



Insulin Dependent Diabetes Trust

January 2003 Newsletter



2003 - Happy New Year!

And this year we really do have something to celebrate!

'After careful re-consideration and acknowledging that approximately 20,000 patients are using our animal insulin, it has been decided to continue to supply Novo Nordisk animal insulin products to the NHS. We will of course from time to time review this strategy, but I thought you would be pleased to know that there will be no imminent change in this strategy.'

We received this statement from Novo Nordisk UK last October. After so many years of apparently failing to convince Novo Nordisk, the Dept of Health, doctors, nurses and diabetes associations of the need for continued supplies of animal insulins, suddenly here was the news

that we have all wanted to hear! Despite our long hard battle and the innumerable letters to innumerable people, I confess that I didn't really expect a company as large as Novo Nordisk to actually change their minds. But they have and their pork insulins WILL continue to be available. To Novo Nordisk, we say a big thank you for showing care and compassion towards the people that need animal insulin. We also need to say a big thank you to CP Pharmaceuticals - throughout these long uncertain times, they have given us reassurances that they will continue to supply pork and beef insulins. They also expanded their range to include cartridges so that people using animal insulin can also have the choice of using injection pens.

I would also like to thank everyone who has written to thank the Trustees of IDDT. The overwhelming emotion in your letters was one of relief. Relief that you are not going to have to live with the fear of losing the insulin that suits you or face the prospect of being forced to

use synthetic insulin that has caused so many difficulties. But there is also relief at knowing you are not alone. 'You are the only person in my clinic taking animal insulin' is a familiar statement made to so many of us. Now no one need feel alone or different because there are 20,000 other people taking it too! In fact, there must be significantly more because this figure applies to Novo Nordisk insulin and does not include all those using CP's animal insulins.

Maybe we will never quite know what brought about the change of heart but there are several factors that must have played a part:

Biobras - the takeover of Biobras, the world's largest supplier of insulin crystals, by Novo Nordisk caused us to step up our campaign. Another round of letters went to the DoH and this time to the Dept of Trade and Industry to argue that if Novo Nordisk stopped supplying pork insulin, there would be only one supplier for the whole of the UK. This monopoly would put people that need animal insulin in a very vulnerable position.

The Cochrane Review, July 2002 - provided evidence that synthetic insulins are NOT superior to animal insulins, that the majority of the research comparing the different types was 'methodologically poor' and that little research had been carried out into the adverse effects of synthetic insulin. We should never underestimate the importance of this review - it has provided reliable, independent evidence that has given information and therefore power to patients, especially those who have difficulty persuading their diabetes clinic to prescribe a change to animal insulin.

The Daily Mail, 29.8.02 - this excellent article followed closely on the heels of the Cochrane Review. Yes, it read like a John Le Carrier novel but it told the truth. The Trustees of IDDT have refrained from putting much of this information in the public domain, but we were about to lose the insulin that we all need so desperately and we were about to lose the choice of natural or GM synthetic insulins. We make no apologies for this action. In fact, we can only express gratitude to Jo-Ann Goodwin and all those involved at the Daily Mail. The article

helped huge numbers of people in many different ways. [See page 2]

Determination - this must surely have played a part and for that we thank our members for their continuing help and support. The one thing that IDDT and its members have not done, is give up. We have been dismissed, not believed, even accused of being 'mad or 'neurotic', sometimes treated badly and sometimes with disrespect. We haven't deserved any of this, when all we have done is report adverse reactions to synthetic insulin. All we have done is to ask that our experiences are believed and respected as valid. Without this the stated aim of good diabetes care being an equal partnership between healthcare professionals and patients will not be achieved.

Year in and year out we have fought not only for what we want but what we know we need, that everyone requiring insulin treatment should have the choice to use GM synthetic or natural animal insulin. The battle for respect for us as patients, may be longer and may be harder but it is one that we need to approach with equal determination.



'The GM Injection', Daily Mail 29.8.02

Most of our readers will have read the article in the Daily Mail entitled 'GM Injection' but perhaps you don't realise what a huge impact the article had. Our phone started ringing at 8.30 on the morning of publication and one call just followed upon another until eleven o'clock at night and this went on solidly for days but for weeks afterwards we were receiving calls from people that had heard about the article. We took several hundred calls and many e-mails.

Who contacted us?

- The majority of people both with Type 1 and with insulin treated Type 2 diabetes were those that recognised the symptoms of the adverse reactions to synthetic insulin, saying 'it's just me' or family members

saying 'it could be describing my husband, my wife, my son or my daughter'. Most people had not previously used animal insulin.

- Parents - some with children that were displaying some of the symptoms described in the article and some who were concerned that their children were taking a GM insulin and they were concerned about any possible long term effects.
- People who had already had problems with synthetic insulin and were much better after changing to animal insulin - they wanted to support IDDT in any way they could.
- Sadly we received calls from the parents of healthy young people who had died suddenly in their beds, the 'dead in bed syndrome', notably all were using synthetic insulin. Naturally they were upset by the article but not angered by it, mostly they felt a sense of relief because at last they had found a probable/possible explanation for the death of their son or daughter, something they had never been given. There was also a sense of relief to know that they were not alone in their grief.

Who didn't contact us?

Previous press coverage has nearly always resulted in IDDT receiving angry letters, usually from healthcare professionals. This time there was not one! Surprising as the article was more in depth and detailed than any previous ones. Perhaps there was little to complain about because the article calmly and clearly made the point that the majority of people could use GM insulin satisfactorily and it's accuracy was indisputable.

What did people tell us?

- The effects they had suffered since being treated with synthetic insulins - joint pains, extreme tiredness, hypos without warnings, confusion and memory loss, depression, frequent yeast infections and erratic blood sugars were the most commonly described by people of all ages. In most people these problems had come on gradually and many had not connected them with the type of insulin they were using, although some people actually said that it felt like the insulin was slowly killing them because their health

was deteriorating.

- The majority had discussed these problems at their clinics but no explanation or help was offered and certainly not a change of insulin. A lot of the people had joint pains but tests for arthritis were negative and so they were just left with the pain and no explanation. Many people with frequent hypos and loss of warnings reported that they were made to feel to blame for not achieving 'good' control, when they were doing their very best.
- The vast majority of people did not realise they were actually using insulin that was made by genetic modification of yeast or e-coli and certainly did not know animal insulin existed. This caused a great deal of anger with many people saying that they shopped for food very carefully to avoid GM products and then the Daily Mail suddenly told them they were injecting a GM insulin 4 times a day!
- So many people said that in talking to IDDT, at last they had found someone that listened and understood - a sad reflection on the system.

What did IDDT do?

- We listened, we sympathised and we told people they were not alone. We sent IDDT Information Packs to everyone that contacted us.
- We told them that although the majority of people were fine on synthetic insulin some people were better suited to animal insulin. We told them that the findings of the Cochrane Review showed that there was no reason why their doctor should refuse to change them to animal insulin to see if this improved their symptoms.
- We advised them to talk to their GP first and if necessary their hospital consultant. In our experience GPs show more understanding of adverse effects and patients' rights to choice and while some may feel unable to switch insulins, many GPs offer support to give people the 'courage' to discuss changing insulins with the hospital diabetic clinic.

[This shouldn't be necessary but in far too many cases it is!]
In the weeks that followed people started to call back???

It was good to hear that some people had received a sympathetic ear with no objections raised to the changeover to animal insulin. So people rang to say how grateful they were because they had started to feel better, now had warnings of hypos and had lost significant amounts of weight - these reports continue to come in. Unfortunately, a lot of these people had received no accompanying advice about dose adjustments, more frequent testing, different peak of actions or duration of animal insulins etc.

However, there were a lot of reports of 'just give it another few months' when they had been using synthetic insulin for years!. Some were told to try Lantus, the new 24hour GM insulin - when the patients had specifically requested natural animal insulin with its long history of safety!

Many people reported that their diabetes specialist nurse either refused to change their insulin or tried to 'block' them for changing insulins. IDDT has written to Diabetes Forum at Royal College of Nursing to raise awareness of this problem for patients but the RCN has already confirmed that diabetes specialist nurses are NOT allowed to prescribe. So to change insulins you must see a doctor.

But some people came back to us because the clinic contradicted the information they had received from IDDT and the Daily Mail. So we are going to set the record straight yet again by giving the facts:

- *'Animal insulin is dirty'* - no it's not! All insulins are highly purified.
- *'Animal insulin is only used on animals these days'* - rubbish!
- *'Animal insulin is old fashioned'* - what's fashion got to do with it? Having been around for years, animal insulin has a known history.
- *'Animal insulin causes skin reactions'* - so do synthetic insulins in some people. This probably originates from years ago when the only available insulin was impure beef insulin but beef has been highly purified for years.
- *'It's not available any more'* - it has always been available from CP pharmaceuticals and only Novo Nordisk animal insulin was ever under threat. Anyway this one is now solved!

- *'You'll have to go on to syringes because it's not made in cartridges for pens'* - CP animal insulins are, only Novo Nordisk pork insulin is not available for pens.
- *'Animal insulin is more expensive than 'human''* - no it's not. In fact a vial of Novo Nordisk pork insulin is nearly £4.00 cheaper than a vial of synthetic!
- *'Human' insulin is not made by genetic modification'* - dear me, no answer to this!
- *'Human' insulin is better'* - no evidence to show this.

Apart from displaying a lack of knowledge, misinformation of this sort only serves to destroy patients' faith and trust in health professionals. Giving this sort of misinformation may just be an attempt to dissuade people from changing to animal insulin but why should they want to do this?

However, although persuasion to do otherwise may have been quite strong, it was noticeable that only a very few were actually refused animal insulin by a doctor - a very different situation from a few years ago. Again GPs came out of this very well as many were happy to change people to animal insulin. If not GPs said that they had no experience of animal insulin and so referred people to their hospital clinics. This honest approach received approval from their patients with no loss of faith or trust.

Just on a lighter note, the misinformation we like the best, 'IDDT is an extremist organisation'. If fighting to preserve the animal insulin that people need or fighting for people to have the informed choice of treatment to which they are entitled makes IDDT extremist, then so be it!

What have we learnt?

- Just how many people had never been told that 'human' insulin was made by gene technology and how angry they were. They had assumed it was real human insulin. This may sound silly to doctors and healthcare professionals but if something is called

'human' and the packet doesn't say otherwise, then why should people think it is not genuine insulin from humans. IDDT has again written to the Medicines Control Agency [MCA] about the misleading naming of 'human' insulin. We have also requested that at the very least the insulin package should state the origin ie GM - the animal insulins state their origins. The MCA has replied saying that the matter is under review - this is an improvement!

- The majority of people had no idea that natural animal insulins are available and even fewer people knew that some people have adverse effects to synthetic insulins. This can only mean that people with diabetes are not being given an informed choice of insulin treatment and nor are they being warned about possible adverse effects. These are basic NHS rights and essential requirements for doctors to fulfil their NHS contract according to information supplied to us from the General Medical Council. IDDT is planning to increase our activities to reach people with diabetes with the information they need to make informed decisions about their treatment.
- Maybe not news, but people are 'frightened' of 'asking' their doctors about changing insulin - so much for the aim of shared care and joint decision making between doctor and patient! Additionally many people felt that clinics were not interested in the difficulties they were experiencing and that they were not listened to or offered any useful advice.
- Again maybe not news, but loud and clear came the message that many people feel they do not receive enough support, both emotional and practical or enough understanding of the difficulties of living with diabetes. In many cases the Steve Redgrave role model, simply made them feel inadequate.

What surprised us the most?

The answer is simple! Just the vast numbers of people that phoned to tell us of the all too familiar problems - the adverse effects that showed in our survey in 1994 and in the unpublished 'Posner Report' commissioned by Diabetes UK [BDA] in the early 1990s. And these are only the people that read the Daily Mail and that actually picked up the phone to ring IDDT! How many more people are out there that

are having the adverse reactions and could benefit from a change to natural animal insulin?

Novo Nordisk has listened, the Dept of Health has listened, is it so difficult for doctors and healthcare professionals to listen? They are the very people that can make a difference to the lives of their patients with diabetes and to the lives of their families.



Animal Insulin Availability

setting the record straight

As there is so much confusion amongst patients and professionals about exactly what animal insulins are available, here are the details:

PORK INSULIN

Name of insulin	Manufacturer	Vials	Cartridges
Hypurin Porcine Neutral [short]	CP Pharmaceuticals	Yes	Yes
Hypurin Porcine Isophane [intermediate]	CP Pharmaceuticals	Yes	Yes
Hypurin Porcine 30/70 Mix	CP Pharmaceuticals	Yes	Yes
Pork Actrapid [short]	Novo Nordisk	Yes	No
Pork Insulatard [intermediate]	Novo Nordisk	Yes	No
Pork Mixtard 30	Novo Nordisk	Yes	No

BEEF INSULIN

Name of insulin	Manufacturer	Vials	Cartridges
Hypurin Bovine Neutral [short]	CP Pharmaceuticals	Yes	Yes
Hypurin Bovine Isophane [intermediate]	CP Pharmaceuticals	Yes	Yes

Access To The Cochrane Library Is Free!

The good news is that for people with internet access, access to the Library in England, Wales, Ireland, Norway and Australia is now free. You can gain free access by logging on to: www.update-software.com/clibng/CLBLogon.htm

The true value of the Cochrane Collaboration and its library of reviews may only have been appreciated by readers with the publication of the review that compared 'human and animal insulins! For the first time, we have been provided with high quality, independent evidence for insulin treatment and it has empowered us, the patients, to be able to make informed decisions about what insulin we want to use.

It has been said rather dismissively that the review highlights that there are no answers yet as to why the medical problems are occurring but this totally misses the point! The review actually highlighted that the 'medical problems' [ie the adverse reactions] have never been investigated! That's the point and this is what angers people! As we know, the review highlighted that most of the research was 'methodologically poor' and that synthetic insulins are not superior to animal insulins, despite years of claims to the contrary - this is the point!

Anatural Look

By Beverley Freeman

Over the past few years we have all heard about natural remedies to cure or help our minor ailments and in some instances doctors and the Dept of Health actively encourage us to use them - nothing will cure a common cold, so go to bed with hot lemon and honey. Some of the natural remedies we take with a pinch of salt but others can easily become part of our routine.

Research in the US has shown that nearly two thirds of people with diabetes are using supplements but this is based on their own beliefs or experiences and not as result of hard evidence from research. We know that some supplements and natural remedies can affect blood sugars and so it is vital to discuss any natural products you are taking with your doctor. Alternative treatments such as reflexology can lower blood sugars too and I am going to give this a try with a trainee reflexologist who is going to look at the effects of reflexology on my blood sugars - I'll keep you posted!

Searching!

There is a vast amount of information out there and it can be overwhelming so that you don't know whether to go to the nearest health food shop and buy the lot or ignore it all and walk away! Because I have diabetes, my search was easier - I looked for any natural supplements that may help to alleviate problems associated with diabetes. When I started looking at natural remedies and supplements, I must admit that I was a bit of a cynic, but the more I read the more I started to wonder. I wondered about the validity of the information I was finding but also if enough research has been done to look at whether or not people with diabetes are lacking in vital minerals.

I found the following information in my searches, but it's by no means gospel or necessarily supported by good research. But there are thoughts and ideas here that may be worth discussing with your doctor.

Vitamin C - people with Type 1 diabetes have been shown to have low levels of Vitamin C. Vitamin C lowers their level of sorbitol, a sugar that can accumulate and cause damage to the nerves of the eyes and kidneys in people with diabetes.

Vitamin B12 - is needed for normal functions of the body's nerve cells. It may reduce nerve damage caused by diabetes and has been used to treat diabetic neuropathy. It is not clear whether the success of the use of Vitamin B12 is due to correcting the deficiency or due to

the normalising of Vitamin B12 metabolism.

Chromium - lowers glucose and cholesterol levels and appears to work by increasing the sensitivity of the body's cells to insulin so that the insulin is utilised more effectively. Research in Israel has also shown that chromium is effective in lowering both blood glucose and cholesterol levels in elderly people with Type 2 diabetes.

Magnesium - it appears that magnesium levels are low in people with diabetes and may be lower still in people with diabetic retinopathy. This may suggest that diabetes-related eye damage may be more likely to occur in people with magnesium deficiency. Some scientists believe that a deficiency of magnesium interrupts insulin secretion from the pancreas and increases insulin resistance so that injected insulin is not absorbed as efficiently. Thus magnesium deficiency may mean that an increased daily intake of insulin is required and some websites go so far as to claim that 'Insulin requirements are lower in people with Type 1 diabetes who supplement with magnesium.'

Zinc - helps the functioning of the immune system. People with diabetes can be deficient in zinc so impairing their immune system and causing slow healing and increased susceptibility to infections. There are recommendations that state that if you take over 30mgs of zinc a day, you should also take 1-2 mgs of copper each day to maintain a correct mineral balance.

ALA and GLA - what are these? Alpha lipoic acid [ALA] is a powerful natural antioxidant and has been shown to improve pain in diabetic neuropathy with an intake of 600mg per day. Gamma linolenic acid [GLA] is found in black current seed oil and evening primrose oil and has been shown to be helpful in improving damage to nerve function. Supplementing GLA with evening primrose oil everyday for 6months has been found to reverse the course of nerve damage and improve painful neuropathy in people with Type 1 and Type 2 diabetes.

Carnitine - is a substance that the body needs to properly utilise fats for energy. There is research that shows that when carnitine

was given to people with diabetes with high levels of cholesterol and triglycerides, these dropped by 29-39% in just a few days. In addition, carnitine improves the breakdown of fatty acids, so may play a role in preventing ketoacidosis.

Taurine - is an amino acid found in the protein rich food. People with Type 1 diabetes have low taurine levels that can lead to thickening of the blood which increases the risk of heart disease. Supplements of taurine may restore levels to normal and correct the problem of blood viscosity.

My conclusions? There are an awful lot of possibilities here but there is a lack of good quality research to advise us, so many people are trying supplements for themselves on a suck it and see basis - not the ideal way forward either from a health or cost perspective. There are proposals to regulate supplements in the same way as drugs are regulated and this is causing a lot of controversy. It strikes me that the one thing that my searches have shown is good evidence that people with diabetes are lacking in many supplements the body needs. Maybe it is time that our dietitians provided us with information about foods that naturally are high in the supplements we need. If you have any other information or experiences with supplements, please write to me at IDDT, PO Box 294, Northampton NN1 4XS or e-mail bev@iddinternational.org



Don't Be Confused!

As many of you are aware, IDDT is based in Northampton. It is interesting that both Diabetes UK and the Diabetes Research and Wellness Foundation both use PO Boxes in Northampton although neither of them is based here. They both send out mail shots and/or begging letters some of which do not feel portray diabetes or people with it in a positive way. The usual approach is used - when begging for money an awful picture of the complications is painted conflicting

totally against their ongoing arguments against discrimination of people with diabetes because they are 'normal'. I hope that you do not associate any correspondence along these lines with IDDT.

Exemption From Prescription Charges

People with diabetes treated insulin and tablets are entitled to free prescriptions, providing they have a medical exemption certificate. These have been obtained from your local health authority but from October 2002, the Prescription Pricing Authority [PPA] has taken responsibility for issuing Medical Exemption Certificates, Pre-payments Certificates and Maternity Exemption Certificates. There are new arrangements for applications that are an improvement on the old system.

Redesign of the application forms [FP92A] - the patient completes parts 1 and 2 and the GP fills in the rest. As part of this arrangement the GP can authorise someone in the practice to sign the forms. The PPA has supplied GPs with pre-addressed envelopes and asked them to return these on a daily basis.

Redesign of the exemption certificate - this will now be a plastic credit card style to fit easily into a wallet.

Start dates and reminders - the start date of the exemption certificate will be the first day of the month in which the application is received. The certificate is valid for 5 years and 21 days before the end of this period a renewal reminder will be sent out. In the past reminders have not been issued, so this improvement will ensure that the exemption does not lapse.

Note: IDDT welcomes this new reminder system, although we have to wonder about the administrative costs involved for a condition such as diabetes which is not going to go away and therefore exemption

will continue indefinitely.

The Dream Trust

'Sponsor a Child' - in October, IDDT started our new scheme to help children with diabetes in India. The Dream Trust is a registered charity set up by Dr Pendsey and his wife to look children with diabetes. The cost of supplying insulin and all the other medical care for each child is £17.00 a month and we asked our members and their friends to give just £2.00 a month to help to sponsor a child at the Dream Trust. A tremendous thanks goes to all of you that have already arranged to sponsor a child. Within two months of our request, you have committed £2000 for the first year to help to save and prolong the lives of these children. Dr Pendsey has asked me to pass on his gratitude for your care and generosity.

Understandably some people have been concerned about how much of their donation actually goes to help the children at the Dream Trust. The answer is quite simple - all of it! IDDT collects your donations and transfers the total amount to the Dream Trust. Living in a country where it is almost unimaginable that children with diabetes die for lack of insulin and treatment, the Trustees believe that this is the least we can do to help the children at the Dream Trust.

If you can give just £2.00 a month to help a child with diabetes, then contact IDDT, PO Box 294, Northampton NN1 4XS Tel 01604 622837 e-mail bev@iddtinternational.org

Diabetes supplies for Dream Trust and developing countries - we must thank everyone for taking the time and trouble to send IDDT unwanted, in-date insulin and other products. Diabetes specialist nurses at diabetic clinics are doing a tremendous job and we are very grateful for all their help. IDDT has been able to send the following supplies to Insulin for Life and the Dream Trust:

622 insulin vials, 1115 insulin cartridges, 420 pre-filled insulin pens, 61 boxes of blood testing strips, 56 blood glucose meters and masses of syringes and lancets.

THANK YOU!

Europe Rejects Drug Advertising

October 23, 2002

As readers know, IDDT is totally opposed to the advertising of drugs and we were pleased that Euro-MPs overwhelmingly voted against the European Commissions proposal to relax the ban on drugs advertising direct to the public. In a vote of 494 to 42 the EU Parliament adopted an amendment that removed the Commissions proposal to allow the pharmaceutical industry to supply '*disease information*' to people with asthma, diabetes and AIDS.

Supporters of the proposal argued that '*disease information*' from drug companies is not advertising and that patients need more information about the drugs that they are taking. No one would disagree with this sentiment but opponents of the proposal, including IDDT, believe that this information should come from independent sources and not the drug companies with a vested interest in selling their products. They are also concerned that the words '*disease information*' disguises the underlying intent to move towards direct to consumer advertising of drugs.

The European Parliament's environmental committee claimed that the pharmaceutical industry was incapable of providing impartial information about medicines. The UK Consumers Association said that patients urgently needed high quality unbiased information, 'However, we do not believe the pharmaceutical industry can be trusted to provide this.'

Catherine Stihler, Labour's health spokesman in the EU Parliament, said 'If we open the door to direct advertising it is a slippery slope down the American road where pink pills on television advertisements offer a miracle solution to everything from baldness to chronic fatigue. Medicines are like no other product. The aim must not be to maximise sales but to ensure that the product is used appropriately. The fact that the 10 most advertised drugs in the US are the 10 biggest selling drugs is a cause for concern.'

What happens now? The proposals will now go to the EU's Council of Ministers before returning to the EU Parliament again. Let us hope that the MEPs once again give a resounding no to the proposal.

Medical Charities And Patient Groups Should Declare A Conflict Of Interest

Readers may remember that IDDT Newsletter reported that results of a study into a new arthritis drug, COX-2 inhibitor, were published 6months before the end of the study, although this was not said. At the 6month stage there were less adverse reactions than with the older widely used and much cheaper drugs but by the time the trial ended at the 12month stage, there was little or no reduction in adverse reactions with the new drug compared to the older ones. Some time later the true results that contradicted the findings at 6months came to light by which time the sales had increased from £1752m in 2000 to £2080m in 2001, yet the drug did not have significant proven benefits for patients over the older, cheaper drugs! [COX-2 inhibitors cost around 10 times more the older drugs.]

So where do charities come into this?

Arthritis Care launched a campaign for the wider prescribing of the new drug based on the positive results of the incomplete study to ensure that people with arthritis received the most effective drug

treatment. But guess who funded the campaign? Yes, Pharmacia and Pfizer, the manufacturers of the COX-2 inhibitors!

Conflict of interest!

There are many issues here that are questionable, not least that Arthritis Care have not withdrawn their campaign and apologised for misleading both patients and doctors, once the truth was discovered. But the wider issue is that the charity did not declare that their campaign was being funded by the drug companies who clearly stand to gain more from it than most patients! So they did not declare a conflict of interest. In reality, their campaign was nothing more than a means of advertising the product but with adverts, we know who funds them and that they are designed to paint the product in the best possible light. We make judgements about whether or not to use a product in the light of this.

But when information comes from a medical charity that we are supposed to trust to look after our welfare, then we expect this information to be unbiased and uninfluenced by the charity's funding sources. If that charity feels that it is right to accept money from industry, especially in a campaign such as this, then we, the patients, should be told this so that we can seek further information from more independent sources rather than disguised advertising.

It is amazing that charities do not appear to realise that the pharmaceutical industry do not donate money to them out of the goodness of their hearts but because they know that patient groups are often a strong lobby and have power to influence government and the NHS. If the charities do realise and merely want the money to help them expand, then they should first weigh up the disadvantages that arise from accepting industry funding - the main one being that their independence and the independence of the advice they offer has to be questioned. If they do accept industry funding, then they should declare it as a conflict of interest, so that their members and those receiving their information can make judgements in the light of this knowledge. Researchers involved in trials of drugs have to do this, MPs have to declare conflicts of interest, so why not medical charities?

Some charities have become aware of the potential conflict of interest and have started to declare in their accounts exactly how much they receive from industry:

The MS Society Accounts now list all donations from the pharmaceutical industry over £500 and states 'The Society is aware of public interest in the financial relationship between medical charities and the pharmaceutical industry.' Similarly Alzheimer Scotland has a strict policy to maintain the charities integrity so that their activities are not influenced by industry.

According to the Sunday Herald, June 23 2002:

Many charities, as well as Arthritis Care, do not declare in their accounts exactly how much they receive from individual pharmaceutical companies or from the industry in total:

- The National Asthma Campaign lists 8 drug companies as donating at least £10,000 per year but they received £185,000 from industry.
- The Patients Association says that between 15 and 20% of their income is from drug companies through them paying £5000 each for platinum membership.
- Diabetes UK received around £1million from 11 pharmaceutical companies manufacturing diabetes drugs but this is not mentioned in the Annual Report despite the much smaller sum of £300,000 raised by the London marathon receiving a whole page.

Accounting procedures

It is difficult to see that donations as large as these can just be filtered into the accounts without special recording or indeed, without being able to express gratitude for them, which presumably the charities must feel. Presumably they are slotted into 'general donations' but the lack of acknowledgement of sums of this magnitude and the vagueness of percentages of income as opposed to absolute numbers, leads people to be suspicious. Why not simply declare the true figures to the public? What is there to hide?

Can Diabetes Specialist Nurses Prescribe?

The increased calls to IDDT as a result of the Daily Mail article brought home to IDDT an issue that has been raised regularly over the years from people wanting to change their insulin but who felt that they were 'blocked' from doing so by their diabetes specialist nurse [DSN]. Another frequent concern was that people felt that specialist nurse the seemed to be acting like a gatekeeper and prevented people from seeing the doctor at the clinic. For many people this raised the question of whether or not a diabetes specialist nurse can prescribe, especially when the nurse would not consider a change to animal insulin. In view of the questions raised by people contacting IDDT, we have contacted the Royal College of Nursing [RCN] and they suggested that IDDT writes to their Diabetes Forum about the problems some people have been experiencing. We have done this and will let you know the outcome in the next Newsletter.

The RCN have confirmed that diabetes specialist nurses are not allowed to prescribe although nurse prescribing is under review. In the new proposals, diabetes nurses and pharmacists who have gone through a designated training programme will be able to prescribe diabetes medications as part of an agreed 'clinical management plan'. Importantly, the proposal says that any prescribing arrangement will depend on the agreement of the patient, their carer or parent.

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Driving - Two Important Topics!

Jenny Hirst

Driving And Visual Field Loss

IDDT's July 2002 Newsletter drew attention to the DVLA implementing more stringent standards for visual field assessment and driving. This has resulted in greater numbers of people losing their driving licence because of reduced visual fields after laser treatment for retinopathy. IDDT has written to the DVLA for clarification on this matter.

Jackie Banks had laser treatment for her retinopathy 25 years ago and there was no need for further treatment. She has been classed as fit to drive ever since - that is until these stringent regulations came into effect. She has almost led a one-woman campaign for the last 3years which has resulted in her retaining her licence as well as helping many other people to do the same.

The seriousness of the new regulations was brought home to us when IDDT member Stephen Chadwick applied to renew his driving licence as a matter of routine and he visited a DVLA nominated optometrist for a field test. Then like a bolt from the blue, a letter arrived from the DVLA informing him that he could no longer drive because of his visual field loss. Stephen had laser treatment some years ago but his retinopathy was non-progressive and in the opinion of his ophthalmologist, had never interfered with his visual fields to prevent him driving. So what had changed - certainly not the state of Stephen's eyes, at his last routine check with his ophthalmologist. The answer - the system!

The visual field test

Visual field are measured on instruments called perimeters and there are two types:

- A manually operated perimeter eg Goldmann using a system on moving lights.
- An automated perimeter that uses static flashing lights and automatically prints out the results. This is widely used because it requires less skill on the part of the operator.

The manually operated Goldmann type is often easier to use for the person being checked and may well give better results. Clearly your results could be different according to which perimeter is used. The results of these tests will influence the renewal of your licence.

DVLA regulations

These are very difficult to interpret, even for qualified people. There are several problems with this system that we have raised with

the DVLA:

- perimeters were never designed to be a definitive test on which to base such vital decisions.
- The DVLA has commissioned research to look at the best way of testing for visual field defects and driving which will be available in 2-3years time. We have therefore queried the appropriateness of this stringent interpretation of the EU Directive BEFORE the results of the research are known.
- The DVLA perimeter uses a static fixation point ie your eye has to be fixed on a central point while trying to recognise the flashing lights in the peripheral field. Actually no one drives like this, the eyes are moving all the time and therefore minor defects in the peripheral field are not noticed because of the eye movements.

The response from the DVLA

As simply as I can put it, the DVLA only accept the results of automated perimeters and not the Goldmann. However, where there is some doubt as to the width of the visual field, then they may request a further test on a Goldmann to 'avoid erroneously refusing or revoking the entitlement' to drive. However, they also acknowledge that the automated perimeter was recommended as the standard for consistency of quality of testing and accessibility, ie the ability of the tester and the fact that not many optometrists possess a manually operated perimeter. Is this a good enough reason for choosing one particular instrument, the Goldmann, the results of which could affect the lives of so many people, especially when the research has not been completed yet?

Application for renewal of driving licence

- In the past, a report from your own ophthalmologist was sufficient information for the DVLA but now many people are being required to attend a DVLA nominated optometrist [optician] for a field test, apparently to speed up the process. The optometrist's report goes to the DVLA and they make the decision.
- As an optometrist myself, I have already reported to the DVLA

that in some cases, the visual field test is not carried out by the optometrist but by an 'operative' in the shop. When the future of your licence is at stake, my advice to readers is that you ensure that the test is carried out by the nominated optometrist, who actually receives the fee for this anyway, NOT by an unqualified person.

- It is important to note that if you have recently seen your ophthalmologist for your routine visit, then you can request that his/her report is sent to the DVLA and so avoid using the optometrist system. In my view, this is preferable because not only is your history known but hospitals will have both types of perimeters. My advice would be to try to organise your routine eye check within weeks of your licence being up for renewal. This requires a bit of forward planning but it may be worth it.

So what happened to Stephen?

On receipt of the letter from the DVLA, he immediately went to see his ophthalmologist who was very supportive and confirmed that his visual fields had not deteriorated over the years since his laser treatment. He carried out field tests with BOTH types of perimeters and Stephen appealed against the decision to revoke his licence. Several months later he received his new driving licence. But in the meantime, he had to have taxis to work everyday because he starts early in the morning and he had several months of unnecessary stress and worry to say nothing of the inconvenience and costs. Other people have not been so fortunate. Clearly if there is significant visual field loss, then it is unsafe to drive but if the loss is borderline by the DVLA standards, then it is important to be aware that you do not simply give up.

Note: It appears that other EU countries have not adopted the same stringent interpretation of the EU Directive as the UK [what's new?]. In most EU countries, it is the ophthalmic consultant that tells people whether or not they should be driving following laser treatment.

Driving And Hypoglycaemia

IDDT's October 2002 Newsletter included a letter from Jo Taylor whose husband was killed in a motor accident by a driver with diabetes who went hypo at the wheel. He was acquitted of dangerous driving because he had a hypo at the time. Jo has written to thank IDDT for publishing the letter and stresses that she wants to prevent other people from suffering as she and her family have done. She does not want to tar everyone with the same brush but wants to raise awareness of the need for blood glucose testing before driving.

But it really is not as simple as that, as we all know. Blood testing itself does not stop you going hypo, it tells you what your blood sugars are at that moment in time so that you can eat if necessary. Many of us equally know that they can drop quite quickly, especially under a stressful situation- the M6 on a Friday afternoon! So it is essential to be vigilant all the time and to test before driving and at frequent intervals on a long journey. But the real problem when driving is loss of hypo warnings, reduced warnings or sometimes you have warnings and sometimes you don't. Loss of hypo warnings or reduced warnings is dangerous and if this is the case, then driving should cease.

Statistics not dubious!

Details of this case were published in the magazine of Diabetes UK, Balance, Sept/Oct 2002. However, the article failed to point out that the driver's doctor gave evidence that he did not tell his patients to blood test before driving and that education of doctors as well as patients is clearly essential. The article also said 'There were also some rather dubious statistics given [in the newspapers] for the number of hypos people with diabetes have, which tended to exaggerate the dangers associated with driving when you have diabetes.'

This last comment brought in a sharp response in the next Balance from Secretary and Chairman of the government's Medical Advisory Panel on Driving and Diabetes. The statistics are not dubious at all:

- The DVLA receive on average 12-15 police notifications per

month relating to significant driving incidents associated with hypoglycaemia at the wheel from a driving population of about 100,000 drivers with insulin treated diabetes. [This does not include those not reported to the police!]

- In the past 12 months, the DVLA has been made aware of at least 5 fatalities in hypoglycaemia-related traffic accidents.

They add that hypoglycaemia is not a major contributor to the overall number of road traffic accidents, it is a potentially preventable cause of serious road accidents and/or fatalities and if hypo awareness is lost or diminished, then patients should be advised to cease driving.

Education

As if proof of the need to educate doctors and patients about the dangers of hypos and loss of warnings, the Birmingham Post [29.8.02] reported that a lorry driver was jailed for 3 years after a traffic accident that caused the death of a young couple and their baby. Despite the fact the driver had a history of 'blacking out' his GP had signed his DVLA form to say that he was fit to drive. The GP was reported to the General Medical Council for serious professional misconduct.

Driving and diabetes - do we have to be liars?

As a result of Jo Taylor's case, IDDT received a letter from one of our members that highlights the difficulties and conflicts for people with diabetes who drive and have hypo problems - almost a no win situation. Here it is:

Dear IDDT,

People with insulin dependent diabetes who want to keep their driving licences may feel that any disclosure to their GP or consultant about hypos could affect the renewal of their licence. In my own case, in the past there have been things that I would very much have liked to discuss with my doctors but the practicality of disclosure may have jeopardised my driving licence and so my livelihood. Hypos? What me? Never!

I am sure that most people with diabetes take sensible and appropriate precautions when driving. In reality, it could be that the risks are less than those of a non-diabetic driver's tendency to doze at the wheel on a motorway who selfishly and dangerously continuing to drive rather than take a break.

But being placed in this situation where discussions of hypos may lead to the doctor having to inform the DVLA of hypos, means that we are probably not receiving help and advice from them that we need. This in turn means that we are restricting the help we need in controlling the problems. I can see the sense in both the DVLA questionnaire about hypos and the need for disclosure but we do seem to be in a vicious circle. If we have hypos and tell the truth, then we risk losing our driving licences but if we don't seek the advice of our doctors on how to try to prevent these, then nothing will change.

This highlights the very real conflicts that arise - the doctor is the person from whom we need help to try to resolve the problems with hypos but he/she is also the person that says 'yes' or 'no' to our driving licence renewal. Unless we resolve this conflict so that patients feel able to discuss with their doctors ways of trying to avoid hypos and/or regain their hypo warnings, then the risks of traffic accidents will continue.

'Good control is not just the avoidance of hyperglycaemia but also the avoidance of hypoglycaemia.'

This statement was made by Professor Stephanie Amiel at IDDT's annual meeting some years ago and it is one that perhaps we all need to remember, patients, doctors and healthcare professionals.

The achievement of 'excellent' HbA1cs may be at the expense of increased frequency of hypos and this in itself increases the risk of loss of warnings, as Prof Amiel's own research has shown. We have to remember that the HBA1c test does not measure low blood sugars, only the high's so a good result could mean that there are frequent undetected mild hypos

Diabetes poses many conflicts and driving is certainly one of them:

- the conflict between 'good' control that reduces the risk of long-term complications and perhaps relaxing control a little to avoid hypos.
- the conflict of quality of life now against the unknown quality of life in the future if blood sugar levels are relaxed.

The effect of loss of driving licence should not be underestimated in terms of quality of life - it can affect self-esteem, jobs, income and pleasure therefore the quality of life of the whole family.

Apologies For Error - A Big One!

To members of IDDT - the Annual Report for 2001 contains a serious error 'animal' has been used instead of 'human' I apologise for this. Page 2, column 2, paragraph 4 of course, should read:

'The Trust has always believed that maintaining a choice of insulin to suit all needs will be achieved through the recognition of the adverse effects of **HUMAN** insulin by medical teams and patient-based organisations.'

Latest On Lantus

IDDT's October 2002 Newsletter announced the arrival of Lantus [glargine] in the UK but so also did large numbers of the newspapers up and down the country. Considering that drug companies are not allowed to advertise to the general public, the manufacturers of Lantus did pretty well from using press releases! In many ways press releases are worse than advertising because they are not subject to

any regulations about content such as the inclusion of warnings or of adverse effects. So according to the newspapers, Lantus the new 24hour acting insulin, is the best thing since sliced bread! Maybe, time will tell when it has been used for long periods on large numbers of people???

The press did not warn that Lantus is the first and only long-acting insulin that is clear and as we reported in the last Newsletter some patients in the US, where it has been on sale longer, have confused it with their clear short-acting insulin. In the US some doctors have advised that to avoid confusion Lantus should be used with a syringe and the short-acting insulin with a pen and they have added that this problem could worsen if Lantus becomes available for pens.

So because of the media hype, we have taken a look at the advert for Lantus to doctors and health professionals in Practical Diabetes, a UK medical journal.

Here are some facts from the manufacturers adverts:

- In the UK Lantus is available in vials, cartridges and pre-filled pens and the ad doesn't mention whether the insulin is clear or cloudy or the risk of confusion.
- Due to more sustained basal insulin supply with Lantus, less night time hypos but more early morning hypos can be expected. Neither the manufacturers own headlines, the newspapers or people contacting IDDT after visiting their clinics, have been told that it would reduce night hypos but instead 'more early morning hypos can be expected'.
- In circumstances that increase susceptibility to hypo- or hyperglycaemia it should not be mixed with other insulins or diluted. [What does this mean? Isn't everyone with diabetes susceptible to hypo and hyperglycaemia?]
- The safety and efficacy of Lantus has NOT been assessed in children, people with impaired liver function or people with moderate/severe renal impairment ie trials haven't been done in these groups. Equally there is no information about its use in

- pregnant women or during breastfeeding.
- NHS cost - a 10ml vial is £22.29, 5 cartridges of 3ml £37.89 and 5 prefilled 3ml cartridges £39.00. Expensive!
- Just to clarify the question most frequently asked of IDDT - Lantus is a synthetic insulin made by GM technology.

This press coverage certainly resulted in a lot of enquiries coming to IDDT, many from people that have asked their diabetes team if they can change to animal insulin following the Daily Mail article [29.8.02] but in many cases Lantus has been suggested. Amazing that there is reluctance on the part of the professionals to change people to animal insulins with a 60 years history of safety and effectiveness. And yet there is no hesitation in directing patients to a new synthetic insulin without a history and on which we await the results of post marketing research!

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Blood Glucose Tests Compared

The Soft Sense meter by Medisense is advertised as enabling blood glucose tests to be done in the forearm and other areas, as well as the fingertips. Naturally this is attractive to people because these areas are virtually pain free and they give the fingertips a rest. However, as we discussed in the July 2002 Newsletter early research showed that there were differences in the results according to the site of the test. Two further studies have now been published.

The first [ref 1] looked at whether rapid changes in blood glucose levels result in significant differences in the results when the blood is taken from the forearm and the fingertips. The results showed:

- In the fasting state the blood glucose results were the same for the fingertips and the forearm.
- When there is a rapid decrease in blood glucose after an insulin injection, the blood glucose levels at the fingertips were consistently

lower [about 5.0mmols/l] and the tests in the forearm were delayed by 35 minutes relative to the fingertips.

- When there is a rapid increase in the blood glucose levels after ingestion of glucose, the results at the fingertips were consistently higher [about 4.7mmols/l] than those at the forearm and again there was a delay relative to the fingertips.
- Rubbing the forearm skin decreased the differences but these differences varied in the same person at different times and in different people.

The second study [ref 2] looked at the blood glucose levels before and after meals when tested at the fingertips, the forearm and the thigh. The results showed:

- Tests at the fingertips are accurate at all times.
- When the blood glucose levels rise rapidly after a meal, again the fingertips produce higher results with lower results at the forearm and thigh.
- The alternative sites may be an option before meals when there are no rapid changes in blood glucose levels.

The studies concluded that there are clinically relevant differences between blood glucose testing at the fingertips compared to the forearms and other sites. These are particularly significant when the blood sugars are low. The practical implication of this is that if you are hypo, say with blood glucose of 3.5mmols/l at the fingertips, then that test if carried out in the forearm would give a result of about 8.5mmols/l.

Ref 1 Diab Care, June 2002, Vol 25. No 6, 956-960

Ref 2 Diab Care, June 2002, Vol 25. No 6, 961- 964

Needle - Free Injection Device Available On The NHS

Needle-free injection devices from The Medical House Group have been approved for use by people with diabetes on an NHS prescription. The device will be sold to the NHS at a similar price as has been charged privately - around £120 for the device and £20 a quarter for the nozzles.

From Our Own Correspondents

The report that was never published - patients were listened to!

Dear Jenny,

I welcomed the clear summary in the October newsletter of the recent Cochrane Review which found no evidence of superiority of 'human' insulin over animal insulin. The article suggests the review highlights 'the research that has NEVER been carried out', and further that 'this absent research' looking at the impact on health, wellbeing and on lives, is essential. However, these statements ignore the research which was carried out in this area, and they play into the hands of those who dismissed this work because the evidence was inconvenient and was not in the form of a trial. Such research was indeed absent from Cochrane review because the terms of reference stipulated that only published randomised controlled trials (RCTs) should be included. But RCTs are not the only valid way of collecting evidence and they have their limitations. One limitation is that they tend to focus on easily measurable and discrete outcomes. Many patient-oriented outcomes are not like this - not simple biomedical parameters.

'If patients had been listened to?' the article continues - well, they were listened to. The research I was commissioned to carry out for the British Diabetic Association (BDA as it was then) was a review

of nearly 400 letters documenting the experiences of people with diabetes who had been changed over to human insulin from animal insulin. The subsequent report (December 1992) for the BDA Loss of Warnings Task Force, systematically documented the impact of human insulin on diabetic control, health and wellbeing, and quality of life, using the kind of evidence that is used everyday by doctors in the clinic ie direct reports from patients of their accumulated experiences with a particular insulin regime, often accompanied by glucometer readings and detailed reports of symptoms. This was gold standard evidence because it came from those people with direct experience of the problem.

The evidence described significant problems with loss of warnings of hypos and more aggressive hypos, deterioration in diabetic control, deterioration in general health with a range of associated symptoms, and poorer quality of life due to a number of factors, including depression and personality changes. The proportions reporting problems in

these areas were presented, as well as the proportion who had 'returned to normal' after

going back on animal insulin. In other words, this research mapped out the nature of the problem for a group who were experiencing significant difficulties with their diabetic control and general health on 'human' insulin. It did not claim to be able to estimate the size of the problem in the diabetic population 'which would have required a large-scale survey. The paper I wrote intended for publication in a medical journal to report on these findings, was titled 'Are we listening to patients?' The BDA decided that this paper should not be published after the committee that commissioned the research had disbanded.

However, this did not stop various members of the committee freely quoting from the report to UK newspapers and in one instance drawing on it (quotation and reference) for an editorial in the Medical Journal of Australia (19 July 1993) headed 'Human insulin: lessons from the UK?' Unfortunately, these lessons were not heeded in Australia.

The editorial suggested that by then there was agreement that there was indeed a problem. For a decade we have known the nature of the problem, but not its size or long term consequences. IDDT was founded because it also listened to patients and treated their accounts as valid and authoritative evidence.

Dr T Natasha Posner
Senior Research Fellow
University of New South Wales, Australia

Let down!

Dear Jenny,

I read the article in the Daily Mail and it seemed that some of the problems described were very similar to mine. I have since changed to pork insulin and feel much better. After reading the article, as life member of Diabetes UK I rang them and spoke to someone on the Careline. I explained that I had read the Daily Mail article and had similar problems of large weight increase, feeling very tired, sudden hypos with no warnings and frequent thrush and asked for advice. The person I spoke to was kind and listened to my problems and said that the article was scare mongering and that there were no differences between animal and human insulin and that insulin only does one job, lowers blood glucose levels. I asked if I should see my specialist and received a very vague response. I was told that my problems could be due to the fact that I had a young baby, lifestyle changes, that the body is constantly changing and that my problems may not be due to my diabetes at all. There was no suggestion that I should think about the possibility of trying a different type of insulin.

I then contacted IDDT and realised that human insulin is not any better than animal insulin and that a lot of other people seem to have similar problems to me. My doctor raised no objections to me changing to animal insulin. I feel let down that even after the Daily Mail article, Diabetes UK didn't discuss this possibility with me and suggested that my problems were due to almost everything except the possibility that I am one of the people that cannot use human insulin.

Thank you to IDDT.
Mrs M.K
Midlands

Mum's had a personality change!

Dear Jenny

I contacted you after reading the Daily Mail article and received one of your Information Packs. I have now changed back to pork insulin and cannot believe the difference. For the first time in a year I have actually woken up without a headache, I do not feel so tired nor do I need the afternoon siesta everyday. My diabetic doctor did not hesitate in changing my insulin.

Thank you very, very much for your support. My daughter thinks her mum has had a personality change!

By e-mail

Thank you for the Cochrane Review

Dear Jenny,

Thank you for sending the summary of the Cochrane Review comparing 'human' and animal insulins. I hope that the full review has been sent to the Dept of Health as the plight of people with diabetes unable to tolerate 'human' insulin would be disastrous if animal insulins were to be phased out. In the 1980s I was changed from pork to 'human' insulin and the number of serious hypos I had in 2 years convinced my GP to change me back to pork insulin.

Last year I was in a surgical ward for a minor operation and I told the admissions nurse, the admissions doctor and the anaesthetist that I was allergic to 'human' insulins and that I had brought in my own insulin. I also wrote this down for them and it is in my Medic-Alert bracelet. After the operation I returned to the ward and at bedtime a nurse came to give me my insulin injection as my blood glucose was 26mmols/l. Without giving me a chance to get out my own insulin, she injected 6units into my arm. When I asked what type of insulin she had

injected, I was told that it was 'human' so I told her that this caused me hypos without warnings. The answer was that they would keep an eye on me through the night! At around 1.00am a patient called the nurse because I was on the floor under my bed in a massive hypo!

What more could I have done to make sure that I received my insulin that I know suits me? It seems that hospitals don't listen to patients and neither do they read their own notes!

Mrs E.M.
West Mids

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Is It Hypocrisy?

Lilly responds to the actions of pharmacy chains to switch Lilly insulin users to Novo or private label [ie ReliOn] insulin in the US - July 2002

One of our members in the States received her 'annual pack' from insulin manufacturer, Eli Lilly. This in itself is fascinating because in the UK, drug companies are not allowed to deal directly with patients and indeed should not even know who uses insulin, let alone which brand. This is exactly why IDDT opposes direct to consumer advertising!

However, this latest package contained a letter from Dr John H. Holcombe, Lilly's Medical Advisor. Here are quotes:

- All brands of insulin are **not** the same. We at Lilly believe that the pharmacy should not switch your insulin brand without your physician's approval.
- The **type** and **brand** of insulin you use have been clearly selected by your personal physician, based on your diabetes history and need for blood sugar control.
- No pharmacy can force you to switch your insulin brand. Simply insist on the same Lilly insulin you have always relied on.

IDDT would not disagree with a word of this!

Lilly made this statement soon after Novo Nordisk agreed to sell their insulin at a much lower price through the huge pharmacy chain Walmart [who now own Asda in the UK], under the name of ReliOn. Interesting that Lilly do not appear to apply this advice to their own pork insulins! Increasingly pork insulins are not available in many pharmacies and people are told to change to 'human' insulin that is in stock - a different **TYPE** of insulin.

So to people in the US that are unable to obtain pork insulin, we would suggest that you take Dr Holcomb's advice and 'Simply insist on the same Lilly insulin you have always relied on and the insulin you are using has been prescribed for your particular needs'. So if pork satisfies your particular needs you should not change to 'human'!

It brings a smile!

How does Dr Holcombe square this advice with Lilly's removal of beef insulin that satisfied many people's needs? How does he square the lines we have all had that 'there are no differences between animal and human insulin'? Well, even Dr Holcombe has now knocked this one on the head! Amazing how companies can change their advice when it suits them or when their sales are likely to be affected, in this case by Novo's cheaper ReliOn insulin in a country with no NHS and where price matters!

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Patient Self-Management And 'Empowerment'

Professor Priscilla Alderson

Social Science Unit, University of London

The government is very worried about the cost of trying to treat diabetes and its complications. The cost is now over 10% of the NHS budget and is set to rise to over 20%. There are not nearly enough staff, time or resources to help everyone with diabetes. Many doctors

also say that knowledge and skill are missing.

The government has set up a National Services Framework (NSF) for diabetes, to review current treatment and research knowledge, to identify gaps, and plan future services [ref 1]. One NSF subcommittee was for patients' self management and empowerment.

An obvious motive is to cut NHS spending by transferring knowledge and responsibility from staff to patients. Another motive is the firm belief among many people that this could lead the way to much more effective diabetes control and better health for people with diabetes.

In many ways this transfer is long overdue. The real practical experts in managing diabetes are the people with the condition. When doctors and nurses respect them as the experts, and work as partners with them, treatment is likely to be more acceptable, helpful and effective.

Yet it is not easy to persuade all health care staff to work in this way. I was travelling with someone with type 1 diabetes when, hundreds of miles from home, we suddenly realised in the evening that we had forgotten to bring the insulin. We called in at the nearest Accident and Emergency Department and asked for a little insulin. Of course they cannot hand it out like smarties. But my friend was treated like a shocked accident victim, who knew nothing about her condition, and had to have a battery of tests, and a wait of nearly 2 hours.

The nurses seemed determined to treat us as if we were too upset and emotional to think. Anything we said seemed to be taken as either angry or pathetic, and nurses either reprimanded us or pitied us. It was as if their training stopped them from being able to listen to our message 'all we need is some insulin, thank you', as one reasonable person talking to another. IDDT Newsletter suggests that this is a familiar experience for many people with diabetes. Traditionally, patients are not supposed to tell staff what they need, but to ask staff to explain their needs to them.

So before patient self-management and empowerment become

realities, some deep beliefs will have to change. This article reviews a few of these changes, linked to ideas of power as a cake, or as control, or as energy.

Power as a cake The word 'empowerment' assumes that power is like a cake, which can be divided and shared. The more you keep, the less I have. If patients are to have a bigger share of the cake, at least five things will have to happen:

1. Health care staff will have to give some of their power away. This is not mentioned in policy reports, and what would it involve?
2. Empowered patients could choose which cake they want, and how much. Yet the NSF has firm ideas on what services and information patients should have, how they should use them, and what detailed life-style they should adopt. This could be seen as patients losing rather than gaining power, in terms of choosing life-styles and use of health services. [Even the usual 'cake' image hints at the limits of power for people with diabetes, such as over their diet.] If people do not want to be 'empowered' by taking on much more responsibility for their diabetes care, should they be forced to? And would that make them feel more or less powerful? They might eventually feel they have more power over their physical health if they follow medical advice strictly, but possibly at the cost of their social freedoms and relationships.
3. The cake image implies that doctors and nurses have the kinds of power that patients want, and are able to give it to them. Yet many practitioners report feeling fairly powerless themselves, such as in lacking time, resources, up-to-date knowledge, training or support from progressive managers. Do health care staff feel that they have any cake to spare? Or that in giving it to some patients, they will deprive others?
4. Even if individual doctors and nurses try to transfer power to patients, this would only really work if big changes happened in the NHS - in staff training and team work, in new knowledge, attitudes and behaviours, in different risk-management, and in legal changes. Staff tend to be too worried that if any mistakes or accidents happen they will be blamed and sacked and sued, to

feel encouraged to share more risks (power) with patients.

5. People have different views on how much of which cakes should be shared by whom. How will clear answers be agreed?

Power as control There are three kinds of power as control [ref2].

- a. Obvious force, that may be recognised and resisted.
- b. Limited information, which restricts people's choices without their realising this, so that they are more likely to give in to the power.
- c. Persuasion, so that people believe they have only one correct option, which they want and 'own' without any force or choice.

The human/animal insulin debate illustrates the three kinds of power:

- a. People know animal insulin supplies are being restricted and they protest.
- b. People do not realize there is a choice and they accept human insulin.
- c. People are convinced that human insulin is by far the best choice.

Type c) is the most invisible and powerful form of power for the people who provide or withhold information. And it is the most dis-empowering form for patients, if power is defined as being able to make free, open, informed choices.

At its most effective, NHS diabetes management would achieve type c) with everyone complying. But that would be through control rather than empowerment. Even use of the word 'empowerment' could be seen as part of a mystifying process, when people are told they have more power but may actually have less.

Power as energy Power can also be seen as personal energy and motivation. These qualities cannot be given, although they can be damaged and taken away. No one can make your friends or your reputation for you. But they can easily damage and destroy these. It is the same with power. People can give you information but no one can give you the energy, wisdom, determination and skill that enable

you to have some power and control in your life. Yet they can stop you using these. So people can be dis-empowered but not empowered.

Many people with type 1 diabetes are children, and many of them are exceptionally knowledgeable and responsible. If power-sharing is to work well, then ways for adults to work as more equal partners with children, setting up life-long healthy habits, will also have to be promoted [ref 3,4].

New NSF plans to transfer power/control into patients' hands will work better if each person has a say in how much and what kinds of control they want to have. These will be personal flexible arrangements [ref 5]. They may require more time, resources and power-sharing from the staff.

Unfortunately, the NSF might plan a more standardized and cheaper approach. Perhaps IDDT could advise on basic standards for new approaches to power-sharing between people with diabetes and health care staff.

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Research News

Another delay with inhaled insulin!

We have read much in the lay and medical press about the development of inhaled insulin to prevent injections in people with both Type 1 and Type 2 diabetes. In May 2002 the manufactures of Exubera, the inhaled insulin made by Pfizer and Aventis, removed it from its list of drugs seeking approval during 2002. They are conducting further trials into the breathing difficulties that have already shown up, although these trials also showed that Exubera did lower blood glucose levels. A vice-president of Pfizer said in October, 'Additional rigorous testing and assessment of all pulmonary function measures are appropriate to deepen the medical understanding of diabetes and Exubera's role in the future management of diabetes.

Insulin skin patches

There is renewed interest in this method of administering insulin. It is a two stage process. First the patient applies the electronic adhesive patch powered by a small battery directly on to their skin. In less than a second, the cells on the skin surface are painlessly vaporised creating microscopic openings through which the insulin can pass. Second a small adhesive patch that contains a reservoir of insulin is applied to the skin, like an Elastoplast. Researchers are suggesting that this could be used for delivery of the longer acting basal insulin.

Insulin as fine as smoke

Researchers in Australia have produced miniscule insulin particles as fine as smoke - they are under 100 nanometres and one nanometre is one billionth of a metre! These tiny particles of insulin appear to have increased its potency and make it last longer than normal insulin, possibly due to the chemical make up of the particles. If this is successfully developed, then it could mean less injections per day. It could be delivered through skin patches or nasal or oral sprays and it could help people in developing countries to afford insulin because they would not need to use as much. Early days yet!

Can You Help?

From time to time we receive letters or calls from people that would like to know if other readers of our Newsletter have similar problems to theirs so that they can exchange information, experiences or just to know what treatment was effective for them. Sometimes people contact us simply to gather information. Can you help these people? If so we will put you in touch, just write or phone Jenny or Bev at IDDT 01604 622837 or e-mail jenny@iddtinternational.org

Is anyone out there?

- Anyone with diabetes suffering with systemic candida and have they found a successful treatment. Our reader's symptoms are vaginitis, fungal infections, aching muscles and joints, headaches and bloatedness and she is on a yeast free diet and nyastatin but after 3 months this treatment has not been completely successful. Her GP will not prescribe any expensive fungal treatments.

Mrs H

- It has been known for many years, that diabetes can be diagnosed after a shock or traumatic event and that this can happen in people that are already susceptible to diabetes. The shock or trauma is the trigger. One of our members is interested to know how many of our readers had their diabetes diagnosed after a shock or trauma. If this was the situation for you, can you just ring Jenny or Bev.

Mr G

- Do you have a child with diabetes and coeliac disease? One of these conditions is difficult enough but the two together can make life really difficult for the child and for the Mum. One of our new members would welcome a chat to another Mum in a similar situation. Does this apply to you and would you like to have a chat on the phone? Call Jenny or Bev to be put in touch.

Mrs E

Have you any ideas for a 'mission statement' for IDDT - a short statement that describes IDDT, its aims or what it means to you. If so contact IDDT on 01604 622837 or e-mail jenny@iddtinternational.org

News About Eyes

Combination treatment for diabetic retinopathy

The most common cause of blindness in the over 50 general population is age-related macular degeneration where central vision is lost through a build up of abnormal blood vessels that damage the retina. Scientists are developing a new treatment called photodynamic therapy that uses a combination of laser treatment and a special dye. The dye is injected into the arm and it flows into the eye and the laser beam triggers it to disrupt the blood flow so that the damaged vessels can be sealed. This could allow people that are blind from this cause, to see again.

New drugs to combat to combat blindness

Several new medicines under development are designed to stop the two top causes of blindness - the 'wet' form of macular degeneration that affects the elderly and diabetic retinopathy. In one trial the vision loss seems to have halted for most of the participants if they took the drug soon after their symptoms began and some experienced remarkable reversals in the progression of their condition. None of the drugs under investigation will work if the eye damage has been present for months. The researchers warn that the results of the trials will not be known for some time. The possibility of these drugs means that an efficient system for screening everyone with diabetes for early retinal changes is vital and needs to be put in place sooner rather than later.

Artificial retinas

Also in the US, scientists have fitted 6 virtually blind people with artificial silicon retinas in the form of a microchip. The artificial retina

mimics the actions of a normal retina by converting light into electrical impulses so restoring sight.

approved for use in the UK. It is 600 times sweeter than sugar but is calorie free so can be used to sweeten drinks etc without affecting blood glucose levels.

Snippets

- Research has shown that aggressive, bullying doctors are more likely to be faced with a law following a mistake than are doctors with a soft voice who appear to be more sympathetic. No matter how petty or how serious, the aggressive doctor is more likely to face legal action than his mild mannered colleague even if his mistake is far more serious. [Surgery, 2002;132]
- Chest pain is a classic sign of a heart attack but in a 5year study nearly half the patients had atypical symptoms such as shortness of breath, cardiac arrest, dizziness, weakness or fainting, abdominal pain and other symptoms. [Ann Emerg Med 2002;40]
- Scientists in Rotterdam have taken muscle cells from a heart patient's thigh and then cultured them in a lab before implanting them into the damaged heart. The idea is that the new cells will colonise the damaged area and rejuvenate the heart.
- In Baltimore trials are taking place in people paralysed as a result of a stroke in which stem cells are injected into the spinal fluid. The stem cells are attracted to the problem areas where they develop into neurons and repair the nerve damage caused by the stroke. Trials on paralysed rats enabled them to walk again.
- Women are more prone to oxidative damage than men. Research suggests that to stay healthy, women may need a higher intake of antioxidants such as Vitamin C, fruit and vegetables. [Am J Epidemiology, 2002;156]
- A survey of the 490 chief executives of charities showed that their salaries varied considerably according to the income of the charity. For charities with an income of less than £250,000, the average salary was £29,847 and this increased to £75,000 for organisations with an income of more than £25 million.
- New sweetener on the market - Splenda [sucralose] has been

The City Of Glasgow Great Scottish Run

We would like to thank Andy Walker for running for IDDT in the Great Scottish Run. Andy raised £259 and the company he works for, United Utilities, matched his achievement with a further donation of £250. Andy wanted to help IDDT because sadly his brother had diabetes and died suddenly and without explanation. We are grateful to both Andy and to United Utilities for their help and support.

If anyone can help with obtaining sponsors for our runners in the London Marathon, please contact Bev Freeman, 01604 636471

Newsletter On Tape

Remember that the IDDT Newsletters are available in large print or on tape. If you find the large print format difficult to read, then please do ask for the tape version - it is just as easy for us to provide this and may be much easier for you.

Contact: Bev Freeman, IDDT, PO Box 294, Northampton NN1 4XS

Tel 01604 622837 e-mail

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

IDDT

PO Box 294
Northampton
NN1 4XS

Name: _____

Address: _____

Postcode: _____

Tel No: _____

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From Your Editor – Jenny Hirst

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