the two different types of diabetes. The researchers also point out that in doing so, the number of tests and the discomfort that people experience with testing is reduced, as is the cost, by unnecessary testing.

### **Unanswered question?**

Bearing in mind that the main purpose of prescribing rapid-acting insulin analogues is to lower post-meal blood sugars and reduce the risk of complications, does this study suggest that this actually is not the case?

It seems so. We looked for the answer to this question in the Summary of Product Characteristics documents [SPC] [ref 2] for NovoRapid. This cites two long-term trials in people with Type 1 diabetes that

demonstrated lower post-prandial blood glucose levels with NovoRapid compared to soluble human insulin. But it also states that the HbA1cs were reduced slightly with both NovoRapid and human insulin but the very small difference was ‘of doubtful clinical significance’ – in other words, it would not make much difference to patients. So the effect of lowering post-prandial blood glucose levels with the rapid-acting analogues did not lower HbA1cs to any significant degree. It seems that the manufacturer’s own documents have confirmed the answer to the question, yet this was the original reason for prescribing rapid-acting analogues!

Once again, we have confirmation of the Cochrane Reviews and the German Institute for Quality and Efficiency [IQWiG] that insulin analogues have not demonstrated any benefits for patients.

### **Does lack of benefit matter?**

Perhaps the straight answer to this is, no lack of benefit does not matter if there is no difference in cost. But this is not the case insulin analogues cost a third more than the equivalent human or animal insulins which is money that could be far better spent on patient education or providing better care in schools for children with diabetes.

Ref 1 Derived Average Glucose (ADAG) study, reported at the European Association for the Study of Diabetes annual conference in Rome, Sept 2008

Ref 2 SPC for NovoRapid, downloaded November 20, 2008 [www.emc.medicines.org.uk](http://www.emc.medicines.org.uk)

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## **Latent Autoimmune Diabetes [LADA]**

Sometimes IDDT receives calls from people who don’t really know whether they have Type 1 or Type 2 diabetes and no one has actually told them! It could be that they have latent autoimmune diabetes [LADA] also called Late-onset Autoimmune Diabetes of Adulthood, Slow Onset Type 1 diabetes or Type 1.5 diabetes.

People with LADA are usually diagnosed at an older age than people with typical Type 1 diabetes [usually under 40 years] and are mistakenly thought to have Type 2 diabetes because of their age at the time of diagnosis and the fact that they initially respond to treatment with tablets. It is now thought that 20% of people diagnosed as having Type 2 diabetes could actually have LADA.

Unlike Type 2 diabetes people with LADA do not have insulin resistance and are not obese/overweight at diagnosis. The characteristics of LADA are:

- Adult age at diagnosis (usually over 25 years of age)
- It initially appears to be non-obese Type 2 diabetes and at diagnosis diabetic ketoacidosis is not present as is typical with Type 1 diabetes.
- Initially it can be controlled with diet with or without tablets.
- Treatment with insulin gradually becomes necessary and frequently within months.
- Positive antibodies and low C-peptide levels.
- People are unlikely to have a family history of type 2 diabetes. Some diabetes specialists treat LADA immediately with insulin rather than using tablets but it is not known whether early treatment with insulin is beneficial for the remaining insulin producing beta cells.

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## 'Diabetes' Blurs The Lines

IDDT was recently contacted by a mother asking about the symptoms of diabetes because she was worried that her two year old had diabetes as he seemed to be drinking a lot. She added that he didn't eat a lot and was not overweight. It is not difficult to see that her understanding of 'diabetes', even in her two year old, is that it is caused by eating too much and being overweight.

People with Type 1 diabetes are telling IDDT of their frustration, and sometimes anger, at being 'blamed' for having diabetes with statements such as:

- "You have diabetes, but you're thin! Well I expect you were fat as a child."
- "I expect you have been eating all the wrong foods."

As a parent people have said to me that I must have given my daughter a lot of sweets when she was young. As many of us know, parents feel guilt about their children having Type 1 diabetes, albeit irrational guilt, and certainly are not helped by this attitude.

### Two very different types of diabetes

Type 1 and Type 2 diabetes are two very different conditions, they have different causes and affect different groups of people. They should not be put together under the general umbrella of 'diabetes' as happens in press articles and even NHS information and diabetes organisations' magazines are guilty of just referring to 'diabetes' and blurring the lines between Type 1 and Type 2. This not only can cause unnecessary fears but leads to confusion and misunderstandings that can be dangerous and can also adversely affect attitudes towards people with both Type 1 and Type 2 diabetes – the general public, employers and schools. As one person with Type 1 said:

*"When people are talking to me as if I have Type 2 diabetes, they may as well be from another planet. I know very little about Type 2 diabetes and equally people with Type 2 diabetes know very little about my Type 1 diabetes unless they are using insulin and then we do have some things in common, such as hypos."*

People with Type 2 diabetes especially those treated with insulin do have many of the same worries as those with Type 1 – similar worries about hypos and similar worries about the long-term complications. But Type 1 and Type 2 diabetes are still two very different conditions.

### Casting blame can only have negative effects

Whether people have Type 1 or Type 2 diabetes, casting blame is negative and achieves nothing. The understandable anger and

frustration of people with Type 1 is for being wrongly blamed for causing their own diabetes – it happens through no fault of their own. People with Type 1 diabetes live healthy and active lives for many years without any complications and this is how they want and should be to be seen – as fit and healthy people. Complications can happen simply as a result of the length of time they have lived with Type 1 diabetes, again not through any fault of their own.

Yes, in people with Type 2 diabetes lifestyle factors are often involved in the cause but there are hereditary factors involved too and there is nothing they can do about these. We must also remember that society in general also has to take some responsibility for modern lifestyles which contribute to the increase in Type 2 diabetes.

Blurring the lines between Type 1 and Type 2 diabetes and misconception that 'diabetes' is simply a lifestyle condition, minimises the public perception of the seriousness of both types of diabetes.

### **The effects on research**

The image that people are to blame for having 'diabetes' can result in a less sympathetic attitude towards them as people and towards diabetes in general, whether Type 1 or Type 2. It may reduce donations towards independent research with people giving to what they see as more deserving medical research. However, there is a real problem with the funding of research which can justifiably make people with Type 1 diabetes unhappy. It does seem that research into Type 1 diabetes is being sidelined in favour of Type 2 – no doubt because Type 2 diabetes affects many more people and is more costly to health services. Type 1 diabetes only affects around 10% of the overall number of people with 'diabetes' but it deserves just as much attention as it affects children, young people and adults and is with them for a lifetime.

There are some very clear messages that we need to get across to the media and the general public. But how do we do it and is it IDDT's role?

IDDT formed to help and support people with diabetes, especially those experiencing problems with synthetic GM insulins. This can apply just as much to people with Type 2 diabetes using insulin as those with Type 1 diabetes. In addition, on average people with Type 2 start to take insulin 7 years after diagnosis and there is now research which questions whether they should be put on insulin much earlier to reduce the risk of complications.

So to use marketing language, IDDT's target audience is increasing all the time. And yes, we do have a role in getting the right message across as this protects the best interests of people with both types of diabetes – a core function of IDDT.

How we do it, is up for discussion and we would love to hear your thoughts and views – contact Jenny Hirst, PO Box 294, Northampton NN1 4XS, call on 01604 622837 or e-mail [jenny@iddtinternational.org](mailto:jenny@iddtinternational.org)

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## **Don't Take This Seriously**

It's a joke but it does reflect the mixed messages that research can give!

### **The final word on nutrition**

After an exhaustive review of the research literature, here's the final word on nutrition and health:

1. Japanese eat very little fat and suffer fewer heart attacks than us.
2. Mexicans eat a lot of fat and suffer fewer heart attacks than us.
3. Chinese drink very little red wine and suffer fewer heart attacks than us.
4. Italians drink excessive amounts of red wine and suffer fewer heart attacks than us.
5. Germans drink beer and eat lots of sausages and fats and suffer fewer heart attacks than us.
6. The French eat foie-gras, full fat cheese and drink red wine and

suffer fewer heart attacks than us.

Conclusion: Eat and drink what you like. Speaking English is apparently what kills you.

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## 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:

### **Byetta - Making an Informed Choice**

Dear Jenny,

I was interested to read the 'warning' on Byetta in the October 2008 Newsletter but a little surprised to think that patients are not being told about the risks of pancreatitis.

I was put on Byetta in March this year but I have been kept informed of all risks from day one. From day one I was told of the side effects and everything I needed to know and at every appointment since all the symptoms and side effects have been reiterated to me so that I fully understand what I am taking. In the previous 12 months my daily readings had been above 16 but since taking Byetta they have dropped to about 8 and my HbA1c has dropped over 2 points to 7.3. For me, this benefit far outweighs any risk I am taking and I have full confidence in the medical team looking after me.

I have had Type 2 diabetes for about 8 years now and in that time have been under the supervision of several diabetic nurses who, although within the same Health practice, have all had different ideas as what people should eat and what they should aim for. Also when talking to other diabetics the information they have been given is totally different, WHY!!! Can we not have some National guidelines that are consistent.

Mr W.M., South West

Jenny's comments: good to hear that Mr W.M. is getting on so well with Byetta and his diabetes team have provided him with so much information so that he could make a fully informed choice of treatment. But I am sure that many of us would agree with his comments about dietary information!

### **High Doses**

Dear Jenny,

I have been reading about the problems some people are having with injecting high doses of insulin – larger than their injection pens will dial up. I take 76 units of Isophane and I just dial up 70 units, inject it and leave the needles in the skin and dial up the remaining 6 units. This means only one injection.

Mr A.G., North East

### **Persuasion**

Dear Jenny,

My visits to the diabetic clinic go well and have continued to go well since 1981. BUT whereas in the old days the doctors used to try on every occasion to get me to go on to 'human' insulin, nowadays it is the analogues they are pushing! It does not seem to matter whether my blood sugars are high or low, good or bad it is always the same old question: "I see you are still on the old animal insulin injection system, why don't you try analogues, they are the new wonder drug." I always say that I don't wish to change something that ain't broke especially as I had terrible side effects with human insulin.

About two years ago a very good doctor suggested I should go on a course to be shown how to adjust my insulin to the amount of food I eat and I said yes to this. She said I would receive an appointment in a couple of weeks but nothing happened. At my next 6 monthly appointment the same doctor said I had been 'very naughty' for not attending but said she would put the recommendation in large print this time. This went on for three visits until after two years it was discovered my notes said "This patient is not on the analogue system

and therefore does not fit into the scheme.”

I have managed my diabetes for years by adjusting my insulin to the food I eat anyway using pork insulin – years ago we were all taught to carbohydrate count and adjust insulin doses. Taking pork insulin does not mean that this cannot be done, so is denying me the opportunity to be updated about diet and managing my diabetes unless I change my insulin, just another way to try to make me change to analogues?

There are several things that concern me – firstly my consultant recommended that I went on the course knowing full well that I do not use analogues, so why have I been refused and by whom? Are all the people using human insulin excluded from the course as well? Is this yet another way to persuade people to change to analogues? My view has always been that drug companies have too much influence, is this yet another case of this? Thank you for listening to my ‘rant’ and thank you for a good magazine.

### **We Are Not Automatons**

Dear Jenny,

I am chalking up 44 years of diabetes. I would just like to say that we must be allowed to take into account life’s stresses in our blood sugar readings. Sadly my brother died recently and my blood sugars have been very high and at times very low. My regime has gone to pot! We are all human, we are all individuals and we are not automatons. We cannot always stick to the rules and we cannot always keep our blood sugars at the targets set by the clinic. Your work over many years has been outstanding and your last Newsletter was jam packed with valuable, essential information and I always pass it on to my nephew who has had diabetes 38years.

Mrs M. J. , Glasgow

### **Insulin Expiry Dates**

Dear Jenny,

I cannot find an essential piece of information about expiry dates. The

expiry dates on insulin packs just give the month and year so does this mean the expiry date is the first of the month or the last day of the month? I tested this by trying my insulin right to the end of the month of expiry and it caused problems.

B.G., East Anglia

Comment: IDDT does not know the answer to this either. However, insulin does not go ‘bad’ over time but it can lose its potency, in other words it can become less effective and blood sugars may rise or be erratic. So, if in doubt about the quality of your insulin as it reaches its expiry date, then play safe and discard it.

If you have a view, write to Jenny Hirst, IDDT, PO Box 294, Northampton, NN1 4XS or e-mail [jenny@iddtinternational.org](mailto:jenny@iddtinternational.org)

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## **Avandia No Longer Recommended A Decision At Last**

Regular readers can hardly have missed the debate about whether Avandia [rosiglitazone] is safe to use in the treatment of Type 2 diabetes. The findings of a meta-analysis last year showed increased risks of heart attack and death from cardiovascular causes. [A meta-analysis looks at all the research carried out in a particular topic.] However, the debate continued with differing views from professional bodies and of course, the manufacturers, GlaxoSmithKline, vigorously defended their drug. In August 2007 the FDA in the US issued black box warnings about Avandia [rosiglitazone] and Actos [pioglitazone] and in October 2007 the European Medicines Agency issued its own warnings. Further concerns were raised earlier this year. At the end of October 2008, both the American Diabetes Association [ADA] and the European Association for the Study of Diabetes [EASD] issued guidelines that explicitly advised against the use of Avandia for Type 2 diabetes. RECORD, a study assessing the cardiac outcomes of patients with diabetes using Avandia is due to finish at the end of

2008 and the results of this study may dictate the future of Avandia.

### **So where do we go from here?**

Current US guidelines for treating Type 2 diabetes state that:

- doctors should prescribe metformin [cost of \$30 a month] to lower blood glucose levels in newly diagnosed patients AND should urge them to eat healthy food and get more exercise.
- Other drugs can be added later on top of metformin to help people who do not meet their blood sugar goals.
- The latest guidelines do not include Avandia [cost of \$225 a month].

### **Does this differ from the UK guidelines for treating Type 2 diabetes?**

The latest National Institute for Health and Clinical Excellence Guidelines for Type 2 diabetes issued in May 2008 are broadly similar. Unlike the US, Avandia and all the drugs in this class [glitazones] are in the recommendations but there are warnings to doctors to take into account the most up-to-date advice from regulatory authorities, the cost and safety. The most up-to-date advice now is that Avandia is not recommended.

Note: The US advocacy group Public Citizen has petitioned the Food and Drug Administration [FDA] requesting that Avandia be banned on the basis that its review of the FDA data found 14 previously unpublished cases of severe drug-induced liver failure, including 12 deaths. The petition states that this risk coupled with other known complications including heart failure, fractures and vision loss is too great to allow Avandia to continue to be sold, especially as there is a lack of evidence of any clinical benefit compared to other drugs for Type 2 diabetes.

## **Date For Your Diary**

IDDT's 2009 Conference will be held on Saturday, October 10th 2009 in Birmingham, so we hope that many of you will be able to join us.



## **Depression And Diabetes Update**

It has been known for many years that people with diabetes are more prone to depression than the general population. It has also been known that people with many other chronic conditions are also more likely to have depression, so are mothers of children with Type 1 diabetes. An international report showed that having diabetes and depression has the greatest negative effect on quality of life compared to diabetes or depression alone, or other chronic conditions. [Lancet 2007;370:851-8]

So although the newspapers have treated research about depression and diabetes as headline news, does it really tell us anything we didn't already know? Possibly not, but it highlights the need to ensure that depression does not go undiagnosed and emphasises the need to provide children, adolescents and adults with diabetes with greater support and where necessary psychological assessment and treatment for depression.

### **Research in young adults with Type 1 diabetes**

Research in Australia surveyed 92 young adults with Type 1 diabetes with an average age of 22 and found that 35% of them reported depressive symptoms. Importantly those with depression tended to have poorer blood glucose control than those without depressive symptoms, so putting those with depression at greater risk of complications such as cardiovascular disease. [Diab Med, 2008;25:91-6] The study concluded that as many young adults reported significant levels of psychological distress health teams caring for young adults with Type

1 diabetes should provide psychological assessment and support.

### **Research in older people with diabetes**

Research in Canada has shown that people with heart disease maybe at risk of further attacks if they suffer from depression or anxiety. People with diabetes are more at risk of developing heart disease so this study again emphasises the importance of treating depression in people with heart disease as well as those with diabetes. [Arch Gen Psychiatry 2008;65:62-71]

Research in the US looking at the relationship between diabetes and depression found that depression treatment reduced mortality by half in older people with diabetes. Again this emphasises the need to diagnose and treat depression in people with diabetes. [Diab Care 2007,30:3005-10]

### **Depression link with poor blood glucose control**

As the recent research showed in young people with Type 1 diabetes, depression tended to be linked to poorer blood glucose control. While this could be due to hormonal changes, it is thought that the most likely cause is the negative effects that depression has on people so making self-management of their diabetes more difficult:

- lack of exercise
- increased smoking and alcohol consumption
- lack of or poor blood glucose monitoring

Depression is also associated with increased weight and obesity.

### **The need for diagnosis**

Recent estimates suggest that up to three quarters of cases of depression in people with diabetes may go undiagnosed. This may be because of poor detection rates but it could also be that some people with diabetes don't report their symptoms of depression because they see them as 'just part of having diabetes'.

Screening for depression [not specifically for people with diabetes]

has been recommended by national and international bodies and now in the UK, the Dept of Health recommends that all GPs use two simple questions to screen for symptoms of depression and these questions are:

- During the last month, have you been bothered by feeling down, depressed or hopeless?
- During the last month, have you often been bothered by having little interest or pleasure in doing things?

If people answer 'yes' to either of these questions, they are given a questionnaire to answer to measure the extent and nature of the symptoms. It is important that similar methods are used in diabetes hospital clinics where many people with Type 1 diabetes receive their treatment.

### **Treatment**

Treatment for depression in people with diabetes has been shown to be effective and has the additional benefits of improving blood sugar control. The evidence suggests that cognitive behaviour therapy and anti-depressant medicines are as effective in people with diabetes as in those without diabetes. One study found that not only did treatment improve blood sugar control but during treatment there was an improvement in mood and weight. So treating depression can improve blood sugar control, so reducing the risk of complications but importantly, it can also improve quality of life.

So if you answer 'yes' to the two questions above or you have more mild symptoms, you are not alone and the clear message from research is to seek help from your doctor because there is a good chance that your life will improve.

### **Do antidepressant medications work?**

A recent independent analysis of the results of all trials [a metaanalysis] of the newer antidepressants has raised questions about their benefits when compared to a placebo or 'dummy' pill. [PLoS Medicine: <http://medicine.plosjournals.org/perise>] These newer antidepressants are

known as 'selective serotonin reuptake inhibitors' [SSRIs], Prozac being the best known SSRI. A previous meta-analysis already indicated that SSRIs had only a marginal clinical benefit. However, the drawback of looking at averages is that it may hide benefits in different groups of patients so this latest meta-analysis investigated whether the severity of the depression at the start of treatment affected how well the SSRIs work. The results confirmed that:

- the overall effect of this new generation of SSRIs was below the level of clinical significance.
- There was little difference in improvement for the drug or the placebo for moderate depression and only a small but clinically insignificant difference for severe depression. But there was an improvement in depression in the most severely depressed patients using SSRIs compared to a placebo although the effects in this group appeared to be due to less responsiveness to the placebo rather than increased responsiveness to the antidepressant.

So these findings suggest that when compared to a placebo, the new generation of antidepressants only show significant effects in the most severely depressed patients. This study has sent shock waves going across the medical community as millions of people have been prescribed drugs such as Prozac and it raises questions about the quality of initial studies and the marketing of the drugs by the pharmaceutical industry.

It is also known that depression itself can cause Type 2 diabetes. After analysing information from health databases researchers found that people with a history of depression had a 30% increased risk of Type 2 diabetes. They then studied the health records of 2,400 people who had been diagnosed with depression and were taking antidepressants. The group was divided into 4 groups:

- Those who took older antidepressants [tricyclic antidepressants, TCAs]
- Those using newer antidepressants
- Those using a combination of older and newer antidepressants

- People who were switching medications.

The results showed that the risk of Type 2 diabetes almost doubled in people using a combination of the two types of antidepressants, TCAs and SSRIs, compared to people using only one antidepressant. People are usually prescribed multiple medications if they have severe depression or having difficulty finding the right one for them.

The researchers recommendations emphasise the need for regular screening for Type 2 diabetes in people with depression, especially in those taking more than one antidepressant and that diabetes and depression organisations should educate their members about the link. So that's what we are doing! [Diabetes Research and Clinical Practice 2008:DOI:10.1016/j.diabres.2007.07.009]

Note: If you would like a copy of IDDT's free leaflet 'Diabetes and Depression' contact us on 01604 622837, e-mail [enquiries@iddtinternational.org](mailto:enquiries@iddtinternational.org) or write to: IDDT, PO Box 294, Northampton NN1 4XS



## 61 Years With Diabetes

An article in the daily telegraph [1.11.08] described how Dr Chris Whitworth a GP in St Agnes, Cornwall cleared out his attic and found pictures of his uncle, grandfather, greatgrandfather and great-great-grandfather who all practised there before him. This was particularly interesting to Peter a member of IDDT who was diagnosed by Dr Henry Whitworth in 1947.

Peter remembers that his diagnosis by Dr Whitworth was by testing his urine with Fehlings solution in a test tube – the solution changed from bright blue to orange. This was his introduction to diabetes. There was no such thing as Type 1 or Type 2 diabetes in those days.

He was sent home with a glass syringe, needles, a vial of insulin and a bottle of Fehlings solution. At this time there was no NHS so he also had a doctor's bill for 2/6d. Food was still strictly rationed at the time, and although the coupons for sugar were cancelled in his ration, people with diabetes had the compensation of cheese, butter, milk and eggs.

As Peter says: *“How times have changed. Now here I am 61 years later, still on twice daily insulin injections and I am eternally grateful to the NHS and all the improvements in treatment since my early days.”*

It is worth noting that Peter's experiences of diagnosis and managing his diabetes was 61 years ago but people diagnosed as recently as the 70s had similar experiences – glass syringes that had to be boiled once a week and long, large needles that had to be reused time after time although Fehlings solution had been replaced with tablets for urine testing. So for 30 years there were few improvements in the way people looked after their diabetes. It was not until the late 1970s and the introduction of home blood glucose measuring that things started to improve for those with diabetes, not to mention the availability of disposable syringes and fine needles!

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## Asking Questions About Your Health

The government is continually telling us all that patients are at the centre of the NHS and that patient choice is a key part of today's health policies. As regular readers will be aware, IDDT strongly believes in informed choice of treatment which involves people asking questions of their doctor or nurse. With the background that one on 10 people experience some type of error with the medical treatment while in hospital, a study was conducted to assess factors that influence patients' willingness to ask health professionals questions related to the safety of their treatments. The 80 people surveyed had all recently

undergone surgery. The results showed:

- patients were far more likely to ask factual questions of all health professionals, eg the length of their hospital stay, than they were to ask questions that could be seen as challenging clinical abilities, such as whether that health professional had washed his/her hands.
- They were more willing to ask factual questions of doctors than of nurses but were more willing to ask challenging questions of nurses than of doctors.
- However, when doctors encouraged patients to ask difficult questions, they were more willing to ask both doctors and nurses questions on safety and quality issues.
- The people least likely to ask questions of health professionals were men, people with lower levels of education and people who are out of work. Almost by definition but also shown in the survey, women were the most willing to ask questions.

The authors comment that patients need to feel they can ask questions that may be seen to be challenging without causing offence to health professionals. This comment seems to put the responsibility for change on patients and without doubt we all need to be a bit more courageous, but health professionals also need to adopt an attitude that enables patients to feel sufficiently comfortable to ask the questions.  
[Quality and Safety in Health Care, April 08]

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## Snippets...

### Could “Guinness is Good For You” be true?

Research at a Wisconsin University suggests that drinking a pint of stout may be as effective at preventing heart attacks as low-dose aspirin because it can reduce clotting. Blood clots can trigger a heart attack if they lodge in the arteries supplying the heart.

The researchers used dogs with narrowed arteries similar to those in people with heart disease to compare effects of drinking stout with those of drinking lager. They found Guinness reduced clotting activity but lager did not and concluded that the antioxidants found in Guinness are similar to those found in certain fruits and vegetables.

Older readers will remember that Guinness were ordered to stop using its famous slogan 'Guinness is good for you' many years ago. This came from market research in the 1920s which showed that Guinness drinkers felt good after a pint. At one time blood donors and people in hospital used to be given a pint of Guinness a day. Even pregnant women and nursing mothers used to be advised to drink stout because of its high iron content.

### **Belonging to a patient organisation improves blood glucose control in people with Type 1 diabetes**

researchers looked at the effects of belonging to patients' organisations and found that blood glucose control as measured by HbA1c was better in people with Type 1 diabetes and about the same in those with Type 2 diabetes. The people with Type 1 who were members were older and had a longer duration of diabetes than non-members, had lower HbA1cs and tested their blood sugars more often. The Type 2 members were also older than nonmembers, both had similar HbA1cs but the members had better lipid profiles. The researchers suggest that belonging to a patient organisation may make people take more responsibility, be more empowered and / or compliant with diabetes management. Of course it could be the opposite way round – that people who take more responsibility or feel empowered actually are the people who join patients' organisations! [Diabetes & Metabolism, Vol 34 Jan 2008]

### **Obesity levels higher than first thought**

In October 2008 the Dept of Health announced that if no effective action is taken to stop the rise in obesity, it could cost the NHS in England £6.3billion. The costs to local councils will also increase as they are already spending thousands of pounds on what they refer to as 'fat-friendly services' – social services for the housebound obese

adults, re-equipping ambulances with extra wide stretchers, investing funds to encourage people to exercise and replacing school furniture that is too small for large pupils.

Tom Fry of the National Obesity Forum said "draconian" interventions were necessary. He warned that, as a nation, we are all getting fatter and risked early death as a result. Chief Medical Officer Sir Liam Donaldson said: "In England almost two-thirds of adults and a third of children are either overweight or obese.

### **Ethics – not unexpected results!**

The results of an ethics study [Oct 08] has shown how people's moral thinking differs with age, gender, occupation, religion, politics and education. Apparently the UK is low on moral philosophy but as I am writing this just after the UK public raised over £21 million on the first night for Children in Need, I am not too sure! Some of the results were not unexpected – bankers and others working in financial services have relatively immature moral profiles and scored lower than average in social conscience. Homemakers, people working in religious institutions, health care, the health service and law enforcement scored the highest but those working in central and local government, oil and gas, and technology scored the lowest. The UK scored the lowest compared to Australia, Ireland, S Africa. New Zealand, Canada and the US. [I picked this up in my general reading but apologies for not finding the reference!]

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

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## From Your Editor – Jenny Hirst

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