



# Insulin Dependent Diabetes Trust

January 2006 Newsletter



## Happy New Year!

The arrival of a New Year is a time when we look back over the last year but also look forward to the next with our plans and hopes for the future. In this respect IDDT and its members do this too. We can look back at 2005 as the year in which we made achievements.

There was the recognition by the UK and the Canadian Health Departments that some people with diabetes cannot tolerate GM insulins and they made to a commitment that animal insulins will remain available.

Also in 2005, IDDT bravely published a paper, *'Insulin Analogues, should patients be concerned?'* which addressed issues surrounding

the lack of long-term safety of analogue insulins and their potential for carcinogenic effects.

There was the International Diabetes Federation Position [IDF] Statement on Animal, Human and Analogue insulins which confirmed IDDT's long held stance:

- animal insulins are safe and effective to use
- there is no overwhelming evidence to prefer one species of insulin over another
- insulin analogues have not shown any overall benefits, they are expensive and their long-term safety is unknown so they should only be used for people experiencing particular problems.

Finally in a recent letter to IDDT, the UK Minister of Health described the IDF Statement as *'a very balanced reflection on the use of insulin'*.

So yes, we can look back on 2005 as a successful year but its success will be measured by actions in the future. Success will have been truly achieved if these published statements are followed by changes in attitudes and actions.

- If the government's message that some people are unable to tolerate GM insulins is received and understood by doctors and healthcare professionals treating people with diabetes, then we will have succeeded. But if people who have adverse reactions to 'human' and analogues insulins are still not listened to or are refused their choice to change to animal insulin, then our success is limited.
- If doctors and health professionals fail to look at the evidence and recognise that our concerns about the use of insulin analogues are justified, then our success is limited.
- If doctors and health professionals fail to recognise the clear messages in the IDF Position Statement, then again, our success is limited.

Our degree of success will be partly measured by changes in attitudes and actions of others - often not an easy task when it comes to changing long-held views of professionals.

But our success will also be measured by how IDDT's 2005 achievements affect you, the people living with diabetes. The information and evidence to inform your insulin choices is now there in the public domain for all to read, so you are no longer relying on IDDT's views but on statements from governments and an international organisation of experts. If the government assurances that animal insulin will continue to be available, have given you peace of mind, then 2005 was a success. If the statements have given you the courage and confidence to be more involved in decisions about your treatment and choices, given you the courage to ask more questions or to be more assertive about your needs and concerns, then 2005 was a successful year.

## Nurse and Pharmacist to be Independent Prescribers - arguably one of the biggest changes in NHS patient care that we have ever experienced

On November 10th 2005 Health Secretary, Patricia Hewitt, announced what is arguably one of the biggest changes there has been even been in health care in this country. From Spring 2006 nurses and pharmacists will be able to independently prescribe any licensed medicine for any medical condition [with the exception of controlled drugs] once they have completed a training course [38 days according to a BMA spokesman] and have registered their qualifications.

In a Dept of Health Press Release, Patricia Hewitt said, *'extending prescribing responsibilities is an important part of the government's commitment to modernise the NHS' and that 'patients will be able to more easily access the medicines they need from an increased number of highly trained professionals'*.

Modernisation or not, highly trained or not, let us be under no illusions about what these new prescribing arrangements mean. Independent prescribing means that a nurse or pharmacist, who has been on a course, will be able to prescribe any medicine WITHOUT the supervision of a doctor. But prescribing is not simply a matter of *'accessing medicine more easily'* to quote Patricia Hewitt - in order to prescribe, nurses and pharmacists will have to be able to diagnose.

There is no doubt that nurses are highly trained professionals but they are trained as nurses. So it is difficult to see how a short course can give them the same diagnostic and prescribing skills as doctors who have undergone years of training to be able to safely diagnose and prescribe for patients.

### What is happening now?

There are currently three types of non-medical prescribing but only supplementary nurse and pharmacist prescribers are able to prescribe any medicine and then ONLY within a framework of a patient-specific

management plan agreed with a doctor. The new proposal means that nurse and pharmacist prescribers will NOT have to work within a management plan agreed with a doctor.

### **What consultation has taken place?**

According to the Dept of Health Press Release, consultation has been within the Dept of Health itself with the MHRA and the Committee on Safety of Medicines. So despite Patricia Hewitt saying that 'this is another step towards a truly patient-led NHS', patients who are supposed to be leading the NHS have not been asked for their views!

The government put forward the proposal to the British Medical Association [BMA], in February 2005 and they fought hard against it so are seeking urgent talks with the Secretary of State.

- **Mr James Johnson, Chairman of the BMA, said:** *'It is difficult to see how healthcare professionals who are not trained to diagnose disease can safely prescribe appropriate treatment. The BMA will be seeking assurances that patient safety will not be compromised.'*
- **Hamish Meldrum, Chairman of the BMA GP Committee, said:** *'While we support the ability of suitably trained nurses and pharmacists to prescribe from a limited range of medicines for specific conditions, we believe only doctors have the necessary diagnostic and prescribing training that justifies access to the full range of medicines for all conditions. This announcement raises patient safety issues and we are extremely concerned that the training provided is not remotely equivalent to the five or six years every doctor has undertaken.'*
- **Dr Paul Miller, Chairman of the BMA Consultant Committee went even further:** *'This is an irresponsible and dangerous move. Patients will suffer. I would not have me or my family subject to anything other than the highest level of care and prescribing, which is that prescribed by a fully trained doctor.'*

### **What are the concerns of patients?**

**On what evidence is this proposal based?** Has a rigorous pilot study been carried out to provide evidence of safety for patients,

evidence of benefit for patients and evidence that patients will receive the same standard of care that they have been receiving from a fully trained doctor? How and for how long is the system to be monitored to ensure that patients do not suffer as a result of these changes and when will an assessment be made?

**Is this proposal a means of saving money?** If so, again a pilot study is essential to provide evidence that this actually does save money. Any savings could be swallowed up by prescribing errors, subsequent treatment for the errors, patients' complaints or even litigation and by patients seeking a second opinion from a doctor, assuming that right is incorporated in the changes.

**Is this to be a two-tier system of care with some patients consulting a fully trained doctor and others consulting a nurse prescriber?** The vast majority of patients will view the doctor as better trained to diagnose and prescribe than a nurse who has been on a course. So surely most patients will actually PREFER to see a doctor especially for a new diagnosis and prescription, so are some people going to be 'forced' to see a nurse and not a doctor? If this is the case, then we will have a two-tier system.

**Choice?** Patricia Hewitt said 'this is another step towards a truly patient-led NHS, giving patients the power to choose where and by whom they are to be treated.' But will this really happen? Will patients really have the choice of whether they see a fully trained doctor or a nurse? Will more assertive patients be more likely to obtain an appointment with a doctor? Who will be the gatekeeper - the receptionist? IDDT is already aware that some patients who want to see a doctor have a struggle to do so and are booked in with the nurse.

**Are prescribing nurses and pharmacists to take the Hippocratic Oath like doctors?** If they are to prescribe and therefore diagnose, then they should. Can patients be assured that independent prescribing nurses will carry total responsibility for their actions, as doctors do and will patients be assured that rigorous action will be taken against them if/when errors are made? Will patients be made fully aware of

the complaints procedure in case errors are made?

**So where does IDDT stand on this issue?**

After discussion the Trustees can see the benefits of nurses being able to sign repeat prescriptions within guidelines and benefits of nurses being able to prescribe within an agreed management plan and we fully accept the excellent and essential role that nurses play. However, we have to raise concerns, fears and objections that after a short course, nurses and pharmacists will have the necessary skills to independently diagnose and prescribe all medicines, especially as diabetes has been mentioned as one of the specific areas that will be affected.

While we do not want to enter into a large lobbying campaign, IDDT has asked various politicians to raise our concerns and we ask any of our members with similar concerns to write to their MP. This issue will be discussed in Parliament and so it is important that MPs receive your views or objections. As patients and regular users of the NHS, you will undoubtedly point out some of the pitfalls and difficulties that could or will arise and ones that MPs may not be aware of or have considered.

**Questions arise for all of us.**

Who would I want to see if my child was ill? A fully trained doctor. Do I want my family, or me, diagnosed and treated to the highest standard of care? Yes and this must mean by a fully trained doctor.

So once again, I am asking that if you have concerns about this big change in how you and your family will be treated in the NHS, then write to your MP. Doing nothing means that is likely to happen. It may happen anyway, but acting now may mean that MPs can ensure that some of the safeguards are put in place.

## Clamp Down on Violent Patients in Hospitals

In an initiative to combat violent patients, NHS Glasgow has launched a zero tolerance campaign which will train nurses in close combat skills and will also allow doctors to deny treatment to the rising number of patients who disrupt hospitals, clinics and GP surgeries. According to NHS Glasgow, the ‘Saturday night drunk’ has always been a fact of life but now offences occur 24/7.

The Royal College of Nursing said that the new policy was sorely needed but the Independent Federation of Nurses warned that care has to be taken because people who are seriously ill may be turned away without treatment.

It is exactly this situation that is of concern. Hypoglycaemia in some people can cause violent behaviour and we wonder if healthcare professionals are fully aware of this as it is not immediately obvious that the violence is due to a hypo, especially to strangers. Obviously treatment is eating something sugary but if a person in this violent hypoglycaemic state ends up in a hospital and is refused treatment, then blood sugars will drop even further and this could result in coma. So perhaps zero tolerance to violent behaviour is just too much as it could put people who need medical help at risk.

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## The Carbohydrate Question Revisited

In 1986 the UK government issued dietary guidelines for the general population recommending the high carbohydrate/low fat diet to reduce the risks of heart disease. Diabetes experts followed suit in recommending this diet for people with diabetes.

Nearly twenty years later, we have a population that is more obese and overweight than ever before and the incidence of Type 2 diabetes is greater and growing at frightening speed. People with diabetes are

using more combinations of anti-diabetic drugs, anti-cholesterol and anti-hypertensive drugs and people with Type 1 diabetes are having more daily injections, larger daily intake of insulin to cope with higher carbohydrates and also many of the drugs described above.

While fully accepting that in the last 20 years lifestyles have become more sedentary with people taking less exercise, but have people with diabetes really benefited in any way from the high carb/low fat diet? If so, it's hard to see where!

So what happened to people with diabetes before 1986? They had a restricted carbohydrate diet and counted carbs. How did we do it? We had a book, 'Carbohydrate Countdown' that listed the carb values of every food imaginable.

For some of us with diabetes this diet never has made sense! A high carb intake will push blood sugars up high and for people using insulin, this then requires higher doses of insulin. If lower amounts of carbohydrate are consumed, then smaller insulin doses are required for people. Lower doses of insulin result in more predictable blood sugars and less hypoglycaemia. Many people who have had diabetes a long time never changed to the high carb/low fat diet and stayed with carb counting and restricted their carb intake and contrary to popular belief, this does not mean that this diet has to be high in bad fats!

Despite this, it is almost heresy to suggest that a low or restricted carbohydrate diet may be a better option. It has to be said that people using insulin pumps are now encouraged to carb count but once again, it is difficult to understand why this is sensible for people using a pump but not for people using insulin injections.

The following article is by Katharine Morrison, a GP and mother of a 13 year old son with Type 1 diabetes. In initial discussions with Katharine she made the point that it is surprising that there is not more interest in promoting a diet that does all of these:

1. Prolongs honeymoon phase in type ones.

2. Prolongs pancreatic function in type twos.
3. Promotes a healthy weight.
4. Reduces need for insulin.
5. Reduces need for oral hypoglycaemic drugs.
6. Promotes high HDL and low triglycerides.
7. Reduces hypoglycaemia.
8. Reduces development of glucose intolerance to type two diabetes.
9. Optimizes glycaemic control including post prandial blood sugars.

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## The First 20 Months

By Katharine Morrison

I diagnosed my 12 year old son Steven with diabetes on April 1st 2004. Fortunately he had only had symptoms for two weeks on and off and was not in ketoacidosis.

The Paediatric Diabetes Consultant even came in on her Friday night off with her own wee girl and briefed us in the mechanics of how to work meters and pens so we could go off on a planned holiday next morning. I don't think we would have got away with this if I hadn't been a doctor.

We were self-catering in London and moved into an apartment with only a few teabags and a salt shaker. There was a Waitrose across the road from which we could choose a marvellous selection of foods many of which seemed to have been specially packaged for individuals in bedsits. I had decided even as I suspected the diagnosis, that if it was diabetes the most sensible diet to follow was a low carb one. At least there were no cupboards of crisps and biscuits and breakfast cereals here to sabotage my efforts.

Over the next week we got to grips with the jags, blood sugar testing and food choices. Normally I work very long hours and my husband works off shore. Having a week of us altogether and with none of the

usual household chores and phone calls from worked helped settle my nerves. We just had to concentrate on helping Steven through his first week of diabetes and having fun. Well, it wasn't fun all fun. Chitty, Chitty Bang Bang for instance.

Since the initial stabilisation period Steven has had HbA1cs of around 5 and is currently at 5.1. His insulin dosage is unchanged over this time. He is still in honeymoon which has a great deal to do with this level of control without hypos. [*Honeymoon is the period after diagnosis when the pancreas is still producing some insulin*] The other factor about honeymoon however, is that it will continue longer if blood sugars can be kept as normal as possible. Blood sugars of only 6.1 start to kill off pancreatic beta cells in tissue culture but if sugars are normalised some recovery can take place from damaged cells.

Reducing the total amount of carbohydrate the pancreas has to deal with and making most of it slow acting, as in non-starchy vegetables, seems a sensible strategy to avoid overburdening a dying pancreas. There is after all nothing at the present time to stop the autoimmune destruction. Denise Faustman has managed to cure Type 1 diabetes in mice. Perhaps trials based on her research which are starting on humans next year in the USA, may bear fruit for those who are developing Type 1 diabetes now.

I was fortunate enough to have gone on the Atkins diet myself some ten months prior to Steven's diagnosis. I had seen what it had done for some very rotund doctors and police officers with whom I work.

After several patients came to me at the end of their tethers regarding their poor diabetes control, despite careful adherence to the high carb/low fat diet they were following, I advised them to experiment with carbohydrate reduction. To our delight their HbA1cs dropped to 2-3% of previous levels. I didn't know much about diet for diabetic patients at the time of Steven's diagnosis, but I was convinced enough to insist that cereals, toast, orange juice and bananas were not going to be on his menu for breakfast.

For about 6 months after Steven's diagnosis both my husband and I were hardly off the net. Norman spent his time looking for a 'cure'. I spent the time learning about low carb diets for people with diabetes and experimenting with low carb baking. I had previously had enough experience to have built up a good range of meat and vegetable dishes but no longer could I just open up a box of Mr Kiplings French Fancies if I wanted to give Steven a dessert or a breakfast alternative to bacon and black pudding.

Dana Carpenter's Hold the Toast forum was a great help to me at this time. I have since gone on to buy many low carb cookery books and now know a hundred ways with almonds and whey protein powder.

All this roasting, vegetable peeling and baking takes a lot of time and I cut the hours I work back considerably when I got the opportunity to do so. Living low carb is not difficult but producing a variety of meals on a daily basis is challenging. I used to buy loads from the cook chill counter to avoid having to spend hours in the kitchen but this avoidance strategy is no longer an option.

Fortunately the success of the Atkins, South Beach, Protein Power and other low carb diets in the UK produced a plethora of low carb baking ingredients and goods. This certainly made access to these products much easier for me. Unfortunately there has been a cut back in demand recently. Low Carb Megastore is still going on the net but Tesco's and Holland and Barrett have virtually stopped stocking low carb products in their stores.

Norman meanwhile didn't find a cure for diabetes but he did find Dr Richard Bernstein's website. Dr Bernstein is unusual in that he has had Type 1 diabetes himself since the age of 12 and has managed to reverse many severe complications of the disease. Through rigorous self experimentation he devised a management system that can help people with diabetes to get normal blood sugars round the clock. Central to his plan is a very low carbohydrate diet at 30-42g of carb a day. One of the Bernstein forum members described the adherents as having the discipline of Soviet athletes. I tend to agree. It is a very

demanding routine. Yet, shouldn't patients have the choice over what diet they want to follow?

Although I consider Bernstein's diet to be as optimal as we currently know for diabetes, I also know I would have great trouble eating consistently this way. The lowest I have gone for any length of time is 45g of carbohydrate a day. This is fine for a while and then I really hanker after something like a Cox's orange pippin apple. But I'm not diabetic and I don't have the hellish complications of the disease. I am pretty sure the imminent loss of my vision or the feeling in my hands would focus my mind and motivation.

For any diabetic I do believe that a restriction in the amount and type of carbohydrate and due regard to the effects it has on blood sugars is the key to control. I tend to have 80g of carbohydrate a day and Steven has 115g a day. Other people with diabetes have worked out what works for them.

I have found the members of Dr Bernstein's forum to be of great help with their knowledge, support and humour. I was kindly introduced to IDDT through Ron Raab who is a friend I also met on the net. Ron has had diabetes for over 40 years and uses the low carb diet. He is a Vice President of the IDF and has just disassociated himself from the recent IDF recommendations of high carb/low fat diets.

Until I read IDDT website I had no idea of the struggles people have had to go through to get animal insulins for a start and to get health professionals to listen to them for second. I am pleased to join IDDT and I hope I can help in fulfilling your aims for accurately informed options and support for people with diabetes.

#### **For further information:**

- Dana Carpender's low carb recipes visit her website: [www.holdthetoast.com](http://www.holdthetoast.com) her books can be obtained from [www.amazon.com](http://www.amazon.com)
- Dr Richard Bernstein's website is [www.diabetes-normalsugars.com](http://www.diabetes-normalsugars.com) His book Diabetes Solution, A Guide to Achieving Normal Blood Sugars is published by Little Brown & Co and the ISBN is 0316099066

- IDDT is frequently asked for information about carbohydrate values of foods and there is a comprehensive list on this website: [www.carbohydrate\\_counter.org](http://www.carbohydrate_counter.org)
- Ron Raab - the low carbohydrate insulin regime: [www.diabetes-low-carb](http://www.diabetes-low-carb.com) or the University of Pittsburg site for a Power Point Presentation <http://www.pitt.edu/~super1/lecture/lec17721/index.htm>

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## **Factors Affecting Blood Sugars**

- High sugars in the morning

There are two main reasons why blood sugars can be high in the morning - the Somogyi effect and the dawn phenomenon.

**The Somogyi effect** - if you go hypo in the night but sleep through it, then the body's natural defence mechanism comes into play and the liver releases glucose to prevent the blood glucose dropping even lower. The blood sugar then rises and this results in high blood glucose levels in the early morning. [Somogyi is the name of the man who discovered this effect]

**The dawn phenomenon** - is a sudden rise in blood sugars in the early morning before eating that is not due to a hypo in the night. It means that adjustments to insulin doses and/or evening snacks may be necessary.

Carrying out our blood glucose tests during the night on a series of nights will show what is happening and whether blood sugars are dropping low in the early hours giving the Somogyi effects or whether they are just rising during the early hours.

- Stress has a greater effect on blood sugars after meals

It has always been known that psychological stress affects blood

sugars but studies investigating the link have had conflicting results and so researchers in Zurich conducted a study to test their hypothesis that the response to stress differs between a fasting period and after eating a meal. [Diabetes Care August 2005]

The effects of stress in 20 fasting patients were compared with the effects on 20 patients who had eaten a standard meal 75 minutes previously. The stress test was making a speech as if applying for a job and having to perform mental arithmetic.

Patients were advised to maintain their normal insulin injection schedule and blood sugars and other factors were measured for each group on a day a stress took place and on a day when it did not. The stress produced increases in blood pressure and heart rate in both groups

While fasting patients showed no difference in blood sugar levels in response to stress, stress exposure delayed post-meal lowering of sugar concentrations by 45 minutes. This effect appeared about 30 minutes after the stress test and lasted for roughly two hours.

The largest difference between stress and non-stress sugar levels in the group of patients who had eaten was 1.4 mmol/L at 55 and 80 minutes after the test.

So the study showed that for people with Type 1 diabetes an episode of mental stress should be accepted as a possible explanation of high blood sugars and that stress significantly slows the decline in blood sugars following a meal but has no effects on blood sugars during fasting. The researchers advise that people with Type 1 diabetes should be aware of the potential for this effect when they experience mental stress after eating.

- A tip, and a warning about testing and alternatives sites

There has been discussion about blood glucose testing at sites other than the fingertips with blood glucose meters that only require a very

small drop of blood, such as the OneTouch Ultra. Research carried out in Italy has shown that it is 'feasible and reliable under routine conditions' to use the forearm. However they warn that for the purpose of detecting **low** blood glucose levels, the fingertip should be used for accuracy. So people who are at greater risk of hypos, such as those with reduced or lost hypo warnings, then using the fingertips seems sensible. [Diab Tech and Thera, 2003;5 (6):983-989]



## Thanks to You

Our thanks go to Elliot Roberts and Neil Tamlyn for all their hard work in carrying out a sponsored cycle ride, raising £1400 for IDDT in memory of Shengul Keskin and Tim Seager. Shengul sadly died due to diabetes complications after which her fiancé, Tim became actively involved with IDDT in learning more about diabetes. Very sadly Tim has since passed away.

Our thanks also go to Richard Craven and his friends for raising funds for IDDT with a 'John Peel Evening' on the first anniversary of his death. John had diabetes.

Thanks to the lady from Liverpool who, on November 11th 2005, praised and thanked IDDT on a Radio 4 programme which was discussing marriages break down due to the stress of one partner having a medical condition. The first lady to ring in was from Liverpool she said that she had received lots of help and support from IDDT.

Finally our thanks go to all of you that have supported IDDT by buying our Christmas cards - it all helps to boost the funds.



## EU Driving Rules May Change But???

In February 2005 Members of the European Parliament [MEPs] took a vote on EC proposals for a Third Directive on driving licences. If put into operation, this could ease the restrictions on access to driving licences for British people with diabetes, assuming that the UK government does not introduce extra requirements on top, which is what happened when the restrictions were first introduced.

**From the website of Baroness Sarah Ludford MEP, the proposed changes are:**

- All diabetic drivers will be relieved of the inconvenience or expense of having regular specific medical checks, even for LGV vehicles [Large Goods Vehicles formerly HGV].
- Only people with insulin dependent diabetes will need a doctor's authorisation to get a car driving licence, those not dependent on insulin will not.
- All diabetic drivers can get LGV licences on the same basis as other drivers ie a one off medical check up at first application and 10 year renewal.
- At present insulin dependent drivers can only get LGV licences 'in very exceptional circumstances' but the new proposal is that they will only need a doctor's authorisation and to notify any change in their condition.

Baroness Sarah Ludford comments that MEPs are ensuring that legislation is based on assessment of actual risks in the light of modern diabetic care and treatment, rather than out-of-date bureaucratic hassle.

**Don't get too excited its not law yet and may never be so in the UK!**

**IDDT contacted the Drivers Policy Group at the DVLA for clarification on the UK position. Their letter says:**

- The DVLA 'must make it clear' that the Directive has not yet been agreed and their understanding from the EU Commission is that the proposed amendments cannot be accepted by Member States at this stage.
- The standards are being considered separately as part of an ongoing review by a number of medical expert working groups established by the EC Committee on the Driving Licence and the group looking at diabetes is expected to report to the Committee later this year. [2005]
- In the UK the Dept of Transport has also sponsored a research project to look at diabetes and the risks of hypoglycaemia and this is due to report shortly.
- It will only be appropriate to review current arrangements for drivers treated with insulins once all this information is available.

So the gist of this appears to be that the MEP vote on the proposed new rules was taken BEFORE publication of a review by the EU experts. If changes are made in the EU, it remains to be seen whether the UK government will allow these changes or will continue to have stricter rules than required by the EU and presumably some of this will depend on the Dept of Transport research, yet to be published. So watch this space!

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## Waste Not, Want Not!

IDDT's unwanted insulin collection is part of our philosophy that we don't like waste especially when what we through away can be of value to others. In the office we collect all the used postage stamps and send them to the charity Guide Dogs. We are also helping by sending our ink jet cartridges to them. Could you help in this way too?

**Used postage stamps** - each kilo that Guide Dogs receives is sold for £1.50 to a specialist company in Denmark. Once you have a large envelope of stamps, send them to Guide Dogs Stamps, PO Box 139,

Slough, Berkshire SL1 4PU

**Ink jet cartridges** - with the exception of Epsom cartridges, Guide Dogs collect used cartridges for recycling and receives £1.00 for every one. If you could support this programme Guide Dogs will send you FREEPOST bags, just call 0118 9838 298 or e-mail [www.recycle4guidedogs.org.uk](http://www.recycle4guidedogs.org.uk)

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## Important News For Ladies

For women with diabetes who want a baby, it is important to have tight control of blood glucose levels at the time of conception as well as during pregnancy so a planned pregnancy is the ideal.

With or without diabetes, women who are overweight or obese are advised to use barrier contraceptives as research has shown that overweight and obese women have a greater chance of contraceptive pill failure, particularly important information for women with diabetes wanting a planned pregnancy. Overweight women are 60% more likely to become pregnant while on the pill and obese women 70% more likely. The researchers compared weight and body mass index [BMI] of 248 women who became pregnant while on the pill with 533 women of the same age taking the pill but who were not pregnant. A BMI of over 25 is classed as overweight and the research showed that in women whose BMI was 27.3 or higher, the pill failure rate became evident. The pill is usually estimated to be 99% effective but this assumes perfect pill use but actual failure rates are estimated to be 6%.

## IDDT Goes to Westminster

Shortage of space prevents a full report of IDDT's political activities but rest assured we are not sitting back doing nothing. Parliamentary Questions are still being asked in the UK and the EU Parliaments and we will give a full report in the next Newsletter.

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## Reminder For Your 2006 Diary

IDDT's Annual meeting will be held on Saturday, October 14th at the Paragon Hotel in Birmingham. So put the date in your diary now!

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## Loss of Hypo Warnings and the Disability Living Allowance - one member's experience

I understand that many people with diabetes who are using synthetic insulin and who, like me, have serious problems of sudden attacks of hypoglycaemia without adequate warning to remain conscious and deal with the situation themselves are being refused Disability Living Allowance [DLA]. I have had this problem but twice, on appeal, have won rulings that I am entitled to the middle rate care component and the lower rate travel component of the DLA.

The fact is that if you are liable to become unconscious at virtually any time of the day you must have someone on hand, though not necessarily with you, to be aware of your state of health and be ready and able at any time of day to step in and provide the necessary assistance to revive you.

If you have a problem of becoming hypo while you are out and about, you should only travel with a helper as the resulting confusion and

disorientation which you may suffer during the hypo that can result in you wandering into the road or falling off a railway platform etc.

In all probability your application for DLA will be declined on the grounds that if you only become hypo 3 or 4 times a month, you do not need help for a sufficient amount of time. However, the correct criterion is the amount of time for which you are vulnerable to hypo attacks, which is all day, every day. If you consider yourself to be entitled to these benefits you must pursue the matter through the appeals procedure, where, in my experience, you are likely to get a fairer hearing.

These benefits, although not by any means large, are worth pursuing because they open the doors to so many other benefits and discounts. For instance, I travel free of charge on most public transport throughout Greater London and have a disabled person's railcard which costs £14 per annum and entitles me to 30% off most mainline train fares for myself and my travelling companion. Also because I live alone on incapacity benefit, I automatically receive the severe disability premium.

When preparing your appeal, obtain a copy of a report from IDDT headed HYPOGLYCAEMIA and submit it as additional evidence well in advance of your hearing. This will explain to the appeal panel just how serious hypoglycaemia can be. Do not attend the hearing alone but take a trusted friend or carer into the hearing with you as statistics show that people who attend disability appeals alone are far more likely to fail.

It is time that the staff at the disability and carers service of the DWP are made more aware of the very real problems that severe hypoglycaemia and loss of warnings causes and are also made aware that these problems do qualify for help under the current rules.

Name supplied

**Note:** IDDT is happy to supply our leaflet Hypoglycaemia free of

charge, give us a call on 01604 622837. It can also be downloaded from our website: [www.iddtinternational.org](http://www.iddtinternational.org)

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## Silver Linings

**The fourth in the series of articles by Sue Marshall**

### **'Why I Love': Reading labels**

Today, EU laws mean nearly all ingredients must be listed -- not just some of them. Until 2004, ingredients making less than 25% of product did not need to be on the label.

Labels are good for just about everybody but if you have got a specific condition, such as diabetes or high cholesterol, then labels are invaluable. I read labels out of interest, as well as to count my carbs, which I've been doing for decades now, labels just makes it easier.

Reading labels is a real boon for anyone with diabetes today, with more known about the glycaemic index (GI) and just about everyone getting on the band-wagon as it's a better way to diet than the rigours of Atkins. But the GI was invented for diabetes control and is nothing more than the 'truth' as to how different food stuffs absorb into your blood stream when you have insulin present. Low GI foods absorb more slowly, avoiding 'peaks' which our synthetic insulins can't keep up with in terms of absorption. Nearly everyone who has diabetes knows that, especially if they do blood tests.

Watch out for the terminology though -- the weights might be listing 'dry weight' and not 'wet weight' (i.e. cooked) for something like pasta. And just because it's organic does not mean it hasn't got sugar in it either!

Learning to read the labels is more of an art than might initially be

assumed. The guidelines for what goes on a label seem to be fairly loose, with some manufacturers choosing to do fairly arbitrary listings -- they may do 'per 100g' instead of 'per packet' when in fact both is better for the interested reader. I need to know per packet, as I may not have scales in my handbag to weigh out 100 gramme's-worth!

It's also far easier for children and frankly, anyone who's not a maths whiz, to do per packet or per serving instead of endless divisions of 100gs -- I recently had to calculate how many carbs were in a snack bar when the packet said 64.8 carbs per 100g, and the total packet was 29g. I don't always want to do elaborate arithmetic for every meal, couldn't it just say 19g per bar?

There's an increasing amount of youngsters with diabetes, and the sooner they can learn how to read labels, the better off they will be. The main thing for all of us, young and old, is to get into the habit of reading labels.

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## The Messages From IDDT's 2005 Annual Meeting

150 people attended the meeting - familiar faces, newcomers to IDDT, health professionals and members from Canada, Switzerland and America. This diversity gives IDDT better perspectives of the needs of people with diabetes, diabetes care and corporate activity.

### Introduction - Jenny Hirst

Jenny Hirst said, *'In 1993, five people met in a hotel in Gravesend because they recognised a need for a patient organisation to help and support people like themselves or their relatives who could not use genetically modified 'human' insulin. We didn't have two pennies to rub together, but our aim was, and is, to try to ensure that people have an informed choice of insulin and the opportunity to discuss options with their doctors.'* Jenny still believes that patients do not have an informed choice of insulin: *'If things don't go well on modified or analogue insulins, you should have the choice to try animal'*.

What has IDDT achieved in the 11 years since it has been going? IDDT today has a membership that continues to grow and supplies general Information Packs and more recently packs for Parents and also one for teachers to help them understand the needs of children with diabetes.

A huge achievement, but not easily obtained, was the Minister of Health, Jane Kennedy's acknowledgement that some people can't use GM insulin and therefore animal insulin should remain available. This statement came after a long lobbying campaign and Jenny thanked all the members who had worked so determinedly to achieve this. She also thanked IDDT's adviser James Pawsey, for his unfailing help and support.

Jenny welcomed the International Diabetes Federation's Position Statement that animal insulin was a perfectly acceptable treatment and that analogues should only be used when there are specific problems. She said that doctors, health professionals and the NHS should be informed of this latest international statement.

Finally, Jenny explained that she fully understands that the job of drug companies is to make profits and commercial discontinuations of insulins are part of this but added, *'What is important though, is that people find the type of insulin that suits them best and if they have to change insulin type, it should be for health reasons, not due to commercial decisions of industry. Despite the fact that GM 'human' insulins suit many people, some are being discontinued right now and yet they suit many people. It is worrying that although pork insulin is the nearest equivalent insulin, only other GM insulins, analogues, are being offered as the alternative showing again that people are not being given the informed choice they deserve'*.

### 'Back to Basics' - Professor Arthur Teuscher

Professor Teuscher, from Switzerland, explained that he has worked in the field of diabetes for 50 years and has fought for the choice of animal insulin. In May 2005 the Swiss Minister of Health said, 'I think physicians should prescribe animal insulin more.' Prof Teuscher

believes that this statement should be backed by the Swiss Diabetic Association.

He noted that the drug industry has a lot of power in our society and while our goal is that there must be the choice of animal insulin, the question is who will do ensure this happens?

Prof Teuscher then gave a brief history of Type 1 and Type 2 diabetes. Typically Type 1 tends to be of sudden onset in younger people under 30 years old and the pancreas fails to produce insulin. Type 2 has a slower onset and often in people who are over 40 years and overweight, insulin is still being produced but the problem is with the insulin receptors in the cells. He described this as insulin having a hard time getting into the cells, as if the insulin password is not working.

Prof Teuscher then talked about the three cornerstones of treatment - diet, exercise and insulin. For decades people with diabetes were told to use a diet with a low proportion of carbohydrates and in Switzerland 20 years ago, only 20% of the diabetic diet was carbohydrate. He carried out some research with farmers and people in physically active work and found that they needed about 50% of their diet to be carbs because of the physical nature of their work. His belief now is low fat and elevated protein plus 50% carbs is just about right.

Exercise, is very important for people with diabetes but with different types of insulins used today, there can no longer one recommendation for all of how, when and what exercise to take.

Prof Teuscher explained that insulin type and the regime must take into account the times of the body's natural sensitivity to insulin. He demonstrated this by dividing the 24hour day into 4 sets of 6 hours:

**6.00am to noon** - blood sugars are higher because the body is waking up

**Noon to 6.00pm** - there is a higher sensitivity to insulin and a tendency for hypos between 4 and 6.00pm is quite common

**6.00pm to midnight** - there tends to be a lower sensitivity to insulin

and so there is a tendency to need more insulin during this period

**Midnight to 6.00am** - the body's most sensitive time to insulin is 2.00 to 3.00am, hence night hypos are most common at this time. For people taking their long-acting insulin at bedtime, it will start to take effect at about this time and therefore makes night hypos more likely.

Finally Prof Teuscher asked the question: 'What is the role of research in driving diabetes policy?' He cited two examples where there is a lack of evidence on which to base treatment:

- Today's practice of frequent blood glucose testing and therefore more injections - where is the evidence from good quality wide-scale research to show that this is the best way of treating diabetes?
- Where is the evidence from high quality independent research to compare various insulin types to find out which insulin is best for you? Unless or until this happens, we are really a nation of guinea pigs

### **'Four Minutes and Counting'- Dr Anne St Aubin Roberts**

Anne has diabetes and used to work as a NHS hospital consultant. She was diagnosed about 3 years ago and experienced serious adverse effects to GM human and analogue insulins but after 'discovering' animal insulin she recovered and is a passionate supporter of IDDT. Her talk was based on the premise that if you only get four minutes with your doctor, how do you make the best use of those four minutes.

Anne is aware that the most common complaints that IDDT hears about doctor visits are:

- There is not enough time
- They don't listen to me
- I am treated as an illness and not a person
- Their agenda is different from mine
- Any problems I discuss always seem to be someone else's job or there is another consultant they need to speak to.

Anne said, *'In the old days you built up a relationship with your GP but now that approach is going, and it's about to get worse. So it's very important that you take charge of your own consultations and make them work for you.'*

*The recent development of the National Service Framework for Diabetes [NSF] specifically looks at ways of helping people and has diabetes care at its heart. Said Anne, 'The diabetic is the most important part of the diabetic team. An international study done 20 years ago showed that consultations had become a stick to beat us with. The idea of having low HbA1cs, possibly at the cost of everything else in your life, seems to have taken over and is still prevalent.' This research also showed another interesting fact - the more the patient, and not the doctor, talked, the lower that patient's HbA1cs were. Anne's belief is that this is because the patient is taking control of the situation as well as their diabetes and she said, 'It is this that is going to give you lower HbA1cs.'*

### **Before going into your consultation, you need to be prepared.**

Go with a list of specific topics you want to discuss. If you are having specific problems you want to discuss, explain that you have done the experiments yourself and in a scientific manner eg if you are having night hypos then maybe you have taken the action to dropping your night time insulin dose, or have tried a bedtime snack. Know what you have done and why, as this makes it easier to talk to somebody else about it.

**Take control by the way you hold the conversation.** Say things like, 'my records show', based on your blood test records not, 'I don't like my insulin'. You have to say 'this is why' and 'this is what I have done to address it'.

**It's good to take information in with you to your consultation,** but not pages and pages from the internet. Make use of information from current initiatives such as the national service framework, look into local patient programmes, get involved in them and also make use of local Diabetes UK groups

Anne concluded her message with, *'In terms of managing appointments, do all the basic things that you do for any interview. Make sure you look good, take a carer with you if that is somebody who does a lot to help maintain your control, and be prepared, be specific. Ask about alternatives and ask for copies of letters that are sent to and from your GP.'*

### **'Lobbying Parliament' - Mr Jonathan Sayeed**

Jonathan Sayeed introduced himself as an ex MP and talked how he helped lobby Parliament on behalf of IDDT and the whole process of lobbying. He pointed out that there are 2,700 individuals and organisations lobbying government everyday covering all sorts of issues but they nearly all fail mainly because they do not get their message right. He said, *'Don't shout in the wrong ear, whisper in the right one.'*

He turned to Jenny Hirst, Co-Chairman of IDDT who was hosting the conference; to say, *'She is both a rottweiler and a terrier and she has done a great job. She is persistent, she knows her subject and doesn't give up. She gets to the right people, grabs onto their ankles and does not let go. But she also takes advice.'* Generally speaking, you must refine your message so it is grasped very quickly by those who have no knowledge of the subject.

He said that for IDDT, the message is that tens of thousands of individuals will suffer or die if they do not have access to pork [or beef] insulin, and that message seems to have got through as Jane Kennedy, the Minister of Health, has acknowledged the need to maintain choice. The letter was in the library in the Houses of Parliament and is therefore 'on the books' and a matter of public record.

But Jonathan pointed out, 'It is not over yet. Ministers come and go, governments forget and change policy. The message has to be rammed home and then repeated. It is not enough to say keep animal insulin available, you must ensure it is available and advise hospitals of that fact. I also believe that the government should be funding independent research and we must continue to lobby for this.'

## Messages from the group discussions

### To carb or not to carb groups

#### Group A

1. Most people were carb counting and felt that it is important in controlling their diabetes. The combination of carb counting and other dietary guides, mainly GI, was very favoured.
2. The people who had been on DAFNE or Pump courses found them useful updates or refreshers to their initial training or education.
3. The group recognised that carb counting requires training and practice, but recently diagnosed people were having to do it themselves and not receiving sufficient time from dieticians or others.
4. Because carb counting can be such a vital tool in gaining good control it seems a shame that it is costed out of the current financial equation of management in many hospitals.

#### Group B

1. Some people would like to eat less, not just to lose weight but to fit in with their daily routine but there was apprehension about reducing their carb intake for fear of hypos. After discussion they felt more confident when they realised that it is a gradual change, a little bit less every day and reducing insulin accordingly.
2. All the people who have changed to a lower carb diet recommended it as they felt better and their general health was good.
3. The group felt it was important to recognise that low carb does not mean NO carb and should not be confused with the Atkins regime.
4. Every day does not have to be the same 'if you feel like having more carb one day it can be easily managed. Some did not realise that they could change the quantities of insulin taken at each injection and in particular, did not realise that they did not have to take all their longer acting human or animal insulin at bedtime but could split it between morning and evening to provide 24 hour cover.
5. Some did not even think about using a syringe as they started with a pen!!!!

### Retinopathy Group

1. People who had laser treatment felt that the procedure needs to be explained in detail before treatment commences to allay patients' understandable fears about laser treatment and the possible outcomes.
2. Patients should be given a better understanding of the problems of living with retinopathy to offset their fears of blindness.
3. There is a need to simplify medical terms/jargon into plain understandable English.
4. There is a lack of understanding by medical staff of hypos and the action they should take - especially when patients attending appointments become stressed when they are kept waiting for a long time which may cause a hypo.

### Parents and Carers Group

1. Carers can have difficulty coping especially with their partner's hypos.
2. Carers need support and to be able to talk through their feelings, often of anger and frustration.
3. Carers need to share experiences and know that other carers go through very similar stresses.
4. Carers can learn from others, especially on how to deal with 'hypos'

### How to get what you need from your healthcare team group

#### Group A

1. The importance of good communication.
2. The sense of conflicting agendas between the patient and the professional.
3. The sense that we can't change the professionals' behaviour as easily as changing our own.

#### Group B

This group highlighted points of importance at an appointment:

1. Asking specific questions.
2. Feeding back to the healthcare team a short and specific summary of your Personal Diabetes Care Plan [as in the NSF]
3. That it is helpful if there is one person on the team who knows you and the plan.
4. The need to be persistent.
5. The need to know who to contact quickly if you follow advice and it goes wrong.

### **Insulin regimes**

1. There was a lack of knowledge about the action times of the different insulins.
2. Some people felt powerless to change their insulin regime or reduce their insulin due to lack of information, even after many years of diabetes.
3. There is a need for greater education to provide some tools for understanding why blood glucose control is not what the doctor says it should be.
4. The group went past its allotted time due to the many questions about different regimes.

**Note:** A lot came out of these discussions, including the need for an IDDT leaflet to help people on how to get what they need from a healthcare consultation. This will be discussed later in greater depth.

The Conference ended with a panel discussion time when a variety of questions were asked from what is ketoacidosis to discussion about stem cell research and islet transplantation.

Jenny thanked everyone for attending and for their active participation in the day. The day was summed up in a letter of thanks the following week:

***“Your members are not Mr and Mrs Average, they are standing up for their sake and for others. The general atmosphere was a jolly good one. The more severe the cases discussed, the more***

***positive the general attitude towards it. And it all had a wonderful undertone of a laugh at life in general.”***

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## Opening of the First Charity Shop for Peer Advisers in Diabetes

Barbara Holmes’ middle daughter developed diabetes when she was 15 months old and she is now 27 years old and a teacher. Barbara has raised funds for diabetes for many years and now has opened the first ever charity shop on the Isle of Wight where Dr Arun Baksi and his colleagues have researched, evaluated and developed a training programme for peer advisers.

### **What are peer advisers?**

Patients also have a wealth of knowledge and experience that can be of help to other people with diabetes. It is these skills that Doctor Baksi is harnessing and using in patient-led programmes which address the impact of diabetes on people’s lives. Coupled with structured education programmes to help patients to develop knowledge and skills about their condition, patients are receiving a great deal of help.

We hear much about the ‘The Expert Patient Programme’ but this programme is for people with all conditions and some people feel that it would be more helpful if it is condition led such as diabetes. It is just such a programme that Dr Baksi and colleagues have developed and need £20,000 per year to continue this work. So if you live on the Isle of Wight or intend visiting, pay the shop a visit or even take with you some unwanted items to sell.



## Advice on Exercise May be Too Simplistic

Research carried out at Louisiana State University and presented at the Australian Health and Medical Research Congress [Jan 2005] showed that although exercise has clear health benefits, it may not work for everyone and some people may do better by changing their diet. It involved 742 people from 213 families going through a 20week 'endurance' training programme. None of them had gone through any form of regular exercise for 6 months. Work on stationary bikes was increased until by the last 6weeks the participants were exercising for 50minutes a week 3 times a week at 75% of the maximum output they were capable of before the study.

Trainability was measured by the maximum oxygen consumption, which shows the person's ability to perform work. The results showed large variations between individuals - training improved maximum oxygen consumption by 17% but in the most trainable people the improvement was 40% and the least trainable showed no improvement at all. Similar patterns were seen with cardiac output, blood pressure, heart rate and other fitness markers. The impact of training on insulin sensitivity, a marker for risk of diabetes and heart disease, also varied. It improved in 58% of the people following exercise but in 42% it remained the same or in some cases worsened.

In the 8 participants who showed the largest improvement in insulin sensitivity, 51 genes were expressed in muscles at double the levels of the 8 people who showed the lowest improvement and 74 genes were expressed at half the level. Many of these genes were a surprise to the researchers because some of the genes have not previously been linked with exercise. So this study concluded that although exercise has clear health benefits, it may not work for everyone and some people may do better by changing their diet.

**Note:** If you are going to start exercising it is advisable to discuss this with your doctor first to find out the best form of exercise for you.

## Patients Can Now Report Adverse Drug Reactions

You can now report any suspected adverse reactions you experience, so do use this right. You only have to suspect, not prove, that adverse effects are caused by a drug. Adverse drug reactions can occur immediately or days, weeks or even years after taking a medication.

Here's how to report any adverse reactions:

- **If you have access to the internet:**

Go to [www.yellowcard.gov.uk](http://www.yellowcard.gov.uk) and CLICK on submit a Yellow Card report. On this site you can also check the adverse reactions reports already made.

- **If you prefer to use a paper Yellow Card reporting form:**

telephone the MHRA on 0207 084 2000 or e-mail [patientreporting@mhra.gsi.gov.uk](mailto:patientreporting@mhra.gsi.gov.uk) and ask for a form to be sent through the post.

**Note:** adverse reactions to herbal remedies can also be reported to the MHRA

**IDDT believes that a more effective system for monitoring suspected adverse drug will result in greater safety for patients.**

## From our own Correspondents

### Suggestion for necrobiosis

Dear Jenny,

Concerning the problem of necrobiosis discussed in the last Newsletter, may I add that wearing compression stockings in quite a few of my patients has stopped the progression of the skin lesions at the shin. It may be the increase in skin temperature underneath the stockings that could explain their effect.

Prof E.Chantelau  
Germany

### **I'm frustrated and disillusioned**

Dear Jenny,

Many congratulations on the culmination of all your hard work over many years, in achieving a positive statement from Westminster. They might regret making it with the profound implications, but it is true and hopefully will set the standard in other countries. Please don't accept the Noble Peace Prize just yet as I am certain there will be many more battles to fight!

I know my consultant and GP receive the newsletter, but I am still not receiving any change in heart from either, in fact the opposite. I think they consider the IDDT to be too radical and that I will not listen to their advice to change to modified synthetic human insulins.

I currently have serious gastric problems and am reacting to most new medications. In fact one medication (Erythmyocin) I was recently prescribed by the hospital gastric consultant was listed as a known reactant to Atovastin, but this had to be pointed out by my pharmacist. Researching the various leaflets confirmed this and I now have had to cease the cholesterol medication and the antibiotic (suffering severe muscle pain), but no alternative cholesterol drug has yet been prescribed or appears to be forthcoming.

My GP practice scored full marks for the recent extra cash for patients with diabetes, heart, thyroid problems, etc, but I have to really push to seek constructive advice and even harder to get help or possible treatment. Fortunately I use the IDDT data, and my own wealth of knowledge from Diabetic Care Groups, but am becoming very frustrated at the noticeable "apparent lack of care."

I am fed up of hearing about new synthetic analogue insulins, yet appreciate their faster acting benefits, but until I can get a bit nearer with the gastric problem, am totally unable to even consider their possible [?] benefits. I have reacted very violently twice before on other human

insulin products and must continue on animal with its more known and predictable effects. ie loss of warning symptoms and more stable results, albeit slightly higher blood sugar readings. My quality of life is not good with the gastric problems, but at least I am not introducing new medication where there are other side effects, real or imagined.

Initially it was suggested I take Lantus, but that has been quickly changed, possibly with the advice of it being potentially carcinogenic. Their potentially carcinogenic nature is of concern, as I have severe Barrett's Oesophagus, which can be pre-cancerous is of concern. The inadequacy of tests in quantity and quality for new synthetic insulins is worrying. If drug companies can exploit new research ie synthetic modified human insulin the rewards are huge.

Finally, I needed to use a new pack of blood test strips for my Medisense blood meter. Strips have been changed to allow for end loading of blood, so they do not work in the old meter! The comparative tests between the old and new meters were showing a 3-4 point minimum higher blood sugar reading with the new meter. When queried with Medisense, they replied that new technology was giving more accurate and higher readings, and offered to send me control solutions. These did check their meter which was within their operating parameters. So, if I was between 4-7 before, and OK, I may now be 8-11, and not! or in my case 10-14, now 14-18!! This happened a few years ago when other meters were upgraded and target levels reduced. Who or what do we believe?

From a rather frustrated, very disillusioned professional person who is grateful to the IDDT.

Name withheld

### **Excellent Conference!**

Dear Jenny and Beverley,

Thank you very much for an excellent weekend at the IDDT conference. We both got such a lot out of it, learned a lot and enjoyed it! The group sessions were excellent. I have been diabetic for more than 32 years

now and it always seems amazing that after all this time I am always learning something new. It is so helpful, for both of us to mix and chat with other people with diabetes and their carers - it is good to know that you are not alone or experiencing problems because you are 'doing something wrong'. Sometimes I feel guilty when things go a bit haywire, thinking I must have made a mistake somewhere, so it is very heartening to hear others experience the same problems.

We never cease to be amazed at the amount of work you both put in to run IDDT and to organise the conference - I think you must both have at least 48 hours in your days! I'm sure that most people could not achieve anywhere near as much even if they did have 48hours everyday. We thank you sincerely for everything you do for us all.

Mr and Mrs B. J.

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## NHS News

### **NHS IT system faces a year delay**

The full 'airline-type' booking system intended to cover all bookings between GPs and hospitals by December, is running 12months late. NHS chief executive Sir Nigel Crisp said patients will be offered, as planned, a choice of four or five hospitals for their outpatient appointment or operation, starting at the end of 2005 but most of these appointments would have to be booked either partly electronically or on the telephone. The delay is blamed on GPs being reluctant to use the system and hospitals being slow to put booking slots on to the system.

### **UK medical errors in hospitals**

A survey of 99% of NHS Trusts from the National Audit Office [NAO] shows that from April 2004 to March 2005, 2081 deaths due to medical errors were reported, oddly more than double the 840 figure given by the National Patient Safety Agency in July 2005. About 980,000 patient safety incidents and near misses in the NHS were also reported. The

NAO pointed out that as many incidents are not reported, the numbers of deaths could be even higher. The government response was that while the majority of mistakes were minor it was important the NHS learned from them but the study found about half the incidents in which a patient was unintentionally harmed could have been avoided if lessons had been learned from previous incidents. The cost of the mistakes to the NHS was estimated to be £2bn a year in lost bed days on top of the costs of litigation.

### **Report reveals differences in patients' attitude to the quality of care in the NHS**

The independent Health Commission report that a survey [October 2005] has shown that people outside London are consistently more positive about the NHS than people in London. The report suggests that this may be because London hospitals have relatively high numbers of temporary staff. People who are most unwell, have more complex needs and more exposure to health services tend to have a more negative view of the services. Older people tend to be relatively positive about the NHS care with people under 35 staying in hospital tending to be more negative than those over 60.

### **Audit Commission suggests reasons for postcode prescribing**

The National Institute for Clinical Excellence [NICE] issues guidelines to the NHS on the use of drugs and other treatments with the aim of avoiding the postcode lottery of drugs being available in some areas but not others. The 2005 Audit Commission report on the financial implications of implementing NICE guidance suggests that poor financial planning perpetuates postcode prescribing with many NHS bodies seeing costs as the main barrier to implementation of NICE guidelines. As many of us know the postcode lottery does still exist - insulin pumps are just one example with people in some areas people cannot get funding and yet in other areas it is much easier.

## Better Foot Care is Needed

A conference in Brussels in September 2005 highlighted the need for better foot care for people with diabetes. Around 25million people in the EU have diabetes and it is estimated that up to 5% of these people have foot ulcers and that foot problems account for 12-15% of total healthcare resources.

The numbers of people affected varies from country to country - in rural Germany the amputation rate is 6.6 per 1000 people with diabetes but 2.6 and 3.6 respectively for every 1000 people with diabetes in the UK and the Netherlands. Although diabetic care and diabetic footcare is widely available in many countries in Western Europe, the conference concluded that the availability of specialised diabetic foot clinics where healthcare professionals from different disciplines work together remains inadequate.

John Bowis UK MEP said: *“There is a need for more health education about diabetes, not only for the public but also for healthcare professionals. There is a need for more specialist doctors and nurses, and there is a need for more research to be done to better understand the underlying causes of the disorder. There is an urgent need for action to bring about improvements in diabetes care for the millions of people with diabetes living in the world, and particularly in Europe today.”*

### **Help may be on the way as research finds two new tests to detect early signs of diabetic foot problems**

Reported in The Lancet in November 2005, two new tests have been developed that can detect early signs of diabetic foot problems which may help prevent ulcers and so prevent amputations. Researchers in Boston used new techniques called medical hyperspectral imaging (MHSI) and magnetic spectroscopy to assess the skin and foot muscles of 108 patients. Some of the volunteers had diabetes, some had diabetes and neuropathy, and some had neither. The researchers could detect differences that occurred before ulcerative foot disease develops in the diabetic patients, especially those with neuropathy. The diabetic patients had less oxygen in their skin and also had

smaller energy reserves in their foot muscles, suggesting injury to the small blood vessels.

Foot problems are the most common reason for hospitalisation in people with diabetes but according to the researchers, they are also the most preventable - if they are diagnosed early. These new tests are a step in that direction.

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## Health Committee Report on the Influence of the Pharmaceutical Industry government response seemed luke warm but?

Readers will remember the hard-hitting Report from the Health Committee after its far reaching Inquiry into the influence of the pharmaceutical industry. [IDDT gave evidence] Sadly, the Report came out just before the election, so perhaps it did not receive the coverage it deserved. Eventually the government did respond, perhaps rather luke warm and defensive but there have been changes which appear to be in response to many of the criticisms that were made in the Report.

### **Tightening of code of practice for government advisors on drug regulation**

**November 1st 2005:** the Medicines Commission and the Committee on Safety of Medicines is being replaced by the Commission on Human Medicines [CHM]. The Commission will be advising the Licensing Authority on the regulation of medicines and will be supported by a series of new Expert Advisory Groups and it comes under the umbrella of the MHRA, the government agency responsible for ensuring that medicines and medical devices work and are safe. At the same time the MHRA has tightened the Code of Practice on Interests ie conflicts of interest that could result in bias. In future the Chairman and members of this Committee will not be allowed to hold current personal interests in the pharmaceutical industry that their committee regulates. Under

the new Code personal interests include:

- Consultancy work
- Fee-paid work
- Shareholdings
- Expenses/hospitality provided by a pharmaceutical company
- Unit trusts and similar financial assets
- Pension entitlement
- Interests held by immediate family to be declared.

Readers may remember that some time ago, it was acknowledged that 72% of the advisers to the MHRA had connections with the pharmaceutical industry that could be seen to influence their judgements. So perhaps it is not unreasonable to be surprised that it is necessary to tighten the Code but one would have thought that this should have already been in place! Better late than never!

### **And industry tightens up too??.**

November 16th, 2005: The Association of British Pharmaceutical Industries [ABPI] announced that from January 2006 a new Code of Practice for the pharmaceutical industry will come into effect. This Code governs the industry's relations with healthcare professionals and other stakeholders and the new Code aims to improve patient safety. It does include many of the issues that have caused IDDT concerns over the years. The key points include:

**Patient safety** - a requirement for all printed promotional material to include prominent information about reporting adverse drug reactions. All promotional material will have to be changed to include these details, especially important now patients can report suspected adverse reactions.

**Gifts to professionals** - further definition and restrictions are being applied on what can be provided to health professionals as promotional aids, hospitality, subsistence, travel, and accommodation. It is now specifically stated that items must not be offered for the personal benefit of health professionals or administrative staff and items must be inexpensive. Promotional aids are more likely to be acceptable if

they benefit patient care. In all cases the prime purpose of any drug company paying for any health professional to attend a meeting must be its educational nature and companies must only offer economy air travel to sponsored delegates. Lavish venues must not be used and companies should avoid using venues renowned for entertainment facilities.

Relationships with patient groups and the provision of information to the public - are covered in greater depth. Promotion of prescription-only medicines to the public remains strictly prohibited. There is an important new clause about relationships with patient groups - companies are permitted to work with such groups but their involvement must be made clear, and rules on arrangements for meetings are the same as those for health professionals. Companies must make public through their website or annual report, a list of all patient organisations to which they provide financial support, and a written agreement must be in place with every organisation spelling out exactly the terms of the relationship and funding of every significant activity or ongoing co-operation.

Advertising and Complaints - there will be a reduction in the permitted number of pages of medicines advertising and an outright ban on all promotional competitions. The process of determining complaints will be speeded up and sanctions imposed faster. In cases of serious breach of the Code, the details will be advertised in pharmaceutical or medical press.

The ABPI intend to have a major campaign in early 2006 to ensure that the new Code has a high profile.

### **IDDT's comments**

While it is still a self-regulated system, it is more strict, it provides greater sanctions and the complaints procedure will be more transparent. However, it is a shame that this only applies to prescription only medicines and offers no protection for the safety of patients in relation to over-the-counter drugs. As ever, the proof is in the pudding but the principles have got to be better for patients. The new ABPI Code of Practice can be accessed at [www.pmcpa.org.uk](http://www.pmcpa.org.uk).

## IDDT's Most Unusual Request!

Unusual question for you. I'm a veterinarian and one of my colleagues is starting treatment for apparent insulin dependent diabetes in a pig. We can find no information for this. As the original insulins were pork and beef, and as human testing was probably not done, is there any research for human diabetes that was done on pigs? We would appreciate any information you have on this subject as we are shooting in the dark picking a dose and monitoring and not knowing what to expect with our patient. Please let me know if you have any information or if you can point us in a new direction. Thank you

Received by e-mail

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## It May be Winter in the UK

### **But our friends in Australia must think about the sun, too much or too little?**

Australia is known as the land of sun but a generation of Australians has been brought up to fear the sun because of the risk of skin cancer - they cover up and use factor 30 sunblock. But after 20years of telling people to keep out of the sun, the Cancer Council of Australia has issued new advice [The Medical Journal of Australia. March 2005] saying that a little sun is good for you. The reason for this change is that a new problem has emerged in Australia - vitamin D deficiency.

Vitamin D produced by the action of sun on the skin, is essential for healthy bones, healthy immune system and possibly as a defence against some forms of cancer. To get adequate amounts of Vitamin D, people in Sydney and South Australia are advised to expose their unprotected face, hands and arms to the sun for 5 to 10 minutes before 10am or after 3pm most days of the week in summer and 2 to 3 hours per week in winter. There are two sides to every story, we

need enough sun to provide Vitamin D but not too much to cause skin cancer.

### **And in the UK??..**

We spend a lot of time in cars and have a climate with a lot of grey skies and short days between October and March so do not receive much sunlight. However, the major difference between the UK and Australia is that many of our foods contain Vitamin D. It is in milk, margarines, oily fish, eggs, liver and cheese.

### **Research into Vitamin D deficiency**

Studies have linked shortage of Vitamin D to the incidence of muscular sclerosis which is most common in countries furthest from the equator with less sun. There is increasing evidence that it could play a part in other autoimmune conditions such as Type 1 diabetes.

Very few foods naturally contain Vitamin D so sunlight supplies most of our Vitamin D requirements. Vitamin D deficiency is prevalent in babies who are solely breastfed and who do not receive supplements of Vitamin D and in adults of all ages who have increased skin pigmentation or who always wear sun protection or limit their outdoor activities. Vitamin D deficiency is often misdiagnosed as fibromyalgia.

Studies suggest that the unrecognised epidemic of Vitamin D deficiency worldwide is a contributing factor of many chronic debilitating diseases including some common cancers, Type 1 diabetes, cardiovascular disease and osteoporosis. [American Journal of Clinical Nutrition, Vol 79, No 3, 362-371, March 2004]

**Sunbed use** is a cause for concern because sunbeds can emit levels of UV radiation which are five times as strong as the noon sun and so increasing the chances of skin cancer. Doctors are reporting increases in skin cancer in previously unaffected parts of the body, such as the buttocks, which have been caused by all over tanning by sunbed use.

## Faulty Blood Glucose Meters

On October 26th the FDA in the US issued a warning that several glucose monitors made by Abbott Diabetes Care can give misleading test results. In some cases, mistaken readings have resulted in very high blood sugars. The wrong readings occur when the meters are accidentally switched to a foreign standard of units, can occur when someone is setting the date and time or if the meter has been dropped or the batteries changed. 2.23 million people use the affected meters but they are not being recalled, people are being advised to contact their doctor if they are worried.

The affected Abbott glucose meters sold in the United States are: FreeStyle, FreeStyle Flash, FreeStyle Tracker, Precision Xtra, MediSense, Sof-Tact, Precision Sof-Tact, MediSense, Optium, and private label brands ReliOn Ultima, Rite Aid, and Kroger blood glucose meters. Affected glucose meters sold outside of the United States are: Xceed, Liberty, Boots, Xtra Classic, Easy, and SofTrac.

*Who are you all?*

*E-mails criss cross on who will cover what and when.*

*Who are you all?*

*E-mails have to be translated but the language is the same, we're here.*

*Who are you all?*

*The one word, diabetes; the one cry, help.*

*Who are you all?*

*Many have never met but for the internet, but the need is known.*

*Who are you all?*

*You are parents; you know what it is like to live with diabetes; you know the daily battles; you are caretakers; The last battle was my first with you all and it was a privilege to serve with you; I am only but a servant in your war; The war will continue - it is diabetes - you have amazed me, you have humbled me; I am in awe of your efforts - more than all of this; I am a dad. I know.*

*The world is a better place because of you all - I thank you with all of my heart and soul.*

*You have all made a difference.*

*That is who you are.*

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## IDDT is the UK Arm of 'Insulin For Life'

As reported in our last Newsletter, IDDT responded immediately to the desperate need for insulin after hurricane Katrina. We thought you should know just how much your efforts are appreciated - here's a note of thanks from Tom Karlya in the US who organised receipt and distribution of the supplies sent from IDDT in the UK, from Germany and Australia

*Who are you all?*

*You do not ask anything but how can I help.*

*Who are you all?*

*Packages come from all over the world, it's needed.*

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## In the US Inhales Insulin Delayed Yet Again!

**October 29th 2005** - In IDDT's October 2005 Newsletter we reported that in the US, an Advisory Committee of the Food and Drugs Administration [FDA, the drug regulatory body] had recommended that with certain provisos, approval should be given to Exubera, inhaled insulin developed by Pfizer and Sanofi-Aventis. The FDA usually takes the advice of its Advisory Committees but on this occasion, it has not and on October 29th the FDA decided to delay its decision for a further 3 months while it reviews technical chemistry data on Exubera.

However, an advisory body of the European Medicines Evaluation Agency has recommended approval of inhaled insulin which moves

it closer to regulatory approval. In the UK the anticipated release date of the Assessment Report from NICE [National Institute for Health and Clinical Excellence] is week commencing 23 January 2006.

**Note: Insulin in a capsule?** - British-based company Diabetology Ltd have developed a capsule of insulin called Capsulin. Early trials at Bradford Teaching Hospital in 8 men with Type 1 diabetes showed that insulin could be successfully absorbed by the body. Still a long way to go though and Diabetology are working on further trials of Capsulin in patients with Type 1 and Type 2 diabetes.

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## Snippets...

**Alcohol estimated to kill 1.8million people a year world wide** - so in May 2005, the World Health Organisation [WHO] launched an inquiry into alcohol. A resolution was adopted by ministers from the WHO's 192 member states expressing alarm at "trends in hazardous consumption", or binge drinking, particularly among young people, and cited a growing risk in developing countries. The U.N. agency will conduct further studies and report back in 2years on ways to reduce alcohol-related harm. Alcohol can damage nearly every organ and system in the body and according to the WHO, contributes to more than 60 diseases and conditions, including dependence, liver cirrhosis and cardiovascular disease. It causes at least 1.8 million deaths a year worldwide, slightly less than tobacco at 4.1 percent and high blood pressure at 4.4 percent.

**Cholesterol jab** - a new vaccine for lowering cholesterol is being developed in the US. People receiving the vaccine experienced a 22% reduction in the risk of death and heart attack.

**Numbers of people having stomach surgery to fight obesity doubles** Dept of Health revealed that the number of patients undergoing radical stomach surgery on the NHS to reduce the size of the stomach has more than doubled in the past three years. More than 600 gastric banding

procedures and related operations were carried out in 2003-04, up from 300 in 2000-01 with an estimated 4,300 people having obesity surgery in 2005 compared with 2,287 in 2004, mostly at private clinics.

### **Optical sensor could offer alternative to blood testing**

An optical sensor is being developed that measures glucose levels through the eye's aqueous humour [the fluid at the front of the eye]. The glucose concentration in the aqueous humour is about 80% of that of blood and tracks it with a time lag of no more than 5-10 minutes. Light from a low power source is focused into the eye and the intensity of the light reflected back is analysed and from this analysis the glucose level in the body is obtained. A couple of dozen people have tried the sensor and the company involved want to extend testing to a large sample and build a more advanced prototype.

### **Seaweed could make junk food healthier**

According to research at Newcastle University, adding an extract of an exotic seaweed could make food healthier. The seaweed is called Lessonia and Laminaria and is found in the Far East, S America and parts of Norway and Scotland. The seaweed extract, alginate, is high in fibre and could be used to increase the fibre content of cakes, burgers and other foods which usually have a high fat content. It strengthens the mucus that protects the gut wall and can slow down digestion and the uptake of nutrients. It has been found to be palatable and safe and is already used in the food industry as a gelling agent. The researchers believe that it is hard to change people's habits as many people don't enjoy eating high fibre foods such as fruit and vegetables, so one solution is to improve the food they do eat and adding alginate is a way of doing this.



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

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## From Your Editor – Jenny Hirst

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