



Insulin Dependent Diabetes Trust

October 2004 Newsletter



Together We Are Stronger

Health Ministers, NHS Plans, NHS guidelines are constantly telling us that patients must be at the centre of care. By definition, this must mean patients having an influence over healthcare decisions, but sometimes we have to wonder if this really is possible or just sounds good. Putting a couple of patients on various NHS and health-related committees is a step forward and patients must take every opportunity to be represented, but we don't really know how much this actually affects the final decisions, if at all.

As a patient representative in the past, I have spent many long hours on committees top heavy with medical and healthcare representatives and I know that it can be a difficult and frustrating position to be in. In cases where the patient views differ from the professional view,

you have to have the courage speak against confident medical and health professionals surrounded by their colleagues, who may even be your own doctor and nurse. While you may well have the support of fellow patients, within the committee you could well be a lone voice. Hopefully that lone voice may have some effect but the likelihood of it falling on stony ground is often too high for patients to truly influence decisions.

'Patient Voice', the magazine of The Patients Association, published an article [April 2004] about patients influencing decisions, making the point that 'together we are stronger'. IDDT entirely supports this philosophy. As individual people suffering adverse effects to synthetic GM insulins we are isolated, alone and often find it difficult to be sufficiently assertive to stand our individual corners with our doctors and healthcare professionals who do not know, or do not accept, that these adverse effects exist. Being part of IDDT and knowing that there

are many other people in the same situation gives us, as individuals, the confidence to exercise our rights to a choice of treatment. From a wider perspective, as an organisation with the support of an ever-growing membership, IDDT is more able to influence views and decisions because 'together we are stronger'.

Our lobbying campaign to ensure the future availability of animal insulins, is an example of working together to influence decisions that affect the future health of a great many people. Campaigning may seem long and even tedious, writing letters is a chore and time consuming but it is an essential part of campaigning. It supports the Trustees' discussions at Westminster and with the Dept of Health and it demonstrates the concern and strength of feeling of large numbers of people. Above all, personal experiences are a vital part of ensuring that politicians understand just how important animal insulin is to some of their constituents.

The article in Patient Voice confirms that our campaigning policy is both right and necessary when it says:

- *If you can't make a reasonable calculations about the timing of the change in policy that is causing the concerns - better to be too early than too late. IDDT's OK here then!*
- *There are advantages to a grass roots approach: it places campaigning in the hands of those who have most to gain by a successful outcome and increases the legitimacy of the campaign. This is undoubtedly true for IDDT members - the gain is the insulin that keeps people healthy and thanks to the huge support from our members writing to their MPs and MEPs, our campaign has legitimacy - our philosophy of strength in numbers again.*
- *Maybe the greatest problem facing any lobby is that powerful people often don't react at all - one of the privileges of power! There is a hope that "they can just wait until the campaigners go blue in the face, start foaming at the mouth and eventually give up?.so the campaigners must get a reaction, any reaction in order to flush the target out into the open."*

We may go blue in the face and even start foaming at the mouth - hardly surprising with some of the responses from the Ministers and their selective interpretation of the evidence! But one thing is certain, we are NOT going to give up! When health, quality of life and even lives are at stake, this is not an option. One of the primary reasons for forming IDDT 10 years ago was to build up support to ultimately be in a position to fight for the animal insulins that a significant number of people need. This we have achieved and together we are stronger. We are certainly not going to give up now!

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Code Of Professional Conduct For Nurses

All healthcare professionals have a code of conduct set down by the regulatory bodies of their particular profession. The main purpose is to protect the public and to:

- Inform professionals of the standard of professional conduct required by them in the exercise of their professional accountability and practice.
- Inform the public, other professions and employers of the standard of professional conduct that they can expect of a registered practitioner.

As regular readers will know, one of the problems that many people with diabetes have if they want to change from synthetic GM insulins to natural animal insulin is convincing the diabetes specialist nurse that this is what they wish to do. This has concerned IDDT for some time because prescribing is a doctor's responsibility, with specific exceptions, and a change of insulin is a prescribing issue. However, one recent case made us look into this situation further.

A man with long-standing Type 1 diabetes wished to change to pork insulin, discussed this with his GP who issued a prescription but said that the patient must discuss the details of how to changeover with

the diabetes specialist nurse at the hospital. However, the nurse refused to help, saying that she did not approve of animal insulin and nor would the consultant's attitude be any different. Under duress she did say that to changeover he should lower his dose! Which dose and how much???

So we looked at the Code of professional conduct for nurses and in this instance it seems that the nurse was in breach of several of the main points as the Code states that a registered nurse must:

- respect the patient or client as an individual
- obtain consent before you give any treatment or care
- protect confidential information
- co-operate with others in the team
- maintain your professional knowledge and competence
- be trustworthy
- act to identify and minimise risk to patients or clients.

The full Code can be obtained on the Nursing and Midwifery Council's website at www.nmc-uk.org or by writing to Publications Dept, Nursing and Midwifery Council, 23 Portland Place, London W1B 1PZ.

Who's who in the nursing profession

Titles have changed but do you know what they mean and who they all are?

With the increasing role of nurses within the NHS and the changes that will allow some nurses to prescribe for some conditions it is important that we understand who does what.

Registered nurses are qualified and registered with the United Kingdom Central Council [UKCC] for Nursing, Midwifery and Health Visitors. They can use the initials R.N.

Staff Nurse and sister indicates seniority. A sister or charge nurse [male version] has responsibility for the ward or department.

Clinical nurse specialists have extra qualifications in particular health problems such as diabetes.

Diabetes Specialist Nurses [DSNs] are clinical nurse specialists in diabetes.

Consultant nurses are the most senior nurses and are involved with teaching, research, training and clinical practice.

Healthcare assistants work alongside nurses providing patient care. They used to be known as auxiliaries.

Practice nurses work in GP surgeries.

District nurses provide care and support in the patient's home or in clinics. Some have qualifications in community care and may lead a team of nurses.

Health visitors are registered nurses that promote health in the community, usually working from a GP surgery but some visit people in their homes and schools. They have special training in child health, health promotion and education.

Registered midwives can work in both hospitals and the community.

Nurse practitioners are qualified to examine, assess and treat some patients.

- **First pharmacists and nurse prescribers graduate**

As part of the NHS changes to allow other health care professionals to prescribe, earlier this year Bradford University's course 'Prescribing for Healthcare Professionals' saw its first graduates. 27 pharmacists and two diabetes specialist nurses have became the first supplementary prescribers in England qualifying them to write prescriptions and adjust treatment **within an agreed managed care plan** for chronic conditions such as heart disease, diabetes, asthma and hypertension.

Remember - insulin is a prescription only drug and should be prescribed by a doctor and dispensed by a pharmacist unless your nurse or pharmacist is a qualified supplementary prescriber when there should be an agreed management plan - agreed by you too!

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An Error Waiting To Happen!

You may remember that we expressed serious concerns that Novo Nordisk have removed the word 'HUMAN' from their 'human' insulin range. For example what was called **Human Mixtard** is now just **Mixtard 30**. We feared the this would result in errors at pharmacies for people using the equivalent Novo Nordisk pork insulin which is still called **Pork Mixtard 30**.

Well this has already happened to Margaret Grassing from Kings Lynne, her pharmacist gave her Mixtard 30 instead of Pork Mixtard 30 written on her prescription. Undoubtedly the pharmacist's fault but an easy error to make! So ALWAYS check you have the correct insulin BEFORE you leave the premises.

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Being In Hospital - A Waring To Others!

We are sure that there are some good experiences of being in hospital but several of our members who have all had diabetes over 20years have had bad experiences when in hospital for reasons unconnected with their diabetes. They feel that other people may benefit by learning from their experiences and being prepared! They are concerned that people who haven't their years of experience of managing their diabetes may not have the confidence to question the treatment they are given in hospital. The problems they encountered seem to fit into clear categories: insulin, diet, and knowledge of the staff, or lack of,

not to mention the dirt!

Insulin and treatment

- Difficulty on remaining on their own insulin while in hospital
- Insistence by doctors that during the operation short-acting synthetic 'human' insulin was used despite their normal insulin being pork.
- Locking away the patient's own insulin so they could not access it to control their own blood sugars.
- Not allowed Lucozade by the bed in case of a hypo.

For people that have treated their own diabetes and hypos for over 20 years these are unnecessary restrictions.

Diet

- Not enough carbohydrate 'because you are diabetic'. In one case mashed potato and baked beans was the best meal of the stay!!!
- The last meal of the day was between 4.30 and 5.00pm with no arrangements for night time snack so family members had to bring in not only more food but more appropriate food. What happens to people with no relatives to help?
- One person who has diabetes and coeliac disease said they could just about cope with her diabetic needs but no way could they cope with both conditions.

Knowledge of diabetes of the ward staff - all our reports complained about the lack of basic knowledge about Type 1 diabetes and the lack of understanding that people who have Type 1 diabetes for many years do actually know something about it!

- When blood sugars were high one person was told he couldn't walk around to lower them because this would make them worse and he must stay in bed. Then he was told not to get angry because this would make them worse too!
- One patient was advised not to dispute the treatment because the

nurses have 'all been on a course about diabetes'.

But from one case in particular there are lessons to be learned:

Let's call our member, Jack. Jack had to have a small operation and because of his diabetes went into hospital the night before. His own insulin pens were locked away and despite his protestations that synthetic GM insulin did not suit him, he was told that a drip with sliding scale of short-acting synthetic GM 'human' insulin would have to be used for the operation. This was set up and he was sent to theatre but when he arrived they didn't have the correct plug for the drip. The nurse offered to fetch one but the doctor said 'later' at which point Jack became unconscious.

He came round in the ward to find that his blood sugars were 18 - had the sliding scale not worked then or what? He asked for his own pork insulin but was told that he would have to wait for the other insulin to get out of his system! An hour later his blood sugar was up to 22, still he was refused his insulin! A further hour later it was up to 30, a doctor was called and he was put back on a drip because he was dehydrating. Still his blood sugars kept rising and by this time Jack was feeling very ill. He insisted on having his own insulin pens back and he took the drip out himself [not a good idea really!] and his blood sugars plummeted almost immediately. I am sure by now you can guess why - the drip to prevent his dehydration contained glucose and not a saline! During the next 2 to 3 hours Jack 'secretly' gave himself injections of his own short-acting pork insulin until his blood sugars were down to about 10. Through these errors what should have been a very short stay in hospital was not, but he escaped as quickly as could!

Lessons to be learnt - there are most certainly lessons to be learnt by the staff but there are lessons here for us in case we have to go into hospital.

- Have a full discussion with the hospital doctor about your needs BEFORE going into hospital.
- Take your own insulin with you.

- Take extra food with you.
- Ask questions about what is being carried out.
- If necessary, question decisions about your treatment, especially if you feel that the actions are contrary to all you have learned about your diabetes.

Having said this, Jack did all of these things but to no avail - the nurses had been on a course!

Dirt and hygiene - the dirt and general standards of hygiene was a common general complaint. It was not just dirty floors and dust but cleanliness of toilets with un-emptied bedpans remaining in the toilet areas for several hours!!!!

Hospital-acquired infections such as MRSA cost the NHS about £1 billion a year and kill many patients. [Gastroenterology, Feb 2004] At the time of writing the government has just announced that every bed will have alcohol wipes for the staff to try to prevent infections but interestingly, researchers in Chicago have developed a 'chemical shield' which may stop patients developing infections in hospitals. Bacteria usually act when the body is vulnerable because they sense chemical stress messages. The shield would act as a barrier to stop these messages and so prevent the bacteria from causing infection.

Mice were infected with *Pseudomonas aeruginosa* bacteria that can cause sepsis of the gut and can be fatal in patients who are weakened by surgery. Some of these mice were also injected with a polymer, polyethylene glycol, which lines the gut and prevents the stress messages getting to the bacteria and also protects the bowel wall from the bacteria. The mice treated with the polymer survived but those without the polymer died. The researchers suggest that this is a possible way of preventing hospital-acquired infections without using antibiotics.

Don't Forget To Order Your IDDT Christmas Cards!

If you've lost or misplaced your order form, contact Bev Freeman at IDDT on 01604 622837 or write to IDDT [Cards], PO Box 294, Northampton NN1 4XS.

IDDT Goes To Westminster

Jenny Hirst

I would like to thank all our members who have written and re-written to their MPs and MEPs about Novo Nordisk's possible discontinuation of animal insulin. I thank you too for keeping me informed as this helps me to piece together the picture as it unfolds. Your help has been invaluable in the campaign and has given credibility and support to the many Westminster meetings the Trustees have had with MPs of all parties.

Many of you have felt angry and frustrated at some of the replies your MPs have received from Rosie Winterton, Minister of Health, and Lord Warner, the Under Secretary of State for Health and I can empathise entirely with these feelings! But by continuing to respond through your MP, you are putting our case more strongly and sending the message that we are not going to be fobbed off with half-truths and spin on the evidence.

Our campaign so far has resulted in 29 Parliamentary Questions being asked of the Minister with more set to come when Parliament returns in October and I would like to thank all the MPs who are supporting our needs and taking action on our behalf. We are very grateful to them all.

Progress Report

Novo Nordisk delay their decision about future availability of animal insulin

In July came the news that Novo Nordisk have decided to delay the final decision about future availability of animal insulin for another year - until mid or late 2005. With their guarantee of 18months notice of discontinuation, this means that supplies should continue until the end of 2006 or into 2007. Good news and gives us longer to fight our case!

Novo Nordisk acknowledgement that some people can't tolerate synthetic insulin

Letters from the Managing Director make this statement:

"The company is aware that there are people with diabetes who are only able to tolerate animal insulins."

So after years of IDDT and individual patients trying to convince doctors and specialist nurses of the adverse effects of synthetic GM insulins and basically failing, the manufacturers actually agree with us - there are people who are only able to tolerate animal insulins! It has taken 20years and pressure from you and your MPs to achieve this. We must not underestimate the value of this statement:

- It directly supports our lobbying for the indefinite supply of animal insulin for the people *"who are only able to tolerate animal insulin"*. With a statement like this, if the government doesn't ensure continued supplies, they are knowingly condemning people to a treatment they can't tolerate and this is an unthinkable position.
- It questions the safety and medical ethics of transferring patients *"who are only able to tolerate animal insulin"* to any synthetic GM insulin, including insulin analogues. It leaves doctors who prescribe any of the synthetic insulins to patients *"only able to tolerate animal insulin"* in a very vulnerable and unenviable position, a similar position to prescribing penicillin for a patient known to be allergic to it.

CP Pharmaceuticals

As you will remember, we have expressed our concerns that CP may not be able to meet the increased demand for pork insulin should Novo Nordisk decide to discontinue their pork insulin. This was discussed at our meeting with the Dept of Health in May and in replies to your lobbying letters from July onwards, Lord Warner states:

- CP have given assurances that it currently has no plans to stop the supply of animal insulin. CP have confirmed to the Dept officials that they could meet any increased demand for animal insulin within a maximum of three to four months.
- Given that Novo Nordisk will give 18months notice should it be necessary, there is no reason for the continuity of supplies to be affected.

August 2004 - Lord Warner's latest 'standard' letter contains the following statement:

"Should one of the two companies supplying animal insulin in the UK decide to withdraw their product, the Dept of Health will take whatever steps are necessary to help ensure that patients continue to receive the treatment they need."

This undoubtedly is progress. It answers the key question we asked at our meeting with civil servants from the Dept of Health about who is responsible for ensuring that UK citizens have the essential medicines they require. This statement from Lord Warner certainly suggests that the Dept of Health is responsible. But Lord Warner does not go far enough. What does he mean by 'treatment'? All insulins lower blood glucose levels and simply lowering blood sugars could be classed as the treatment we need.

We need a categorical statement that this promised treatment will in fact be with animal insulin. Putting it very bluntly, we cannot risk that this decision will be in the hands of the doctors and nurses who have never believed that there are adverse reactions to synthetic GM insulin in some people.

We need to be categorically assured that we, as patients, will be actively involved in this decision and that this will not be a battleground where patients have to be assertive to continue to receive animal insulin.

We need to be assured that animal insulins remain available as a choice of treatment for everyone requiring insulin. The phrase "*patients continue to receive the treatment they need*" suggests that all the Department will do is ensure those already using animal insulin will continue to receive it. This is not good enough. IDDT continues to receive new reports of adverse reactions with 'human' insulin and with all the new analogues and if animal insulins are not freely available now and in the future, these people will be forced to remain on a type of insulin that adversely affects their health and lives. So we have to ensure that the choice of animal insulin remains available now and in the future and for everyone, not just for those presently using it. Above all, we want steps to be taken to ensure that everyone requiring insulin is made fully aware that animal insulin is available and that synthetic GM insulins do cause adverse reactions in some people. It is essential that this is done by hospital clinics and not by a charity!

To date:

- MPs have asked 29 Parliamentary Questions of the Minister of Health.
- David Hinchliffe, MP and Chairman of the Health Select Committee has written to the Minister, Rosie Winterton requesting that she meets with IDDT.
- Through the Health Select Committee IDDT has raised questions with Public Finance and Accounts.
- David Amess, MP has put in a request for an Adjournment Debate - this will only take place if successfully pulled out from a ballot.
- Tim Loughton MP is to pursue the following points:
 - a. Government research into comparing animal and synthetic insulins
 - b. Why doctors are not giving patients a fully informed choice

- of insulins
- c. Why the NHS is paying more for synthetic insulins that are not superior to animal insulins for the majority of patients
- d. That there must be a better education programme for people with diabetes and this MUST include patients being given a fully informed choice of ALL insulins.
- We have written to Dr Ian Gibson, Science and Technology Committee on David Hinchliffe's recommendation.
- IDDT has presented written evidence to the Health Select Committee Inquiry on 'The Influence of the Pharmaceutical Industry on Health'

I believe that we are making progress and I am encouraged that we now have supportive MPs who clearly recognise that some people cannot tolerate synthetic insulins. Like many of us, they see the unfairness and the risks associated with denying people the insulin they need and they have difficulty in finding an explanation, especially when a known 30,000 people is not an insignificant number.

They are now questioning not only the present situation but also the past, and rightly so! When there is little or no evidence of benefit for the majority of patients AND an increased cost to the NHS, why did synthetic insulin ever become first line treatment? Who made a decision that synthetic GM insulins would be first line treatment? Why haven't doctors been giving patients the informed choice of insulin that is their right? It simply doesn't add up especially when cost is not the issue and so, as one MP said, it is a matter of peeling off the layers to get to the bottom of all this and to seek answers to these questions.

This could result in discomfort in some quarters but this is nothing compared to the discomfort that people will have to endure if their animal insulin is discontinued! If this is the only way to ensure that animal insulin continues to be available, so be it.

One Parent's Experience - But She's Not Alone

It has been a year since I first contacted IDDT after reading an article in a local newspaper. The article was highlighting the difficulties a teenage girl had experienced with her diabetes and I found myself feeling hopeful for the first time in many years. My son, John now 15, was diagnosed with Type 1 diabetes at the age of 7. I came to terms with this diagnosis with a mixture of pain and a sense of loss, as many parents do. The greatest pain for me was the dramatic personality change that took place from my son being a very gentle and good-natured boy to a bad tempered and incredibly moody child. It is only now that I realise that it was the adverse effects of 'human' insulin which so drastically changed him. Almost immediately after changing to animal insulin there was a change back in John's personality. For the first time in years he was able to concentrate fully again and the tiredness that clouded his thinking lifted. He has become easier to live with and both myself and his twin brother no longer have to listen to doors slamming or deal with his aggressive outbursts. I feel a great sense of relief that we have been fortunate enough to have been able to make the change whilst John is still at school but I also feel a sense of loss and guilt that I was not able to make this change sooner for John.

I think that one of the most difficult aspects of being a parent of a diabetic child is educating others about the hidden aspects of the condition. I have had a constant battle with schools who do not understand the symptoms of hypos and use phrases such as '..he chose to behave?' when referring to incidents when John has been hypo. However I do now feel I have a voice and a say in supporting Ben and this has been helped with the information and advice published by IDDT.

I thought I had won the biggest battle last year when I managed to convince John's consultant that John should be allowed to try animal insulin. I now find that another battle has to be fought. Ben experienced a serious hypo while at school with a blood sugar level of 1.6, he also experienced the worst prejudice. Despite having a blood sugar meter with him showing that he was severely hypo, the school in its wisdom

decided that in their view he was not hypo but behaving very badly. For John this was a huge knock to his confidence and also left me feeling extremely emotional and frustrated.

However if I do not stand up and support Jon then who will? Despite there being legislation to cover the rights of children with diabetes, in education I have found there is still a great deal to be done in having them implemented. Supporting John in the day to day living with diabetes has been the easy part as he has taken on the responsibility of that himself and has never complained about injections or blood testing. Supporting John emotionally however has been the greatest challenge. Nothing prepares you for the ignorance.

I would like to end by thanking IDDT for their continued campaign to maintain the provision of animal insulin in this country. It has changed our lives and given my son back control in his life.

Jenny's comment: It saddens me to read this. My daughter was diagnosed nearly 30 years ago and while there have been technological improvements in the treatment of diabetes, this mother's experience suggests that there have been few improvements in dispelling the ignorance about diabetes and hypos. Equally there seems to have been little improvement in finding ways of offering emotional support not only to the children and young people with diabetes but also to their parents.

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Rae Price's Diary

When we last heard from Rae, she had started pump therapy and was being considered for an islet transplant. Now read on??..

March 2004

March definitely wasn't my month. It started off with my frozen shoulder giving me some real gip and the GP shoving some steroid in

it. As expected the sugar levels went wild and I had 3 days at around 15 then the next 3 days where I couldn't get it above 3.5. I then broke out in an awfully itchy rash and went to see an emergency doctor. 'It's an allergic reaction' he said and gave me some Piriton. Two days later I went back to my GP still in agony and shattered because I couldn't sleep. 'It's definitely an allergic reaction' she said and sent me packing with a prescription for some steroid cream. The relief was immense and I slept for the first time in nearly 6 days that night.

Once again the sugar levels became totally unpredictable and I started to test every hour but it was worth it just to be able to stop itching. Eventually we narrowed it down to some new washing powder with fizzy stuff in it. I decided to email the manufacturers asking but their reply was to get a professional dermatology report - ARGHHHHHHHH!!!

By the third week I was back at the hospital rheumatologist for the first time in two years with this painful frozen shoulder. After a thorough check up by one of the few doctors I'm extremely happy to rave about, he offered me another steroid injection warning me the sugar levels might 'go a bit off'. 'Go for it' was my reply.

Finally after all the ups and downs with the sugar levels I got a stinking cold and off they went again. As usual nothing could be straightforward and I had 3 days of constant hypos with one 5 hour period of not being able to get the level over 1.9. To be honest I'm not really sure how I managed this as in this short period of time I consumed 2 bottles of Lucozade and about 80g of carbs. It took me a further 2 days to get them back down to 'normal' levels in the aftermath.

April 2004

Visited the pump clinic yesterday and it turns out my HBA1C levels are still 6.something. My consultant now classifies me as stable!!! 'Rolls on the floor in hysterics' I wish!! I just keep remembering years ago when you didn't have to worry all the time about going hypo because if you got anywhere near it the symptoms would walk up and smack you in the face.

The pump has made a HUGE difference, especially to my lifestyle but, and it's a massive BUT, it still hasn't stopped the 'no warning whatsoever hypos.' The clinic nurse suggested I reduce my basal rate by 0.1 every hour during the day and I adjusted it whilst she was chatting. Yep, you've guessed it, the level went down not up.

The gym sessions were going really well up until the cold kicked in and I had even started to enjoy them. I'd even managed to go from being able to do 3 minutes to 20 and had started to get a bit jaded at not being able to do more than 3 minutes on the cross trainer.

I had an appointment at the transplant clinic and had sorted everyone out from childminder to transport when I received a call 30 minutes before I was due to leave, the appointment had been postponed. After finding out some more information recently I've come to a BIG decision that I'm not having the islet transplant. I've had this brittleness for 6 years now and am used to dealing with it so unless they can guarantee a cure I'm not putting the problems of the anti-rejection drugs on top of the ones I already have.

May 2004

Started work again after nearly 2 years of not being up to it but can still only manage one day a week and for a charity that helps diabetics with retinopathy. The work is fascinating and pointing out the ins and outs of living with retinopathy to professionals working in the field has been, literally, a real eye opener and I hope that in some small way I can help create better understanding.

Working with other diabetics has been really interesting especially as I thought I would be the first one to go hypo but no it was one of the other girls. She attempted to eat a fruit/oat bar which really didn't help at all so I ended up shoving Lucozade down her neck and lecturing her on how you need something quick acting and then some slower acting carbs afterwards to see you over the worst of the hypo. An amazing eye opener, once again, considering she had been diabetic for more than 12 years and should be aware of this.

June 2004

Whoohoooo heard from Support Dogs today, after applying to them more than 2 years ago for a dog, asking me to go down to Sheffield to give some more details and discuss how long it's all going to take.

It was a long day but very informative and I'm really looking forward to getting this dog who will tell me when I'm going hypo. Wow, what a HUGE difference that will make. I also had another amazing experience with the 2 other diabetics there when neither of them checked how many carbs were in the sandwich before giving themselves some quick acting insulin. IS IT ME?? If I don't check the carb level my blood sugars would be even worse.

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Eye Screening

Is Delivery Of The National Service Framework On Target?

The National Service Framework for diabetes sets two critical targets for eye screening for early stages of retinopathy with NHS delivery over 2003-6. The setting up of registers for all patients with diabetes was the first need to enable Primary Care Trusts [PCTs] to have an accurate list of people who need to be offered eye screening for the early detection of retinopathy. The minimum targets are that 80% of people on the register should be offered screening by 2006 and 100% by 2007.

The evidence suggests that there is great variability in the progress that PCTs have made towards meeting these targets. We all know the importance of early detection of retinopathy, and early treatment when necessary, and we must try to ensure that this is not a low priority for PCT budgets.

It would be wonderful if IDDT members could write to their PCTs to enquire about the plans and progress they are making towards implementation of the screening service for diabetic retinopathy. This

is not a letter of complaint but just an enquiry to let your PCT know that eye screening is a vital issue for people with diabetes.

Silver Linnings

The second in a series of articles by Sue Marshall who has had insulin dependent diabetes since the age of five.

Blood testing

As I said in my first article, no one wants to have diabetes but sometimes I take a look at the plus sides of having diabetes and maybe there are some silver linings! Are there any silver linings in blood testing?

Blood testing is a great way to stand out from the crowd. In fact, it's particularly effective if you are in a crowd and lancing yourself in public!

As far as possible, one must consider other people's sensitivities of course, but if I need to have a blood test I will do a blood test. I do them on trains and tubes, walking down the street, in meetings. One can get used to doing it in all sorts of places.

When I was a child we didn't have blood-testing machines, they just weren't around and it's extremely likely that had I had one, I wouldn't have used it precisely because it would have made me stand out. Thirty years of having the condition means you tend to lose that self-consciousness.

The first blood test machine made its way into my life after I had a particularly nasty turn after having a bug that made me rather sick. The machine, the size of a brick, was kept in my bedroom in my sock drawer and was used once or twice a week.

Boy, have things changed. Now I blood test four or five times a day. I always blood test before a meal and I always have an injection with a

meal. It's an equation. What you eat (carbs counted), what insulin you inject (insulin dose), assessed together with the reading you get from your blood test (6.8 for example).

I do actually love blood testing; I think it is an absolute boon. No-one enjoys the potential of the pain involved. 'Yes', I tell people when they ask, 'of course it hurts, but not always.' Occasionally you feel like you have struck a nerve and your legs are tingling because one tiny finger prick is making you want to swoon. But that doesn't happen that often.

Not everyone will consider punching a hole in yourself, squeezing out a drop of blood and sucking your finger particularly attractive. And the results vary. On a hot day, or if you have been busy, you can strike a veritable geyser. Other times you can find that no matter where you try to mine, you seem to finally have become entirely bloodless.

Doing a blood test is nearly always a pre-cursor to having an injection. And one or the other activity may mean you are expected to explain yourself.

Back in my teenage years I used to sneak off to the toilet to do a test or have an injection, but now I just see it as a chance to educate. Sometimes you will be talking about it and the person you are with takes it as the opportunity to tell you the worst story they ever heard about somebody with diabetes but that kind of thing is discouraging, but such people are just lacking in those sensitivities I mentioned earlier.

More often than not you will get people saying, 'Oh, it's about sugar isn't it?' Then you have to start on the explanation about how that is part of it. Or there are the people who say, 'Oh, I couldn't do that, I don't like needles' but of course they don't know you can get used to anything if your life depends on it.

When it comes to blood testing, these days I've reached the point where, unlike my bank statements, I can take a blood test and look at the resulting reading with a certain amount of bravery. Bank

statements take more guts to some extent but it is the same idea, you are much better knowing than not knowing.

Sue Marshall has had insulin dependent diabetes for 30 years and has started a company that designs kitbags and organisers for people with diabetes to use to carry all their tools with them as they go about their normal daily lives. For more information visit www.desang.net or call 01273-748575.

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Driving And hypoglycaemia

Information from the DVLA website

Meeting of the Honorary Medical Advisory Panel, 5.11.04 - Dr Sheppard, Medical Adviser at the DVLA, reported that she had undertaken a study of hypoglycaemia-related driving incidents in 1997-98 which has now been repeated for police notifications for 2002. In the year 2002, 12% of police notifications of road traffic incidents relating to apparent medical conditions received by DVLA were attributable to hypoglycaemia.

The Panel was of the opinion that it is important that hypoglycaemia related driving events continue to be collected and analysed by DVLA. The DVLA confirmed that over the past 10 years police notifications have increased from approximately 1800 a year to 3000 a year. The notification rates from various police forces differ with some being more proactive in reporting cases to the DVLA.

Emergency response vehicles, ambulance drivers: the Whitehaven News, 3.5.04, reported that new guidance from the DVLA on Group 2 driving recommends that people who have insulin-treated diabetes should not be allowed to drive emergency response vehicles. Previously the DVLA had made it clear that anyone treated with insulin should be assessed for fitness to drive on an individual

basis. The changes are based on concerns about the limitations which would affect the ability of a driver to monitor blood glucose, particularly before driving the emergency vehicle, and to be able to respond accordingly. Regardless of whether there is exemplary diabetes control, the DVLA Panel holds the view that in an emergency situation, drivers would have difficulties adhering to the blood glucose monitoring recommendations that apply to all drivers using insulin such as always testing before driving.

NOTE: Recent research shows that nearly half of ordinary drivers with diabetes do not operate minimum safe practice guidelines! We will take a look at this in the January Newsletter.

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Insulin Analogues And Informed Choice

Lantus [glargine]

This was the first long-acting insulin analogue [made from 'human' insulin] to become available in the UK two years ago and almost immediately many patients were changed to it, whether or not they were having difficulties with their diabetic control or regimes. The very widespread use of Lantus so very quickly and the sometimes excessive pressure on patients to change to it, really has made many patients wonder, with IDDT even being asked if there is a financial incentive scheme for clinics to change people to it! Of course this should not happen but what we do know is this widespread use so quickly is quite remarkable for several reasons:

- It is a new insulin and therefore it should be treated with caution as the research is limited and long-term safety is unknown, to say nothing of the fact that ALL analogues have the potential for carcinogenic effects.
- Most of the research only shows it to be "at least as effective as 'human' NPH [isophane/intermediateacting] insulins". It is claimed that it reduces night hypos but at the same time increases the risk

of early morning hypos and it has the disadvantage of delaying recovering from a hypo because its blood glucose lowering action just keeps ploughing on!

- It is the most expensive insulin on the market and so increases the NHS costs. A vial costs £26.00 and the 5x3ml cartridges cost £39.00 - 'human' Insulatard costs £10.50 a vial and £22.27 for 5X3ml cartridges while pork Insulatard costs £6.58 a vial.

So it is understandable that patients, especially those who have used it and had adverse effects, are questioning this amazing increase in the use of Lantus. It is even more amazing that the supply of blood testing strips is being restricted or denied on the grounds of cost yet Lantus is being prescribed without so much of a murmur! It doesn't make sense!

As readers well know, IDDT firmly believes that patients must be given an **informed** choice of treatment but it is clear from the calls we are receiving that this is not always happening. So here are a few bits and pieces to inform you:

Lantus and pregnancy - the Summary of Product Characteristics [SPC] for Lantus/glargine says "*For insulin glargine, no clinical data are available*" which means the research has not been done and it also says "*Caution should be exercised when prescribing to pregnant women.*"

A letter in Diabetes Medicine [Sept 2003, Vol 20:No9] warns that while the patient information leaflet does not specifically contraindicate the use of Lantus during pregnancy, no systematic investigations of its use during pregnancy have been reported - the reason it is not licensed for this use. They point out that rats and rabbits treated with Lantus showed no adverse effects on reproduction and embryo-foetal development but maternal and embryo-foetal toxicity was observed in rabbits treated with medium and high doses of Lantus, as well as with NPH human insulin. They recommend that well-planned investigations are needed for a final benefit-risk assessment to be made of the use of Lantus during pregnancy - in human beings!

Lantus and breast feeding - the same documentation does not state whether or not studies have been carried out in women who are breast feeding, but merely says: "*Lactating women may require adjustments in insulin dose and diet.*"

Lantus in children and adolescents - the SPC for Lantus says that its "*safety and efficacy has been established in adolescents and children of 6 years and above*" but "*due to limited experience the efficacy and safety could not be assessed in children below 6.*"

Research carried out in Australia [Pediatr Diabetes 2004 Jun.5(2):80-6] reviewed the medical records of 71 children and adolescents changed to Lantus [glargine] with the aim of improving blood sugar control. Information was collected for 6months before and 6months after changing to Lantus [from human insulin]. The results showed that the total daily dose of long-acting insulin reduced by about 20%. The results also showed:

- no significant differences in HbA1cs and blood glucose control before and after starting treatment with Lantus. Overall blood glucose concentrations did not differ significantly throughout the study.
- those who were switched to Lantus because of night hypos had a 65% reduction in blood glucose readings less than 2.8mmol/l. There were 3 seizures in the first week after changing to Lantus.

The authors concluded that Lantus is at least as effective as other long-acting insulins but that care must be taken during the conversion to avoid hypoglycaemia. 'At least as effective' does not mean that it is better than existing insulins!

Lantus and Type 2 diabetes - recent research has shown that in most studies in patients with Type 2 diabetes, Lantus[glargine] did not significantly reduce fasting blood glucose or HbA1cs when compared to 'human' NPH [isophane]. Most trials showed a statistically significant decrease in the incidence of night hypo and symptomatic hypoglycaemia. The authors suggest that this may not be a concern

for most people with Type 2 diabetes compared to those with Type 1 and so conclude that patients who are adequately controlled with NPH [cloudy/isophane] will not gain additional benefit from Lantus. So here's a saving for the NHS!

[Issues Emerg. Health Technol. 2004 Aug; (59):1-4]

Lantus Connection

In addition to their normal website, Aventis have a website especially for people having difficulty managing their diabetes with Lantus. It can be found at www.lantusconnection.com

Levemir [detemir]

This is the new long-acting insulin analogue from Novo Nordisk launched in June this year in the UK, although it again failed to receive FDA market approval in the US. It was launched 3 months earlier in Switzerland and in this short time achieved a high 10% of the market share. It remains to be seen what will happen in the UK especially as Aventis got there first with Lantus. At the time of writing we don't have the costs. Again, we hope that patients will be given a truly **informed** choice but in case not, here is information from the SPC for Levemir.

NB. When reading this, bear in mind that the information is gathered from trials run by the manufacturers.

- Levemir can be given once or twice daily and the SPC says it is a 24hour acting insulin depending on dose. It exerts more than 50% of its maximum effect from 3-4 hours and up to 14 hours after injection.
- Fasting blood glucose levels in patients with Type 1 diabetes were improved in trials but HbA1cs were similar in people on Levemir and 'human' NPH [isophane] with no associated weight gain.
- There was a lower risk of night hypos with Levemir but overall rates of hypoglycaemia were similar with Levemir and 'human' NPH. [Difficult to understand but it must mean that the risk is less but the reality was that the numbers of actual hypos in a 24hour period was the same]. Analysis of night hypos in Type 1 diabetes

showed a significantly lower risk of minor night hypos [able to self-treat] with Levemir but in Type 2 diabetes there was no difference.

- Variability of absorption in each individual patient is less with Levemir than other long-acting insulins.

Common adverse effects with Levemir:

- 12% of patients are expected to experience adverse reactions when treated with Levemir [ie12 people in every 100 people] so let's hope that healthcare professionals believe patients this time!
- Major hypoglycaemia [requires help of a third party] affects about 6% of patients.
- Injection site reactions are commonly seen in patients [2%].

Uncommon adverse effects:

- Lipodystrophy at injection sites
- Oedema [fluid retention] usually temporary
- Allergic reactions, urticaria, rash and eruptions.
- Eyes - refraction disorders [changes in focussing] and diabetic retinopathy, both described as usually temporary.

Rare adverse effects

- Peripheral painful neuropathy - usually due to fast improved blood glucose levels.

Pregnancy and Lactation

There have been no clinical trials in pregnant women or women who are breast feeding. The SPC says '*caution should be exercised when prescribing to pregnant women*' and the same applies to women who are breast feeding. But should it be prescribed at all when there have been no trials? It is important that these groups of women know these facts to make an informed choice of insulin!

Children and adolescents

The safety and efficacy of Levemir has not been studied in children

and adolescents. Again it is important that trials take place before it is prescribed to children and adolescents.

NovoRapid

US adverts for drugs are required to contain a great deal more information than in the UK so it is interesting to look at the information in medical journals - here's a couple of interesting points:

Insulin Aspart [NovoRapid in the UK, NovoLog in the US]

- "The time course of action of insulin and insulin analogues such NovoLog may vary considerably in different individuals or within the same individual. A1c did not differ between patients treated with regular human insulin and those treated with NovoLog/ NovoRapid. To achieve improved glycemic control, some patients required more than 3 doses of meal-related insulin and/or more than one dose of basal insulin."
- "NovoLog/NovoRapid is indicated for the treatment of ADULT patients with diabetes"

Hopefully, this information will help you to make more informed choices so that you are not persuaded to change insulins against your wishes or judgement. Details of all medicines can be found at www.medicines.org.uk

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Allergic Reactions To Insulin

A bit of history

Allergic reactions to insulin have been around since insulin was discovered in 1922. It was estimated that around half of people using these impure insulins had allergic reactions - thought to be caused by the insulin molecule as well as the preservatives or the agents used to slow down the action of insulin, such as zinc. Until the 1970s only bovine insulin was available and this differs from the insulin our

bodies produce by 3 amino acids and therefore is more allergenic than pork which differs by only one amino acid.

Localised allergic reactions are those that affect a specific area, such as rashes at the injection site, and the introduction of highly purified insulins reduced these localised allergic reactions to about 2-3% of people treated with pork or 'human' insulin.

Systemic reactions are those that affect the whole body and these are classed as very rare and can occur at the start of insulin treatment or many years after. In these cases the allergy is usually due to the insulin molecule itself rather than additives such as the preservatives.

Types of allergic reactions to 'human' insulin

There appears to be 3 types of allergic reaction:

First type - is the most common and is an immediate hypersensitive reaction. The symptoms vary in severity and start at the injection site with swelling, redness and itching but they may progress to the rest of the body. This reaction can be very difficult and even life threatening.

Second type - the main reaction is described as an arthus reaction which shows as local tender subcutaneous [under the skin] nodules which develop 30minutes to 6 hours after an insulin injection. Inflammation of the lymph glands, a serum sickness reaction and arthralgia have also been reported. Arthralgia is generalised joint and muscle pains.

Third type - this is a delayed allergic reaction which usually occurs with insulin containing zinc.

Treatment

1. Trying a different type of insulin
2. Mild allergic reactions can be treated with antihistamines.
3. The treatment for allergic reactions to insulin which are moderate or severe is desensitisation. This involves repeating large numbers

of injections of tiny amounts of insulin. This is known to be effective in 94% of people who are allergic to pork insulin but there are no such figures for people using synthetic insulins.

Just a thought?..

The adverse reactions that people report with synthetic GM insulins have not been classed as allergic reactions but one does have to wonder if some of them actually are. For instance, IDDT has received many reports of the arthralgia type symptoms - joint aches and pains. These have been particularly noticeable in people using insulin analogues such as Humalog, NovoRapid and Lantus. So is this the second type of allergic reaction described above?

We have also noted that these symptoms have also been reported in people who have used 'human' insulin for 10 years or more - so is this a delayed allergic reaction?.

Now as we know these arthralgia-type symptoms could be a complication of diabetes itself but if that was the case, then the symptoms would not be expected to disappear after a change to pork insulin and many people have reported that they do! To add to this, people have also described the nodules and sickness [especially noticeable with Lantus].

So makes one wonder whether the adverse reactions some people experience to synthetic insulins have several causes one of which could be an allergic reaction?

Cochrane Reviews

Dietary advice for treatment of Type 2 diabetes mellitus in adults

The purpose of this review was to assess the effect of type and frequency of different types of dietary advice to all adults with Type 2 diabetes on weight, diabetic control; morbidity, total mortality and

quality of life. The included studies were all randomised controlled trials of 6 months or longer where the main intervention [treatment] was dietary advice. There were 18 trials following 1467 patients and the diets assessed were lowfat/highcarb, high fat/low carb, low calorie [1000cals a day] and very low calorie [500 cals a day]

The reviewers concluded that all the studies were at high risk of bias and there is no high quality evidence on the effectiveness of the dietary treatment of Type 2 diabetes. However, the information that is available suggests that the adoption of exercise appears to improve HbA1cs after 6 and 12 months. They also say that there is an urgent need for well-designed studies to examine a range of treatments where the effects are followed over time.

Cochrane Database Syst Rev. 2004:[2]:CD004097

Stimulation of the P6 acupuncture point with an acupressure wristband or acupuncture techniques can prevent nausea and vomiting after surgery Nausea and vomiting are very common after surgery. Drugs can be used to treat or try to prevent this, but these do not fully relieve the problem in many people. Acupuncture or acupressure (stimulation of an acupuncture point) is another option. Cochrane reviewers found that stimulation of the P6 point on the wrist caused no major adverse effects, but could relieve both nausea and vomiting after surgery. It was usually applied with an acupressure wristband but sometimes manual stimulation, needle, electric or laser acupuncture was used. Only a few studies directly compared this to drugs. In those, stimulation of the P6 point appears to be more effective than drugs for nausea, and just as effective for preventing vomiting.

The Cochrane Library, Issue 3, 2004.

Further information - full Cochrane Reviews can be found by visiting www.update-software.com or for easier versions for

those of us who are less scientific, can be found by visiting the Cochrane consumer's website www.informedhealthonline.org

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Research News

Gene may explain why some people have Type 1 diabetes

Genes that contribute towards the cause of Type 1 diabetes have already been found but now US researchers have found a new faulty gene that may explain why some people have Type 1 diabetes. The SUMO-4 gene helps to regulate the body's immune system. Nearly 1,000 families with diabetes were examined and researchers found that family members with Type 1 diabetes were more likely to have a certain natural mutation of this gene than non-diabetic family members. Further studies have found that when the mutation encountered an environmental trigger, eg a bacterial or virus infection, it upset the usual well-balanced activity of the body's immune system. This resulted in a response from the immune system that eventually attacks the person's own tissue. SUMO-4 controls the activity of a molecule, NfkB which in turn controls the activity of proteins called cytokines which regulate the intensity and duration of the body's immune response. The faulty SUMO-4 gene enables more cytokines to be made and this increased immune response is directed at the insulin producing cells in the pancreas. So it appears that the cause of Type 1 diabetes is both genetic and environmental.

Stem cell research a step nearer

Researchers at Toronto University have found immature cells in the pancreases of adult mice that are able to develop into cells that produce insulin. If the same precursor cells are present in humans, it may be possible to prevent people with Type 1 diabetes having to inject insulin. The researchers plan more work to prove that the cells they found in mice are true stem cells ie immature cells that can renew themselves and have the potential to become different types of cells. [Nature Biotechnology, Aug 2004]

DNA blueprint of the bodies most gene-rich chromosome - scientists have worked out the detailed blueprint of chromosome 19 which accounts for only 2% of the human genome but accounts for nearly 1,500 genes. These genes include those responsible for condition such as Type 1 diabetes, muscular dystrophy and inherited high cholesterol.

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Winter's Coming - Flu?

The National Institute for Clinical Excellence [NICE] advice is that Tamiflu, an anti-flu pill, should be made available on the NHS to people 65 and over and younger people with serious health conditions, including diabetes. Tamiflu is the only treatment that can be taken orally in a capsule or syrup and is the first drug to be licensed to treat flu in children.

It is designed specifically to target the influenza virus by stopping the virus sticking on to the cells of the respiratory tract. Normally the virus then reproduces but Tamiflu also stops this happening. It works in the same way as Relenza but this has to be inhaled, making it hard for some elderly people to take.

People in at risk groups entitled to Tamiflu are those with:

- Chronic lung disease, including asthma
- Heart disease
- Long-term kidney disease
- Diabetes
- Weak immune system

Vaccine is still the most effective: the chief executive of NICE told the BBC that vaccination is still the most effective way to prevent flu-related illness but Tamiflu increases the options for at risk groups.

People with diabetes are an at risk group and entitled to free flu vaccinations on the NHS. It is worth noting that all flu vaccine manufacturers warn that their products are not suitable for people who are allergic to eggs.

..... **Been To The Dentist Lately?**

People with diabetes are at greater risk of tooth decay and gum infections than the general population, so it is important to visit the dentist regularly. But it is often impossible to find an NHS dentist and a quarter of dental patients pay privately - the costs of private treatment can be huge. An Audit Commission report [September 2002] showed that 40% of dentists will not take on new NHS patients.

Little seems to be improving but the government has agreed to implement the Office of Fair Trading recommendations. The proposals are that private dentists will have to prominently display treatment information, including prices, and give written treatment plans to patients and itemised bills for any work done. It will also make it easier for patients to complain about private dentists - presently there is no system for this. Dentists will also be required to have indemnity insurance before they can practice and this will ensure that patients are able to seek compensation if they have poor treatment.

Funding: in addition to £1.2billion already been earmarked for NHS dentistry, the government is investing a further £65.2million to improve the quality and access to NHS dental services, £35million of which is to set up new dental surgeries in health centres and to recruit extra dentists in areas where it is difficult to find an NHS dentist. The remaining £30million is to improve IT facilities.

Did you know?

- If you move to a new area and have difficulty finding a dentist that will take you as a patient, whether as an NHS or a private patient,

NHS Direct will help you to find a dentist in your area - call them on 0845 46 47. [This is not necessarily as easy as it sounds!] • If you are lucky enough to be registered with an NHS dentist, you could be removed from their list if you don't visit for a check-up or treatment at least every 15 months.

Note - NICE is looking into dental care and the preliminary proposals are that 6monthly checks for everyone are unnecessary and it could be that 2 yearly check-ups are to be recommended. [Contravenes the above where you can be struck off a dentist's list if you don't attend every 15months!] The proposals are that check-ups and treatment should be based on an individual assessment of dental need and the presence or risk of dental disease. The British Dental Association agree that treatment should be on the basis of need but say that the evidence to support these proposals is weak.

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From Our Own Correspondents

Good News!

Acupuncture for frozen shoulder worked for me
Dear Jenny,

My wife had a problem with frozen shoulder and I thought your readers might be interested to know that she took a course of acupuncture. She was very sceptical that it would have any effect but I am pleased to say that in her case, it has been very positive. Although we understand that it has not fully cured the infection in her shoulder, after 11 visits she is no longer in the pain she was and is again able to lift her arm well above shoulder level without discomfort or pain. For others suffering from frozen shoulder, acupuncture may be worth consideration.

Mr B.B.
London

Note from Jenny: A Cochrane review has found 26 trials of physiotherapy treatments for shoulder pain, and found mixed results, depending on the cause of the pain. If the problem is caused by frozen shoulder then laser can help. There is no strong evidence that ultrasound will be of benefit, and having physiotherapy on its own will not be enough to improve this condition. Exercises can help with pain from the rotator cuff (muscles that stabilise the shoulder joint), and having the shoulder mobilised by the physiotherapist adds more benefit. Cochrane Library, Issue 3 2004

Pleasant surprise!

Dear Jenny,

Following my recent diabetes review and the Cochrane Review findings about analogue insulins, I have changed to pork insulin. Although saying the chances of cancer from analogues were a billion to one, the doctor I saw said that he would be quite happy to change me to animal insulin if I wished to do so. I thought I would let you know as this was a pleasant surprise after reading all the letters in your Newsletter from people who had to scream and shout to change BACK to animal insulin. I have only ever been on analogues.

At my latest review, they said that I had to now also take 'human' Insulatard. I only took this for 5 days before changing to pork and during those 5 days I was very tired. Once on pork, I wasn't tired any more. I have been on NovoMix 30 analogue for 2 years and never really experienced any problems so this seems to prove that in my case anyway, 'human' causes more side effects than analogue insulin.

Mr P.C.
North West

I was amazed!

Hello,

I just want to say a HUGE THANK YOU FOR THE WORK THAT YOU

ARE DOING FOR DIABETICS LIKE MYSELF.

I was amazed when I went to your website to find that there are others like myself who do not cope on human insulin. I am one of the people that have been given their life back after going back to a natural animal insulin.

Here's the comparison chart:

Human insulin	Animal insulin
Lost two babies	Carried two babies that are now two healthy children 7 and 10 years old.
Couldn't control blood sugars or pick up hypos	Now pick up hypos at 3.2
Changed in character	Back to the person I used to be

I work 2-3 days as a Teacher Librarian and do supply teaching which I love. I have a full and independent life,

Again THANK YOU.

H.J
e-mail from Australia

Just carry on NAGGING!

Dear Jenny,

I have been treated with Humalog but after one day on animal insulin I noticed such an improvement in the way I felt, it was incredible! Well into my second week with it and I'm totally euphoric! All my muscle aches, tiredness, feeling sick, fluctuating blood sugar levels and generally feeling unwell have gone and I feel better than I have done in years! All this caused by the wrong insulin and to think I gave myself it everyday for years with 4 injections a day!

It has taken me a long, long time to persuade the powers that be to change my insulin, but my persistent 'nagging' has paid off. I would

say to anyone else out there that if you feel you might be better on animal insulin, don't be put off, just carry on NAGGING. It was the best bit of 'nagging' I have ever done and now I am reaping the rewards and at last I feel fit and happy. Thank you for helping me to achieve this.

Now that my brain is not befuddled [blame Humalog for this!] I have been able to write to my MP!

Mrs JJ
West Midlands

Jenny's comment: these two letters show the difference in attitude from doctor to doctor! It's not just the approach to animal and synthetic insulin but also in the respect paid to patients' wishes!

The Influence Of The Pharmaceutical Industry On health

The power and influence of the pharmaceutical industry has increased hugely over the last 20 years, along with their profits. We are not alone with our concerns about the influence of industry as the Health Select Committee is holding an enquiry on the role of the drug companies on health policy. This will involve interviews with company executives and health policy makers. It is vital that we know that the medications we take are both safe and effective and that the evidence from drug trials which influence prescribing and help to provide informed choices, is good quality and unbiased.

There are many ways in which influence can occur and here are a few examples:

- Three years ago eleven of the leading medical journals developed a code on conflicts of interest. However, since it was published an

analysis in the Journal of the American Medical Association [Vol 287,5:612-17] showed that 87% of researchers who write clinical guidelines for doctors about drug prescribing have financial links to drug companies with over half being connected to the companies who make the drugs they are reviewing. Are they totally independent?

- A study published in 2001 [Science and Engineering Vol 7, 2:205-218] found that only 16% of scientific journals had a policy on conflicts of interest and the majority of the papers they published did not disclose conflicts of interest. In addition 34% of the lead authors of the scientific papers studied were compromised by their funding sources. So the majority of scientists with conflicts of interest are not declaring them.
- The Observer [7.12.03] revealed that UK and US researchers are putting their names to papers they have not written. The papers are ghost-written or co-written by drug companies then signed by researchers - for a fee!
- Schering-Plough, one of the world's largest drug companies, is under investigation in the US for sending cheques to doctors, some unsolicited, and some said to be for 6 figure sums. The doctors giving evidence say that the money was for prescribing its drug for hepatitis C, Intron A, and for taking part in company sponsored trials that were little more than thinly disguised marketing efforts that required very little work by doctors. The doctors were paid \$1,000 to \$1,500 per patient for prescribing Intron A and in return were supposed to report patients' progress to Schering-Plough but the company did little to insist on accurate data. In conventional trials patients/participants normally receive the drugs free of charge, but in this case they or their insurers paid for them so the company made a handsome profit even after paying doctors! These investigations are also concerned with whether company-sponsored trials are simply a way to funnel money to doctors. Schering-Plough say that they have now changed their policy and the company no longer allows sales reps or marketing executives to have any say over its clinical trials, physician education or medical consulting.
- Again in the US, in May 2004 Pfizer agreed to pay \$430million

and pleaded guilty to criminal charges involving the marketing of Neurontin. AstraZeneca paid \$355million last year and TAP Pharmaceutical paid \$875million in 2001, each pleading guilty to criminal charges of fraud for inducing physicians to bill the government for some drugs that the company gave doctors free.

- This year the State of New York is preparing to sue GlaxoSmith Kline [GSK] alleging that the company fraudulently suppressed research suggesting that its new anti-depressant drug was ineffective and unsafe for children. It was prescribed for children with some very damaging results. In response GSK have promised to publish the results of all clinical trials on all the company's approved drugs. It is hard to believe that GSK is the only company that could be accused of publication bias!

Closer to home we only have to look at the Cochrane Review [May 2004] comparing short-acting insulin analogues and regular 'human' insulin. 81% of the studies were sponsored by the drug companies making insulin and the remaining 19% of the studies had no sponsor declared. So in fact, all the studies could have been drug company sponsored! To add fuel to the fire, the reviewers state that 83% of this research is methodologically poor. So not only are we, doctors and patients, making treatment decisions on what may be biased research but also on poor quality research, most of which is sponsored by drug companies!

Note: Novo Nordisk has become involved in a federal investigation in Brazil of pharmaceutical product purchases by the Brazilian Ministry of Health. According to Brazilian media, the police have visited a number of pharmaceutical companies and Novo Nordisk is one of the companies being suspected of involvement in alleged illegal activities in relation to public tenders. Novo Nordisk deny any involvement.

Adverse Drug Reactions And Medical Errors

It is important to remember that millions of people take drugs without any adverse reactions and millions of people are treated safely in the NHS, but there is always room for improvement as research shows:

- **One in 10 patients admitted to hospital is harmed as a result of their care**

The National Patient Safety Agency estimates that one in 10 patients admitted to NHS hospitals is harmed to some degree as a result of the care they receive while there. A survey by research group, Dr Foster, which analysed 4 years of statistics of 50,215,687 episodes of care, found that some trusts reported no mistakes while others report as many as 15%. On average 2.2% of all episodes, about 27,500 a year, included some kind of adverse event, however, over a million people a day are treated safely in the NHS. They also found that hospital acquired infections such as MRSA were also poorly recorded yet the 'superbug' MRSA may contribute towards 72,000 deaths a year.

- **Adverse drug reactions may cause over 10,000 deaths a year**
- Researchers at Liverpool University [BMJ 2.7.04] have shown that more than 10,000 people in the UK may be dying each year as a result of adverse drug reactions [ADRs]. They assessed 18,820 people admitted to two Merseyside hospitals over a 6month period and found that one in 16 [1,225 people] had been admitted because of an ADR to drugs - 28 died. Many were taking aspirin or other painkillers, non-steroidal anti-inflammatory drugs while many others were taking blood thinning drugs like warfarin or diuretics to reduce the water in the body.

The researchers pointed out that these figures could be even higher because they do not take into account those who suffer ADRs from drugs administered while they are in hospital. They estimate that nationally the number of deaths from ADRs could be greater than 10,000.

According to the researchers 70% of these ADRs could have been avoided through simple improvements in prescribing, the use of

computerised prescribing and the involvement of pharmacists in assessing prescribing behaviour. In practical terms adverse drug reactions cost the NHS around £466million a year.

Liberal Democrat health spokesman Paul Burstow told the BBC: "The Government should consider a mandatory report scheme so that NHS staff report all suspected reactions, not just on a voluntary basis." I think many patients and especially those in IDDT would totally agree with him!

- **GPs' computers miss drug errors**

Computers have reduced errors by ensuring that prescriptions are legible but researchers tested GP computer systems in Nottingham, Kent and Edinburgh. They tested four systems that are used in about 75% of GP surgeries. They drew up 18 cases where the computers should have brought up a warning and found that the systems are failing to issue safety warnings of drugs, so putting patients at risk. For example, none warned that aspirin should not be given to an 8year old even though it should not be used in children under 12. The systems do contain alerts over possible drug interactions but do not warn of potential contraindications - the reasons why a person should not be given a drug. The makers of the four systems have agreed to work with the National Patient Safety Agency to improve the systems.

- Anonymous reporting system for doctors mistakes

The National Patient Safety Agency is introducing an anonymous reporting system for doctors to report mistakes made by their colleagues so that lessons can be learnt. A survey by Doctors.net.uk of 2,500 doctors found that 80% of them have seen colleagues make mistakes or had concerns about the care being provided, although only 15% of these could have led to death or disability. The errors range from small prescribing and diagnosing to rare more serious ones. It seems that 81% did not trust their NHS Trust or the Dept of Health to run a blame-free system for reporting mistakes but the majority would support an independent internet site to log such errors. The BMA says that doctors welcome a reporting system that

allows clinical mistakes to be openly discussed and analysed so that patients benefit.

- **Medical students express concerns over lack of science-based training**

At their conference earlier this year, medical students expressed the fear that they are not being taught enough about anatomy and how drugs work because most of their degree courses have moved away from basic science to focus more on communication skills. Daniel Gibbons, deputy chairman of their committee, said that patients were not in danger. Professor Michael Rees, Chairman of the BMA's medical academic staff committee said "It is clear that academic medicine and science might have suffered. There's no hard evidence, but it could be that doctors trained in this way might be more susceptible to drug company advertising?. and won't be able to understand drug mechanisms and so would not have the scientific knowledge to evaluate them." Doesn't this in itself put patients in danger?????

Just a thought - it seems a contradiction in terms to be concerned about adverse drug reactions and medical mistakes and putting systems in place to reduce these when the route of the problem may lie with today's training of doctors.

Nice Publishes Guidelines For Type 1 Diabetes

In July the National Institute for Clinical Excellence [NICE] launched two new guidelines for the NHS to be published in September. The first is on the diagnosis and management of Type 1 diabetes in adults and the second of Type 1 diabetes in children. The press releases for both adults and children state that the new guidelines will ensure that the NHS is working to the same standards across England and Wales.

It is good to note that the NICE press release for adults states:

"The new guideline makes it clear that care should be patient-centred and the views and preferences of individuals with Type 1 diabetes should be integrated into their healthcare. Diabetes services should be organised, and staff trained, to allow and encourage this."

Seems that this further supports patients right to choice and their preferred options and therefore gives greater power to those who wish to use or change to animal insulins. We will take a closer look at the Guidelines in the next Newsletter but in the meantime the Guidelines are available on the NICE website at www.nice.org.uk

High Blood Glucose Levels In The Moring

High blood glucose levels first thing in the morning are not uncommon in people with diabetes taking insulin. Two of the most common causes are the Somogyi Effect [also called rebound hyperglycaemia] and the Dawn Phenomenon. Obviously during the night there is reduced activity and while this is not necessarily a cause of morning highs, it does nothing to help reduce them.

Somogyi Effect

This effect is named after the doctor who first wrote about it. It is caused by a hypo in the middle of the night. The hypo causes the body's defence mechanisms to release counterregulatory hormones, such as adrenalin and glucagon, which in turn raises blood glucose levels. This can then result in high morning blood glucose levels.

Dawn Phenomenon

This is an early rise in blood glucose levels when there has not been a hypo in the night. The cause is a combination of body changes that occur during the sleep cycle. In the early hours of the morning the body increases the production of counterregulatory hormones to

prepare for the day. These hormones work against the action of the insulin in the body making it less efficient. This in turn means that the body finds it difficult to move the glucose from the bloodstream to the body's cells to be utilised and results in morning high blood glucose levels.

Talk to your doctor?..

If you have regular morning highs it is important to talk to your doctor about them so that the cause can be established and advice given on how to avoid them.

New Developments To Inflict Minimum Pain!

Microneedles developed - new microneedles are extremely fine needles, 100 microns wide and very sharp, designed to cause a minimum amount of pain. They are made of plastic, silicon, metal or a mixture of all of them. Although a single microneedle has been developed for drug delivery, research suggests that they are better used in small clusters because the flow of a drug through one needle is very limited. They are just long enough to go through the outer skin where they can work with the interstitial fluid in the skin above the blood vessels and nerves. Research has shown that measuring glucose in this fluid correlates reasonably well with blood glucose measurements and it is thought that in the future, microneedles devices could combine glucose monitoring and insulin delivery.

Microscission - a new technique that uses gas to bombard a small area of the skin with crystals made of inert aluminium oxide. This removes the rough outer surface of the skin and creates tiny holes through which drugs can be administered. The loose skin and particles are blown away by the stream of gas. Trials have shown that holes up to a fifth of a millimetre can be created without even touching the skin, enough for a drug to reach the blood stream. Volunteers said the procedure was completely painless. The technique was tested using

a local anaesthetic. After using the microscission to create 4 holes in a small area, a pad soaked in anaesthetic was applied and within two minutes the patch of skin was anaesthetised. Researchers say that the technique could be used to produce spots of blood for testing blood glucose levels.

Working on painless alternatives to finger-pricking

Scientists are developing two new ways of measuring blood glucose levels without painful finger pricks. The first is a sophisticated analytical technique capable of detecting very low levels of volatile organic compounds exhaled in breath, specifically the analysis of exhaled ethanol and acetone. Early studies in 10 people have proved that this is an accurate measure of glycaemia.

The second method comprises of a chest-belt transmitter and a hand held receiver. The transmitter continuously monitors skin surface and the receiver analyses the results in terms of blood glucose levels. So far this has been tested on 6 people with Type 1 diabetes and 6 healthy volunteers and the results are described as 'promising'.

NHS News

• NHS Fraud Clampdown

A clampdown on NHS fraud by patients and staff has saved nearly £500million over 5 years. The scams committed were patients falsely claiming free medicines and NHS staff fraudulently submitting bogus payment forms for their work. Overall losses from fraud by patients has been cut by 49% and in some areas, fraudulent claims by NHS professionals have fallen by 46%. This is part of a 10year plan to reduce fraud in the NHS.

• Dept of Health gives the go-ahead for internet pharmacies

Following the last year's OFT report the government proposes to allow internet pharmacies in England as part of the decision to ease

the rules on where pharmacies can be situated. Pharmacies opening in large shopping centres or for more than 100 hours a week will find it easier to get a licence and more licences will be available to pharmacies opening in one-stop primary care centres.

Some pharmacies already allow customers to order or buy online but under current rules they must also have a walk in pharmacy. The new proposals will allow licences to be available for internet-only and mail order pharmacies but with strict rules to ensure that they provide a professional service and are strictly monitored to ensure that drugs do not fall into the wrong hands. All this will require new legislation and may not happen until after the next general election.

• Level of satisfaction with pharmacy services

A recent study assessed the level of satisfaction of people with Type 2 diabetes with community pharmacy services. 96% of people said they use the same pharmacy for almost all their prescriptions, their pharmacy is accessible and they were generally satisfied with the services. However, when asked about the role of community pharmacists in explaining the risks of side effects from new medicines, the level of satisfaction fell to 72%. It is expected that the new community pharmacist contract will give more opportunities for pharmacists to help people with chronic conditions but this study suggests that their services will have to improve to provide greater patient satisfaction. [Pharmaceutical Journal 2003;270:446-449]

Snippets

- Another use for pen injection devices! 7,000 pen injection devices similar to those used for insulin but containing nerve gas antidote injections have been distributed to police forces in case there is a chemical or biological attack.
- A consultant paediatrician at Bishop Auckland hospital, Dr Bill Lamb, frustrated by the lack of funding for insulin pumps for

children has started raising funds by running. In the past year he has run 1,700 miles and raised more than £45,000. He wrote to the Dept of Health saying "There is something ironic about children living in the constituency of the Prime Minister in the fourth richest country in the world dependent on a middle aged paediatrician running for charity to provide them with an essential item of medical equipment."

- A nurse who ignored doctor's instructions advising one diabetic patient not to go ahead with insulin injections but to make lifestyle changes and changed the diet sheet of another patient without consulting the dietician, has been struck off the register for 'the protection of the public'.
- A pill to prevent grey hair? Scientists have identified a pair of genes that may play a key role in turning hair grey. Hair turns grey when the cells that give it its natural colour die. They believe that by targeting these genes they may be able to make them live longer.
- In July 2004 the Medicines and Healthcare products Regulatory Agency [MHRA] issued updated guidance to hospitals on the use of mobile phones reinforcing existing MHRA guidance that a total ban on mobile phones in hospitals is unnecessary. Part of their recommendation is that hospitals should consider designating areas where staff and visitors can use mobile phones safely.

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the meantime, UK citizens can continue to use the E111 forms when they travel to any of the EU member states and will not be refused emergency treatment.

Ask The Doctor

Questions raised by our members and the answer from Dr Laurence Gerlis may be of interest to you too.

Question: *"I have an under-active thyroid and have to take thyroxine. Is there a time of day that it is best to take it so that my blood glucose levels are not affected?"*

Answer: Thyroxine is heavily bound to plasma proteins so it does not peak in the blood but is slowly released from the protein pool so it does not matter at all what time of day it is taken.

Question: *I have Type 1 diabetes and have been asked by my GP to have a full cholesterol test and to fast for 24 hours. Is this necessary and how do I fast for 24 hours?*

Answer: Overnight fasting with nothing to eat after midnight and then doing the test at 8.00 or 9.00am is sufficient and hardly affects the results. This way, the injection and breakfast can be given after the test without any problems.

Travel news

Europeans to get new medical card

From June 1st 2004 people across the EU will be able to apply for a new medical card that will replace the E111 form that has entitled temporary visitors to other member states free emergency medical treatment if needed. Some countries are introducing it immediately but others including the UK, gradually over 18months. The government is committed to introducing the new health card by the end of 2005. To cut bureaucracy, eventually this card will replace all health forms - those for holiday visitors, students and job seekers. In

Good Quote!

The Juvenile Diabetes Research Foundation [JDRF] in a congratulatory article to the 20th Anniversary of Practical Diabetes [March 2004], made the following statement:

"20 years ago traditional human insulin worked well when injected directly into the bloodstream via the pancreas, but were absorbed slowly and unpredictably when injected into human tissue".

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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PO Box 294
Northampton
NN1 4XS

Name: _____

Address: _____

Postcode: _____

Tel No: _____

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From Your Editor – Jenny Hirst

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