



Insulin Dependent Diabetes Trust

July 1999 Newsletter



The Guardian, The Daily mail And More!

So what happened next?

As readers will remember the press took up the issue of 'human' versus animal and the fact that the BDA did not publish the study it commissioned into the letters it received from people suffering adverse effects when using 'human' insulin. An article by Paul Brown in the Guardian was closely followed by another one in the Daily Mail and was covered by many other papers, both at home and abroad. We had many telephone calls and letters from people with diabetes and their relatives and some from doctors. I also received letters of support for our actions from our own members. Extracts from these letters speak louder than any words I could possibly write.

- From non- members of IDDT

'I was diagnosed when 13 and have been using insulin for 44 years since then. Looking back the bovine insulin I used until my consultant changed me on to 'human' insulin was the best of all. I had very long warnings of hypos and was able to enjoy a successful 20 years dinghy racing.

'Human' insulin was terrible - as your other members have told you, with no warnings of hypos at all. My consultant told me I would get used to it and it was all due to lower blood sugar levels. After 18 months I made him speechless for a moment when I told him I was not going to continue with it. He agreed to put me on pork insulin because the beef insulin I was on before was no longer available. At least I get some warning now, but nothing like as good as previously. I would not dare go dinghy racing, even now.

All of us who rely on animal insulin depend on you and your co-trustees

to continue to keep our needs at the forefront of the manufacturers' agenda. Keep up the good work, our lives depend on it.'

Mr M.A., South East

'Thank you for all the information you sent me. It was the best news I had in 10 years knowing that there are 50,000 others like me out there on animal insulin. I fully agree with Professor Amiel when she says that hypoglycaemia in its extreme forms can destroy confidence, relationships and livelihoods, if not lives. Ten years on from my 12 months on at least 6 different 'human' insulins, I still feel traumatised. I have had several sleepless nights just recalling the incidents. The very first time I injected 'human' insulin my face and neck went up like a red balloon, my heart was pounding. I called the doctor out and he just said take a smaller dose! Twelve months later they were still trying to convince me. Then I was nearly knocked down by a bus and later developed stomach ulcers. Only then was I allowed back on animal insulin.

I haven't been to the diabetic clinic since April last year when the consultant told me I was 'wasting his time if I wouldn't try 'human' insulin again'. My husband asked him if he would stick his hand in the fire again after he had been burned. Since I sent him the recent newspaper articles about the controversy he has asked me to come back to the clinic, but I am still very much in trepidation and my husband has taken the day off work to come with me, Do we really live in a free society?'

Initials and area withheld for obvious reasons.

'I have had diabetes since 1954, when I was 5 years old. I have used pork insulins now for many years, injecting twice a day. I was inadvertently given 'human' insulin around 1984 but was not sure whether the 'mistake' was with my GP or the pharmacist. I was actually injecting 'human' insulin for 4/5 days without knowing it. The only thing I did know was that I was extremely ill! I could hardly drag myself to work, was experiencing uncontrolled hypos and must have

been unbearable to live with. It was only by chance that my wife and I suddenly thought 'CHECK INSULIN' and I found I had been using 'human'. I felt at that time if I had continued with 'human' insulin I would have been either living on a Disability pension or dead within a few weeks or months.

I have been a member of the BDA for many years. From reading their articles over the years I thought I must be part of such a small minority still wishing to use pork insulin that it was not worth complaining and that in years to come I would be told that I MUST change to 'human' insulin.'

Mr I.R, Herts

- **From IDDT members**

'I was most interested to read that 3000 unsolicited letters were received by the BDA on the subject of 'human' insulin - my own being just one of them, when trouble struck my family in a very soul destroying way regarding my then 19 year old son. I specifically asked if they knew of any other people having problems with the new insulin. I received a casual acknowledgement with no direct answers to my questions.

I then received a phone call from a very kind and sympathetic lady who attempted to do a good job of placating me. Never once did she let me know that I was not alone with my fears and that other people were suffering too.

What I would have given to have the Guardian report to present to the doctors at that time. Not only to help my son, who struggled for 2 years before changing back to animal insulin, but to prove I was not an 'over protective mother of a 20 year old son who should stand back and let him cope'. I sarcastically asked the doctor in question,

if I should step over him when he was lying in the hallway half in a coma vomiting on the carpet?

What a lot of suffering and anguish could have been eliminated if only people were given full ongoing details at the time. However mine is just one story in thousands!

Mrs BR, Midlands

- **Extract from a Press Release from Professor G.H. Tomkin on behalf of the Diabetes Federation of Ireland**

'The Diabetes Federation of Ireland is convinced that there is absolutely no scientific evidence to suggest that human insulin is harmful to patients. It is inconceivable that doctors would advise patients to take a type of insulin that would be harmful to them. The suggestion that synthetic human insulin may harm patients is distressing to patients and their relatives.

The Federation loudly and forcefully advertise their complete confidence in the present range of insulins available in this country.'

NB Only 'human' insulins are available in Ireland, so it is just as well the Federation has confidence in them! The patients in Ireland who do have problems with 'human' get animal by special arrangement, I wonder if Prof. Tomkin knows this?

- **From the doctors**

'I have delayed writing to you until I have been on porcine insulin for a while. It is now 2 months since I changed from 'human' insulin and you will be interested to hear that I am indeed feeling better - more energy, less debilitated etc. my wife says she notices a definite improvement in me generally.

It is hard to know how much of the improvement is psychological or perhaps even due to slightly better control. But nevertheless I shall continue with the porcine variety indefinitely. Thank you for the copy of the Guardian report, I have sent a copy to our local diabetologists. It made interesting reading and I hope the BDA does publish the

report soon.'

Dr R S, Africa

'I very rarely make any effort to reply to letters that are not addressed to me personally, but I feel this must be an exception. As I understand it, this was not a 'study' but a compilation of letters which were solicited on the subject of Human insulin. I cannot see that there is any obligation by the BDA to publish a summary of opinions that can well cause discomfort and even distress to many people who are perfectly happy on Human insulin. Only doing controlled scientific studies, which have been approved by 'Peer Groups' can a true answer to the question you raised be addressed. I do hope that any harm you may have caused to people who are perfectly happy on human insulin has been minimal.'

Consultant Physician, North West.

The rider 'As I understand it' in this letter gave me every opportunity to reply to this because clearly, his understanding of the situation is wrong. For anyone else whose understanding is equally wrong, I am going to clarify the position yet again.

- The Loss of Warnings Task Force [LOW] commissioned Dr Posner to carry out a study into the approximately 3000 **unsolicited** letters the BDA received and the study was intended for publication in the Education and Debate Section of the BMJ. In the event the BDA, strangely, could not find the 3000 unsolicited letters and so in the end 384 were analysed. Dr Posner spent about a month in the BDA office so the letters did not leave the BDA and confidentiality was not breached.
- The LOW Task Force was largely made up of leading diabetologists in the UK [and 2 people with diabetes and a carer, me] and the study was approved and carefully managed by this group. The study was not therefore, merely a summary of opinions but a carefully managed study of patient experiences approved by a

body of eminent diabetologists.

- Our consultant may think that the BDA was under no obligation to publish but a decision was taken by the LOW Task Force that it would be published. At no time was this decision revoked by them and therefore the study should have been published in accordance with the Task Force's minuted decision. Instead of this the Task Force was disbanded and the study was never published. There were no further meetings where pressure could be brought or an explanation offered nor, indeed, do I know who made the decision not to publish despite the fact that I was a Trustee of the BDA with all the responsibility that this implies. This is unacceptable procedure.

While I appreciate all this concern for the people who are happy on 'human' insulin, I find it quite incredible that there seems little concern expressed for the 50,000 people in the UK alone, who need animal insulin. Many of these people had awful experiences, including my daughter - they still live with the fear that they may eventually be denied the insulin which keeps them well especially as this has already happened to people in other countries. They have felt very isolated because they were made to feel that they were exceptions or oddities. If people are well when using 'human' insulin, then surely all that our expressed view will do is to make them aware that there are alternative insulins should they have problems in the future and at the most it may make them ask their doctor for more information. I have difficulty in understanding why this should cause them real harm especially if they become more aware of their options.

And what does happy on 'human' insulin mean anyway? If you have never tried any other insulin you actually do not know how happy you are on 'human'! I always remember a doctor saying to me about being unwell - the trouble is when you are unwell you don't realise how unwell you are until you are well. This also applies to 'happiness' - how do we know if the people who are said to be happy on 'human' insulin are as 'happy' as they could be? We don't, nor do they and nor do their doctors.

Finally I note that the BDA response in Balance is very short and says ' Changing from any insulin to another can cause problems but every individual is different and you should discuss with your GP if you want to make any changes to your insulin regime'.

This really does miss the point, yet again! It implies that the adverse effects of 'human' insulin only happen with a change of insulin. This is untrue and there is evidence from patients that problems occur when they have never used anything other than 'human' insulin. It leaves the responsibility with the patient to detect adverse effects. How does a newly diagnosed person know that what they are experiencing is abnormal? How do they know that there can be adverse effects from an insulin and how do they know that they don't have to just put up with the problems if they have never been told there are alternatives? The initiative should come from the health professionals who should be aware of the adverse effects their patients may suffer and should be on the look out for them - this does not just apply to 'human' insulin but to any prescribed drug. This should be especially so with 'human' insulin because of the controversy and lack of scientific evidence to show its benefits.



British Diabetic Association Responds With A Press Release

We have discussed in previous Newsletters the Cochrane Review of 'Human' versus Animal Insulin carried out by Professor Rhys Williams and his team in Leeds and commissioned by the BDA. Readers will remember that IDDT, amongst others, was asked to comment on the protocol [the design of the review]. This we did, saying that it was too narrow in really only looking at hypoglycaemia and not all the other effects as well and not involving patient experiences. The protocol was not amended to take into account our views or the others that were expressed. So IDDT pulled out of any involvement because our comments were ignored and we did not want to be seen as approving

a review that we felt was only looking at part of the problem.

Presentation of the Review

Professor Williams presented the Review at the BDA Medical and Scientific Conference in May and the BDA issued a press release on April 29th 1999 and it includes the following:

- Findings indicate that 'human' insulin does not increase or affect the symptoms of hypoglycaemia among the general population using insulin. However, it is acknowledged that some individuals have experienced problems while using 'human' insulin. [I apologise for the use of the word 'individuals' - this is their term not mine as I much prefer to use the word 'people' so that we remember that we are talking about real people with names, faces and feelings.]
- Suzanne Lucas, BDA Director of Care says, 'We are aware that a number of individuals experience control and other problems while using 'human' insulin, which is why it is vital that doctors are aware of the availability of animal insulins which may be a more suitable alternative for some people.'

I cannot help but add that if this had been truly acknowledged like this when patients first started to report problems 12-13 years ago, then there would have been no need for IDDT to form in the first place. If this view had been publicised, as it should have been, then 'human' insulin would probably never have become the insulin of first choice because as has been acknowledged it has no advantages over animal insulin.

Dr Matt Kiln, Co-Chairman of IDDT, attended the Conference and the presentation of the Review, which is due for publication later this year. Matt gives us a short insight into what he heard at the presentation:

The review looked at 'human' and animal insulin in two parts, firstly studies that fitted certain criteria - double blind randomised controlled trials, and secondly other studies and case reports.

The Science

- The evidence from the studies reviewed all together does not show a significant difference in the frequency or symptoms of hypoglycaemia
- Studies of this type do not exclude the possibility that there is not a difference in these two factors because it is not possible to prove a negative.
- There are a few trials [7 out of 38] that do show differences and these need an explanation, which we haven't got.
- Rhys pointed out that that these controlled trials could not necessarily be extrapolated to the normal population because patients in trials were often a select group.

The other studies

Professor Williams pointed out that the other studies were prone to bias and the case reports, which reflect the reality of what happened to patients treated with 'human' insulin, do not allow conclusions to be drawn that the problems experienced were actually caused by 'human' insulin. Having said that, he pointed out that several observations can be made:

- The number of hypos does increase when people are transferred from animal to 'human' insulin and the warning symptoms are reduced.
- That in some cases the increase in frequency of hypos and the lower awareness of an impending attack appeared to be linked to a number of deaths associated with 'human' insulin, but this is probably only a small number because the overall death rate in insulin dependent diabetic patients had not risen.**** See Late News in this issue.
- It is likely that any association with sudden death is uncommon.
- It is not possible to say whether these factors are specific to 'human' insulin or due to tighter control and made worse by other effects such as complications in long standing diabetes.
- Professor Williams acknowledged that descriptions of patients' experiences are not included in the studies reviewed and described this as a largely unexplored area. He said that studies involving patient experiences could be done.

He concluded that the Review was in many ways unsatisfactory and that further work needs to be carried out. He also pointed out that not all the evidence is available and that some reports may be unpublished or be kept by the manufacturers for commercial reasons.

Matt's comments - I thought the Review was an honest attempt to give the situation as it appears from the evidence that is in the public domain, given that the protocol was too narrow in the first place. I think the statements about possible deaths as a result of more frequent hypos and reduced awareness, surprised many of the people listening and I hope will make them think about the whole issue of 'human' insulin. Even if it is only a small number of people that actually die, this is very sad and unacceptable if the cause was avoidable. I am also concerned that we still have not examined in any way the experiences of patients using both animal and 'human' insulin because this must be important evidence in judging the safety and adverse effects of any drug. In short the review has only been able to look at one side of the evidence.

Jenny's comments - IDDT, everyone living with diabetes and members of the medical and nursing professions await publication of the Review so that we can read it in full. But from Matt's reports it does look as if we still have no settlement of this issue if only because there is no proof that the experiences of some patients when using 'human' insulin cannot be disproved and have not been disproved by the science. The fact that 'human' insulin is acknowledged to be a factor in some deaths, however small a number this may be, must surely put a big question mark before the eyes of those who prescribe it. If it is your son, your daughter or your partner, then that one avoidable death is one too many. Let us all hope that this report produces some action.

Late News

The BDA Cohort Study - mortality in patients with Type 1 diabetes diagnosed under the age of 30.

The BDA issued a press release about the publication of the above study. 23,752 people who were diagnosed before the age of 30 were entered into the study between 1972 and 1993 and were followed up until 1997. At the end of the study 22,803 were still alive - 949 deaths had occurred. Diabetes was only mentioned in 67% of the death certificates which suggests that diabetes is being under reported as a cause of death. It is important to remember that the number of deaths is small. But the worrying thing is that the death rate in young people with diabetes is higher than in the general population and certainly is not being reduced, which is what we would expect with all the modern methods of treatment and with a much greater number of professionals working in the field of diabetes.

We will have to wait until the study is published later in the year to find out more but in the meantime the BDA have given the following results:

- Of the deaths solely related to diabetes, hypoglycaemia was responsible for 18% of male deaths and 6% of female deaths and ketoacidosis for 54% of male deaths and 76% of female deaths.
- Cardiovascular disease was responsible for the greatest number of deaths from the age of 30 onwards and the number of deaths was the same for men and women under the age of 50. This is unusual because premenopausal women in the general population usually have a much lower rate of cardiovascular disease.
- Acute metabolic complications were the greatest single cause of excess deaths in this group of people. [I'm not sure what 'excess' means but I suspect it means avoidable deaths]

The BDA is calling for the care of young people with diabetes to be urgently reviewed to prevent heart disease later in life. This we have to support because it seems difficult to understand why the

death rate from heart disease should be so high when the advised policy is a low fat diet and 'healthy' eating - 30 years ago the dietary recommendations were high fat diets, including animal fats, and low carbohydrates. Without wishing to pre-empt the full findings of the study, surely we should also be calling for a complete review of the whole of the treatment of diabetes in this group, not simply looking at the situation with cardiovascular disease. We are supposedly having better care, we now have home blood monitoring and the availability of HbA1c measurements, more healthy eating, tight control to reduce complications, greater knowledge from research etc, etc, etc, and yet the death rate is not reducing. It would surely be short-sighted not to take this opportunity to examine all aspects of diabetes treatment to find out why the death rate is not reducing. And what of the mortality rates in the rest of the diabetic population, is that not decreasing either? We will come back to this in future Newsletters when the study is published.

Warning-Look At Your Prescription

We have just had a call from a gentleman with diabetes wanting to alert IDDT and its members to his recent experience. He was about to take a repeat prescription from his doctor to his pharmacist, but being a pork insulin user he was particularly aware of the need to check the prescription first. He noticed that the prescription just said 'ISOPHANE', not pork, beef or 'human'. He returned to the doctor and was told that they had a new drugs list for the computer from the NHS which only had on it the generic forms of insulin - this must mean the type of insulin based on its action profile ie soluble [short acting] and isophane [longer acting]. The species was not included.

We are warning ALL insulin users to check their prescriptions in case their GP is using this NHS database. Whether you are using 'human', pork or beef, your insulin species should NOT be changed by mistake because they all have different time actions and different

peaks of action which could well affect control. As we know from past experience an inadvertent change from one species to another could cause very real problems.

Snippets

Saving time

The Sunday Times reported that a study published in the Journal of Accident and Emergency showed that up to 20% of emergency consultant's time is squandered on non-medical clerical tasks that could be done by a less qualified assistant. Apparently when a doctor's assistant was added to a medical team at a Leeds hospital the time the consultant spent with the patients increased dramatically. [Seems like common sense to me!]

Troglitazone revisited

This was the drug for people with Type2 diabetes that was used for only for 6 weeks in this country before it was banned because it caused liver damage in some people. The USA did not ban it and on March 26 1999 an American panel of advisers decided that in most instances the benefits still outweighed the risks. They did however, say that it should not be used as first line treatment and that patients should be told of the risks of acute liver failure. One panel member actually said 'If I were a patient I would like to know if I am being given something that might kill me'. Apparently the risk is about one in 1800 during the first 6 months of use, but there are conflicting views between the FDA, who approve drugs in the USA, and the manufacturers of the drug. Nevertheless the FDA approved the drug for use with sulphonylureas and insulin. One can only hope that there are some very real benefits from taking the drug because my views are similar to those of the doctor - I'd like to know exactly why I am taking a drug that might damage my liver or even kill me!

More of the Same

A letter in the BMJ [April 3rd 1999] from Dr Landow, a past medical officer of the FDA suggests that the FDA is rapidly approving drugs due to political and economic pressures even when its own medical advisers have serious doubts about safety issues. He quotes discussions of the advisers from the transcripts of a meeting to discuss a drug recently recalled because of deaths - 'I sure don't feel good about what I've seen, you have 8 deaths in patients treated with the drug and 1 death in the placebo or control populations--- are you really comfortable that it is safe?' Dr Landow suggests that the FDA's role has changed to one of partnership with industry rather than one to protect the public's health.

Jenny's comment:

The US has the advantage of Freedom of Information and so they can be more aware of what is happening - the UK regulatory procedures are still shrouded in secrecy and so we have no idea if the same things are happening here. We can only guess! Maybe all the regulatory bodies need reminding of their function to protect consumers not industry and reminding of why they were thought necessary in the first place - thalidomide!

.....

Boots Withdrawn Diabetic Foods

Boots stopped marketing diabetic foods from March this year and so they are only available in the shops while stocks last. Healthcare professionals have been putting pressure on Boots for many years to stop marketing them because of the labelling 'suitable for diabetics'. It is suggested that this is misleading to the public because these foods are unnecessary and have no special advantages for people with diabetes. They are, of course, more expensive and concentrate on being sugar free, rather than being low in fats and calories in accordance with present dietary recommendations. Many of the products labelled as 'suitable for diabetics' are nearly as high in fats

and calories as the ordinary products and they also contain sorbitol and fructose - many of us know the effects these can have!

Nevertheless I have some sympathy with one of our members who likes to have a packet of Boots diabetic biscuits every week and is really quite angry that they have been withdrawn. She feels that she should be the one to decide whether or not to purchase diabetic foods and is angry that the decision has been removed from her. I can also see that people who do not understand their diabetes very well, such as the elderly, will feel safer eating biscuits that are labelled specially for them. I know that this is, in a sense misleading them and costing them more money, but if they are faced with a vast array of ordinary goods in a supermarket then it is not difficult to see that they will not know where to start. We have to remember that a lot of people with diabetes [especially NIDDM] often never see a dietician and so they are confused about what they should eat, especially cakes and biscuits.

Perhaps our angry member is right, we should be able to make these sorts of decisions rather than have them taken for us - this almost implies that we are unable to make decisions for ourselves! Perhaps it should also be remembered that if diabetic products are not really very harmful and some people feel safer using them, then life may be easier and less worrying - this may count almost just as much as the calories!

.....

Another new Insulin Available

Lilly is now advertising a new human insulin analogue called Humalog Mix25 in the UK. [Our friends in the US say that it has not been introduced over there]. It is available in 3ml cartridges for prefilled/disposable pen injectors, disposable ones may not be available on the NHS if the DoH bring in their proposals to blacklist them. Humalog Mix25 is a mixture of 25% insulin lispro human insulin analogue [short

acting] and 75% insulin lispro protamine [long acting]. For those not familiar with Humalog, it was introduced first as a very fast acting insulin designed to reduce the high blood sugars after meals and is given immediately before eating. Research after its introduction has shown that while it succeeds in doing this, its action and duration time is too short when used with intermediate acting 'human' insulin giving highs when it runs out. Trials adding intermediate insulin with meals have produced better control and so presumably this new mixture is designed to sort this out - we will know when it has been in use with large numbers of patients whether this is true.

Contra-indications - special warnings

Research has not been carried out using Humalog Mix25 on children under 12 years old nor on pregnant women. The manufacturers advise that it should not be used in children unless there is an expected benefit over usual insulins and that it should not be used during pregnancy or if pregnancy is being contemplated.

Insulin Pumps

We hear a lot about the use of insulin pumps especially in countries like America but they do not appear widely in the UK, although many of us will remember the trials that took place here in the 1980s. Times have changed and the huge rather unreliable thing that was strung around people's middles has been replaced by a much smaller and more reliable pump. Also the image of the pump here has been that it is really only used for people who cannot achieve good or even reasonable control by any other means, in other words a last resort. Clearly this is not how the pump is viewed in other countries and so we have to wonder whether there should be a re-think about the use of the pump in the UK, especially now that fast acting Humalog is available. Indeed, the pump may be the only device which provides a real use for Humalog. Here are the experiences of one man who

recently converted to the pump. I would remind you that these are his personal experiences, IDDT is not saying everyone should go out and buy a pump. We always have to remember that what suits one person does not necessarily suit another.

Rewriting The Rulebook

By John Neale

Twelve months ago I was cured of diabetes. Well, not exactly - but that's what it felt like. I was 32 and had had diabetes for 21 years. My health had always been good - but never really good. Many different insulin regimes had been tried, always seeking the elusive combination; the flexibility I needed for my work with the good control I wanted for my wellbeing. I changed back to pork insulin and found things easier: I stopped having bad night time hypos. But I still could not that steady predictable blood glucose level through the night. Nor could I eat at a time and place that suited me. These were meant to be the best years of my life and they were rolling by in a whirl of irritability, fluctuating blood sugars and weariness. From the point of view of my diabetes clinic everything was fine: I was articulate, motivated and never showed up at the Accident and Emergency Department. I wanted better and embarked on my own search to establish what was the very best treatment available. I wanted to know what others did in my situation. The internet was perfect for this. One thing repeatedly surfaced: the people who were contented, happy and firmly in control of their diabetes and their lives were using an insulin pump. I had heard a little about pumps in the past but I now discovered that in America and Germany, two countries I know well, pumps were now considered by many doctors to be the treatment of first choice if you lead a flexible life, want good control and are prepared to test a lot.

That's me.

My NHS clinic was unreceptive to my concerns about my less-than-

perfect control and knew nothing about pumps, so I saw a private diabetes specialist in London who was sympathetic to my needs. After several visits he authorised my using the pump but I was essentially on my own.

- The NHS continued to pay for my insulin and testing strips.
- I funded the pump and its ongoing costs myself.
- I negotiated a one month's free trial before I was committed to buying it.

From day one my life changed. I awoke on the first morning from the deepest sleep I had ever experienced and I woke refreshed! Previously I had usually woken tired and exhausted. Now I was bounding with energy and my character had changed. This was immediately picked up by my work colleagues - I became cheerful, contented and enthusiastic. Persistent small health problems also disappeared. I now ate because I was hungry and not because I was chasing the insulin already in my system. In fact I have had to relearn the link between 'I'm hungry' and 'let's get something to eat.' I steadily shed weight and was eating whatever I wanted. I've had no other illnesses since I started pumping when previously I was always going down with something.

What Is The Pump Like?

- It is about the dimensions of a credit card and just over half an inch thick.
- It is light, rugged and sits in my pocket without me knowing it is there.
- It holds about a week's supply of insulin and this travels through a tube to wherever I have placed the infusion set.
- The infusion set is the means by which the insulin actually gets into my body. It is inserted by injecting a needle with a thin plastic coating into the fat around the stomach, the needle is then removed

leaving the tiny plastic tubing coming out from under the skin. It is firmly secured with a small adhesive pad.

- The infusion set is changed every 3 or 4 days.
- The infusion set can be left in place with the pump quickly disconnected to take a bath, swim or have sex.
- At night the pump just lies safely alongside me in bed.

I just use Humalog - the very fast acting insulin and this enables me to throw the old diabetes rulebook away and write a completely new one. Getting the basal rate right is central to good control and mine is about 0.9 units per hour during the day. I need a lower rate during the night and a large increase between 6am and 10am. The morning increase is to take care of the dawn phenomenon where the body releases various hormones as part of the waking up process. Unless I take more insulin at this time I wake up with high blood sugars. All this is pre-programmed into the pumps memory. Since Humalog works so quickly, I can also use it to correct my blood glucose level if it is a little high or sometimes I put my hand in my pocket and take more insulin if I decide to have a second helping of apple pie and custard. I can now actively manage my blood sugars. I know I don't suffer the high blood sugars that used to make me so lethargic and irritable. Pumping does not give perfect control - diabetes is not like that but it gives me the best possible control and puts directly into my hands the ability and responsibility to handle situations myself. That for me is almost as good as a cure.

Jenny's comments - clearly this works for John and that's great but despite all the improvements to the pump and the needles used to put the whole thing in place, it would not suit everyone because it obviously involves much more blood glucose monitoring and more care generally. And not everyone wants to sleep with a pump beside them in bed. We also have to remember that it is not available on the NHS and the cost of purchase is around £1500, and that doesn't suit everyone either! Nevertheless, it is an option and one which obviously suits John and his lifestyle. It is also an option that people should be given, even though it is not available on the NHS.

More Facts About Fats

In the Spring 1999 Newsletter we tried to clarify some of the confusions about the different fats in our diet. This article takes the next step and looks at what the food manufacturers do when they produce lower fat versions of standard foods that are high in fats, such as cheese, mayonnaise, biscuits and crisps. As most of us are aware it is often the fats in foods that make them taste so nice, smell nice and give a creaminess to the texture. So for some foods there needs to be a 'fat replacer' to make them attractive enough for us to want to eat them. Other low fat products such as skimmed milk, do not have fat replacers - the fat content is reduced by simply removing the fat. Low fat crisps are the same, the fat content is lowered by reducing the amount of fat left on the crisps, leaving the actual contents of potatoes, vegetable oils and salt the same. Needless to say, the food manufacturers have spent years finding fat replacers that satisfy our taste buds! There are different ways of doing this.

Mimicking the effect - these fat replacers are designed to mimic the texture and effect of fat. They are usually based on carbohydrates and proteins and may be extracts of fruits, oats or seaweed. They are listed on the food labels as whey powder, gelatin, lecithin, starches, carrageenan, cellulose, guar gum, locust bean gum and maltodextrins. These additives are also used in standard foods but they have a more critical role to play in low fat foods. These types of fat replacers cannot usually be used in frying or baking because the heat affects them.

In some foods water and fats are mixed into an emulsion to give the impression of creaminess but when the fat is reduced the consistency is not the same so emulsifiers are used [eg lecithin] in spreads sauces and salad dressings.

Fats also have a slippery feeling in the mouth and protein replacers, such as milk protein whey, are used. The small particles of protein in the whey act like ball bearings and slide over each other to feel like fat on the tongue. These are used in yogurts, ice creams and mayonnaise.

Modifying the fat - new technology has focussed on developing fat-based fat replacers which work in the same way as fats. They have the same textures as fats but can be used for frying and baking. They have been chemically modified to give fewer calories than standard fats. These sound promising but there are some problems yet to be solved because one product, Olestra approved in the US but not used in the UK, is not absorbed into the blood stream and passes out of the body unchanged. This can cause unpleasant side-effects.

Hopefully this will help you to know a little bit more about the products you are buying to try to reduce your fat intake. However, having written the article I feel generally quite put off all food for the moment!



News

- The Medicines Control Agency [MCA] and the NHS are jointly funding a pilot project in Derbyshire for the reporting of adverse drug reactions in children. The aims are to stimulate the reporting of suspected adverse reactions, to identify and investigate possible signals of new adverse reactions occurring in children and to decide whether it is worth extending the scheme to other areas. [Got to be good!]
- In May 1999 the Royal College of Paediatricians and Child Health will publish Medicines for Children, the first drugs formulary for children. This will be accompanied by a working party report on the licensed and unlicensed use of drugs in children. New research has shown that many of the drugs used to treat new babies and children have been tested only in adults and doctors and pharmacists have had to calculate the required safe dose themselves. 90% of babies in a neonatal care unit in the East Midlands were given drugs that were either unlicensed or used in other ways than those for which they were tested!

Let's Scotch The Rumours - No Shortage Of Animal Pancreases

Whenever the 'human'/animal insulin issue seems to rear it's head there are people around who seem to talk rubbish to try to prove that 'human' insulin is essential for all of us and that it suits all of us. We know this is not true - our own experiences are all the proof we need. But at the time when the major insulin manufacturers are withdrawing supplies from people who need animal insulin, silly statements seem to appear. I do not know where they come from, but they need correcting.

The old chestnut is back again - it is being said that there is a world wide shortage of pancreases from pigs and cattle.

This is absolute nonsense and certainly not the reason for the manufacturer's withdrawals and nor is it a reason why anyone who does not want to change to 'human' insulin should be forced to do so. We covered this the last time these rumours were around but I am going to do it again.

- The total number of pigs slaughtered [for all purposes] in the world in 1997 was 1,032,715,000 heads.
- 60,000 pigs can provide 1lb of pure insulin so the total insulin available from pigs was 17,212lbs.
- Approximately 1lb of insulin is sufficient to supply the needs of 800 people with IDDM and so 17,212lbs will supply 13.75 million people with pork insulin.
- If we look at beef from only the US and Argentina, there were nearly 90 million head of cattle slaughtered in 1997.
- 60,000 beef pancreases produce 1.5lbs of pure insulin and so the total amount of beef insulin from cattle in the US and Argentina alone, is 225,000lbs and this will supply another 180,000 million people with beef insulin.

There Are Enough Cattle And Pig Pancreases To Supply 200 Million People With Animal Insulin

Let us put these figures in perspective and figures that are a little nearer home - in the UK around 350,000 people are insulin dependent. I think we are a long way from being short of pancreases to supply all the world's diabetic population. So to the scare mongers who are trying to frighten and mislead people into transferring to 'human' insulin with incorrect information I say - go away and do your homework, the statistics are very easy to find.

NB I would just like to remind readers that the animals are not slaughtered deliberately to obtain insulin, the pancreases are removed from animals already being slaughtered for other purposes.

Just another tit-bit of information found at the same source, did you know that pigs are a source of nearly 40 drugs and pharmaceuticals?

Driving Restictions - A Response From The Minister

Readers of the Spring 1999 Newsletter will remember the very valid points made by Mr S.D.D. when he pointed out that vehicles over 7.5 tonnes have the use of tachograph. This restricts the amount of time the driver can drive without taking a break. He rightly pointed out that this appears far safer, especially for people with diabetes, than the newly restricted category of vehicles, 3.5 to 7.5 tonnes that have no such restrictions

IDDT took up this point and others with the Lord Whitty of the Department of Transport, and his response was as follows:

'The comparison between the periodicity for the renewal of entitlement

of those suffering from insulin treated diabetes and otherwise medically fit drivers of large goods vehicles is not entirely accurate. Drivers of any class vehicle, irrespective of size, who have certain medical conditions, are subject to more regular review of their entitlement than those who are medically fit. Diabetes is not the only condition involving regular review. The periods of review are between 1-3 years, depending on the nature and severity of the medical condition.

Drivers of large vehicles - since January 1997, including minibuses with 9-16 passengers and medium sized lorries between 3.5 and 7.5 tonnes - are subject from the age of 45 to regular review. This is because of the potentially more dangerous vehicles - in terms of the consequences of an accident - which they drive. This also reflects the fact that health can begin to deteriorate to an increasing and significant degree from that age. We are grateful to Lord Whitty for his response to our queries.

.....

Writing Can Be A Relief

I recently received a disturbing letter from a lady who had read about the BDA's unpublished report of the experiences of the people who have problems with 'human' insulin. The recent press coverage had brought back all the old memories of how awful her life had been while she was on 'human' and before she was changed to animal insulin. The memories had given her a few sleepless nights. She recounted the her experiences in her letter to me and clearly, she had had a very difficult time, made worse by being told the problems were all in her mind - obviously not true because she was fine after changing to animal insulin! But the interesting thing was that at the end of the letter she said she felt better for writing it all down - she had got it 'out of her system'. But what is it? It is the anger, the upset, the fears and the stress of the situation she had been in.

This not only brought back my own memories of my daughter's awful

experiences and my fears for her future health, but it also reminded me of some very good advice I was given by her paediatrician. This was in the early days of diabetes and I was having difficulty in coming to terms with my little girl's diabetes and what it meant for her. He said get a blank piece of paper and write down just how you feel. Then throw it away. I did this on several occasions in those days and it helped. It relieved my feelings and because nobody was going to read it I could be really honest. I still do it on occasions today. I also do it with things that crop up in IDDT - if something makes me very angry and I want to write a nasty, angry letter, I write the first version just as I want, then I write a much calmer, more logical one that I actually send. It works for me and relieves my anger.

So what's the relevance of this?

Well, a study reported in JAMA [ref1] has shown that writing about stressful experiences may help some people who have chronic diseases. 112 volunteers with asthma and rheumatoid arthritis were asked to write about stressful life events or about an emotionally neutral topic [this was the control group]. The results showed that 'Patients with mild to moderately severe asthma or arthritis who wrote about stressful life experiences had clinically relevant changes in health status at 4 months compared with those in the control group.' This included improvements in lung function in those with asthma and improvements in the severity of the disease in those with arthritis.

It seems that the lady who wrote to me was right - she did feel better for writing about the stressful experiences in her life and now there is the science to prove it! As I have said it also works for me - I do not know if my health is better for it, but it certainly relieves my feelings rather than keeping them bottled up. Try it sometime.

Ref 1 JAMA 1999;281:1304-09

Life In School With A Chronic Physical Condition

The NHS Research and development Programme funded a two-year study to investigate the support needs of young people with special health needs attending mainstream schools. They consulted young people, their parents and teachers. I don't know whether young people with diabetes are classed as having a 'chronic physical condition' but the results of the study certainly apply to them. It showed that:

- Young people were making active efforts to manage their own condition in school.
- They felt they needed support from health and education professionals in dealing with absence from school, including keeping up with school work.
- They also felt they needed support for joining in school activities, relationships with other pupils and having someone to talk to about health-related worries.
- Young people and parents said that support from teachers was variable, depending on the teacher's awareness and understanding of the child's condition.
- Teachers felt their need for health information was largely unmet and they did not want to rely solely on parents or school doctors for advice and information.
- Teachers urged the child's health professional to make contact on a regular basis.
- All participants in the study expressed concern about systems in the education services for passing information between and within schools.

These strike me as issues that can apply to children and young people with diabetes and to some extent always have. I am not sure if things have got any better since my daughter was in education, but a parent, who is also a teacher, recently sent me a copy of their school's guidelines for children with diabetes and procedures within the school for handling any difficulties. They horrified me - I think they must

have been written soon after Banting and Best discovered insulin! Obviously the BDA has a school pack and this has always been an excellent way of giving information to schools but clearly more needs to be done. I think the teachers have probably hit the nail in the head when they say that they would like direct and regular contact with the child's healthcare professional.

But one has to ask just how realistic this is in terms of time, effort and cost. I am sure that the effort would be worthwhile, especially, for instance, during the teenage years when both parents and the young people themselves are going through a difficult time, when there may be behavioural problems related to having to conform to the diabetes regime and when parent / child communications may be difficult. The time has to be given by teachers as well as health professionals, and I have experiences of trying to organise meetings for teachers about diabetes in children. I have to say that these were often poorly attended because they were in after school time.

If this problem for children with chronic conditions is going to be tackled, then there has to be real commitment on the part of everyone concerned. It has always seemed to me that the organisations representing children and young people with the various conditions should get together and work with the education system to find a way to answer the needs of the children and young people, the parents and the teachers. It is not simply a matter of producing information sheets that never get read or passed on to the relevant teachers.



Blood Pressure

Blood pressure is something we talk about a great deal, especially as we all get older, and it is of importance for people with diabetes. The recently published research, called the UKPDS, looked at people with Type 2 diabetes over a long period and found that control of blood pressure played a very vital part in reducing the complications

of diabetes. It seems likely that blood pressure and the control of it, is going to play an important part in the lives of people with diabetes in the future. So I thought that perhaps we should have a few facts about it.

History

Blood pressure was first measured by Reverend Steven Hales in 1730. He inserted a small tube into the artery in the neck of a horse and measured how far the pressure pushed a column of blood up the tube. It rose over 2 metres. The next breakthrough came when a French medical student, called Poiseuille, put mercury in the tube and blood pressure was then measured in terms of how far the mercury was pushed up the tube. This made the measurement much easier because mercury is much more dense than blood and does not rise as far in the tube. It could, therefore be measured in millimetres rather than metres and it is still measured in millimetres of mercury today [mm/Hg].

Measuring blood pressure today.

Clearly we don't stick a tube into an artery today to measure blood pressure and it was an Italian, called Riva Rocci, who developed the first sphygmomanometer. This is the instrument where an inflatable rubber bag is put around the arm and air is pumped into it. New technology has led to the development of a wrist monitor which allows blood pressure to be measured by placing an inflatable cuff around the wrist.

Systolic Pressure

The air is pumped until the flow of blood stops in the brachial artery [the artery in the upper arm]. The doctor or nurse can tell when this has happened by measuring the pulse. The pressure of the air in the bag is measured by a mercury manometer.

The pressure in the bag is then slowly released and during this time the heart is trying to force blood through the closed off artery. Eventually there comes a point where the pressure in the bag is equal to the blood pumped by the heart. The blood starts to flow and the artery

walls oscillate as there is an initial surge of blood. The pressure at this point is the systolic pressure. This is the top one of the two figures you are given as your blood pressure is measured and it is the maximum blood pressure caused by the contraction of the heart as it pushes the blood around the circulatory system.

Diastolic Pressure

As the pressure in the rubber tube continues to fall there is a pressure at which the artery walls stop oscillating. The blood now flows steadily and quietly and the pressure shown on the manometer is the diastolic pressure. This is the bottom figure of the two figures you are given.

What is normal blood pressure?

Generally there are 2 boundaries: below 140/90 mm/Hg is regarded as normal. 160/100 mm/Hg is clearly high but the risk to health between these figures varies according to other factors such as age, gender, smoking habits etc. and diabetes has to be one of these factors. Blood pressure varies throughout the day and changes can be caused both psychological and physical factors such as anxiety, exercise, smoking and stress. It is important, therefore, to realise that one high blood pressure reading does not necessarily mean that you have high blood pressure that needs treating. Your doctor will usually do several measurements first.

Why is normal blood pressure important?

There are two main reasons - people with high blood pressure are at increased risk of strokes and coronary heart disease. High blood pressure damages the circulatory system. High blood pressure causes the artery walls to harden. They thicken to withstand the greater force, the inner linings become rough and this reduces the diameter of the blood vessels. The blood flow becomes sluggish and the blood becomes thicker with a tendency to clot more easily. If lumps of solid blood attach themselves to the roughened artery walls, this is a thrombosis, if this happens in the coronary artery [the one from

the heart] it can cause a heart attack and in the brain it can result in a stroke.

High blood pressure can also cause heart failure by increasing the load on the pumping heart. As it struggles to cope it becomes enlarged and as it gets bigger it becomes less efficient and can fail. High blood pressure can also lead to kidney failure.

It becomes clear now why control of blood pressure is important for people with diabetes - diabetes increases the risks of most of these conditions anyway and so high blood pressure must further increase the risks.

Why do people have high blood pressure?

There are some significant factors:

- Genetic
- Weight
- Alcohol
- Lack of exercise
- Smoking
- Stress, if it is continuous so that blood pressure does not have the opportunity to fall.

Symptoms

Generally there are no symptoms of high blood pressure - it is completely silent and not detected until a measurement is taken, so it is important to have your blood pressure checked even if you feel perfectly healthy. About one in seven adults have it.

It is equally important to remember that high blood pressure is not an illness and with correct treatment you are a perfectly healthy person. Professor Ramsey, President of the British Hypertensive Society, is quoted as saying 'Even if you need to take tablets to control hypertension, you are still a healthy person - you should forget your blood pressure and get on with living.' I assume he means after taking

all the sensible measures like stopping smoking, eating properly and taking regular exercise.

If you would like more information from the British Hypertensive Society send a stamped, self addressed envelope to:

British Hypertensive Society, 127, High Street, Teddington, Middlesex, TW11 8HH.



In The Spotlight

A light-hearted look at the Trustees of IDDT.

To most of our members the Trustees of IDDT are just names or voices at the end of the telephone and so we thought that we would give you a little, not too serious, look at them. So we have asked them to fill in a little questionnaire about themselves and we are publishing two in this Newsletter and in subsequent Newsletters.

A Look at Dr Laurence Gerlis, Medical Adviser

- What keeps you awake at nights?
The telephone.
- What is your favourite holiday destination?
Anywhere, as long as it's a holiday.
- What is your favourite television programme?
The Vanessa Show [it pays me].
- If you could have lunch with anyone you like, who would it be?
David Ginola.
- If you could start all over again, what or who would you like to be?
A professional footballer.

- Do you learn from your mistakes?
Even better - I learn from other people's mistakes.
- How would you describe yourself in fewer than six words?
Concise.
- Who has most influenced your way of thinking?
Joseph Heller - Catch 22 [you can never win].
- Who or what makes you laugh?
Dr Harry Hill.
- What is your biggest regret?
Believing what people tell me.
- What is your greatest ambition?
Finishing this questionnaire.
- Who would you least like to be trapped in a lift with?
The England Rugby XV
- What is your pet hate?
Liars.
- If you could change the world, what changes would you make?
If people, myself included, were more secure mentally, they would trust other people more.
- *The Bill. I don't watch much but when I do, I quite like rubbish to take my mind off the real world.*
- If you could have lunch with anyone you like, who would it be?
Paul Newman or Kevin Cosner.
- If you could start all over again, what or who would you like to be?
I would have liked to spend more time being a full time wife and Mum - with hindsight the career bit is no substitute, but knowing me I'm sure I wouldn't really have done things differently.
- Do you learn from your mistakes?
I like to think so, but probably not!
- How would you describe yourself in fewer than six words?
Stubborn, determined, too outspoken, cannot bare injustice.
- Who has most influenced your way of thinking?
My parents and my children.
- Who, or what makes you laugh?
Julian Clarey, Morecombe and Wise.
- What is your biggest regret?
That my daughter has diabetes.
- What is your greatest ambition?
To retire!

A Look at Jenny Hirst, Co-Chairman

- What keeps you awake at nights?
Nothing, I sleep like a to
- What is your favourite holiday destination?
The peace and quiet of the Norfolk coast.
- What is your favourite television programme?
- Who would you least like to be trapped in a lift with?
Margaret Thatcher.
- What is your pet hate?
I've lots! Arrogance. People who grumble but do nothing. People who think they always know best. Advertising.
- If you could change the world, what changes would you make?

Greater equality, tolerance and honesty - most of the world's problems would be solved with the removal greed and the desire for power.

You Really Wanted To Know This!

Last year research was published that showed that body mass index [weight in relationship to height] was the primary fact that determined female attractiveness for men. It has been suggested that women's choice of what makes a man attractive is not so simple. A recent letter in the Lancet has attempted to clarify this problem.

30 female students were shown photos of 50 headless men with different waist/chest measurements, different waist/hip measurements and different weights.

It seems that the waist /chest measurement is the key to whether the women found the men attractive and women prefer men shaped like an inverted triangle - broad shoulders and chest and a narrow waist. So for women, it is shape and not size that determines the attractiveness of men. Interestingly, though, women rate attractiveness in women the same way as men - weight being the important factor.

Some Interesting Posters At The BDA Medical Conferences

Medical conferences have display sessions where posters or abstracts of studies carried out are displayed. These may never be published in full but they can be quite interesting and I have selected a few that I thought might of interest to IDDT readers.

- Effect of hypoglycaemia on mood in non-diabetic and insulin dependent adults.

18 non-diabetic adults and 16 adults with insulin dependent diabetes were studied with normal blood sugars and when hypo [5.0mm/l] and were asked to fill in questionnaires on mood and on an ongoing life problem. Hypoglycaemia caused an increase in tension and a decrease in happiness. Energetic arousal only increased in the non-diabetic people. Both groups appraised life problems with an increased sense of loss and threat. The diabetic group reported an increased sense of challenge during hypoglycaemia but this was reduced in the non-diabetic group. The authors conclude that hypoglycaemia has a negative effect on mood state and appraisal of a life problem.

Jenny's comment - If you live with someone with diabetes, you do not need a study to tell you this!

- IDDM in a routine diabetes clinic: the association of psychosocial factors, diabetes knowledge and glycaemic control to insulin regime.

This study compared 108 people on 2 injections a day and 92 on 4 injections a day [usually classed as intensive therapy]. There were no significant differences in the two groups in terms of age, sex, social class, weight, hypo rate, complications and duration of diabetes. The results were interesting:

- HbA1cs were worse in the intensively treated group than those on 2 injections.
- The knowledge scores were better in the intensive group but treatment satisfaction and wellbeing scores were not.
- The intensively treated people saw themselves as being more in control of their situation than did those on 2 injections a day.

The authors conclude that in a routine diabetic clinic intensive therapy [4 injections a day] is associated with worse glycaemic control despite these people being slightly more knowledgeable about diabetes and

more self directed.

- Impact of patient choice on metabolic control and broader diabetes outcomes in an empowered model of diabetic care.

105 patients with IDDM on twice daily injections were invited to a patient centred education session on 'Informed Choices in Diabetes Care'. This included details of the targets set by the DCCT [tight control] and allowing patients informed choice of metabolic control, setting their own targets for home blood monitoring and professional support. Everyone was given written information and offered further 2 hour education session. Comparisons were made before the start of this and 8 months later and results showed that the patients offered informed choices to set their own objectives for their diabetes showed increased knowledge and felt that they had more personal control with no detrimental effect on their diabetic control.

Jenny's comment - this is good to know, so maybe greater emphasis will be placed on giving patients an informed choice in every aspect of diabetes!!!

- Alcohol Consumption in young people with Type1diabetes

A telephone questionnaire was conducted with 150 young people with diabetes [aged 16-40 years]. 10% were non-drinkers and 50% drank on at least one day a week, while 15% drank over the recommended healthy limits.

- Total alcohol intake for both men and women with diabetes was significantly lower than in the general population.
- Of the 135 drinkers alcohol caused a rise in blood glucose in 10%, a fall in 41% and a mixed effect in 11%.
- 18% reported an increased risk of hypos with symptoms and these occurred within a few hours, overnight or during the following morning. 4 people had a history of severe hypos associated with excessive intake of alcohol.
- 69% took actions to counter the effects of alcohol - extra blood

tests, adjustments to carbohydrate intake or insulin dose.

- Long-term glycaemic control appears unrelated to alcohol intake.

Jenny's comment - I really put this in to show that the majority of people with diabetes are sensible about drinking and also to emphasise the need for everyone to take precautions against hypos and not just within the few hours after drinking.

These last two abstracts bring to mind a quote from Dr R.D. Lawrence, one of the founders of the BDA, made over 60 years ago:

'In the successful treatment of diabetes the patient, the practitioner and the specialist are often partners working together to establish the patient's health. In the long run the most important part, the melody, is played by the patient.'

Sorry Australia - Wrong Phone Number!

My error I am afraid - in the Spring Newsletter we printed the wrong telephone number for Michael Ginges, IDDT's telephone contact in Australia.

The correct Number is 02 94198234.

In his e-mail to tell us Michael says, IDDT Australia is such an important voice for those diabetics who now have very few alternative medications to pork insulin. I am sure the way pork insulin was taken off the market highlights the need for a lobby group in Australia. The Newsletter is a fantastic publication. Many thanks for your continued support and encouragement.

If you want to contact Michael by e-mail his e-mail address is:

michael.ginges@start.com.au.

Complementary Medicine And Diabetes

An article published in Practical Diabetes [ref1] discussed the use of complementary medicine by people attending a diabetic clinic. 247 people were interviewed, 75% of the clinic population, and of these 17% had used complementary medicine. According to an article in the Journal of the Royal Society of Health [ref2] this figure is higher than in the general population. Acupuncture, homeopathy and herbal therapy were the most commonly used. 61% of the people felt that this treatment was beneficial and only 3 people reported harmful side-effects.

Most people used them for non-diabetes related problems with 20% using them largely for relaxation purposes.

The study also showed that people with longer duration of diabetes were more likely to 'perceive' a benefit from complementary medicines and the authors suggest this may reflect their greater dissatisfaction with orthodox medicine. However, this is the group of people who have more of the long-term complications and it could just as easily be that they use complementary medicine to try to reduce the effects of these. This is also the group who have worked out for themselves that stress affects their blood sugars and so use these 'alternative' treatments to reduce their stress levels and achieve better diabetic control.

A study in the USA [ref3] looking at the general population has shown that dissatisfaction with conventional/orthodox medicine has little to do with the increasing use of complementary medicine. 40% of the people using it tended to be better educated, sicker and have a more holistic approach to health than the rest.

Are there any dangers in using complementary medicine?

The authors of the study suggest that the use of complementary medicine by people with diabetes may well be more widespread than they have shown because of their particular clinic population. They also only looked at people who attended the clinic and so they are

only assessing people who are satisfied enough with their orthodox treatment to attend and be interviewed. The authors express concern that the use may be more widespread than estimated and there needs to be 'increased critical evaluation of their efficacy' because there may be effects on diabetes management.

Interestingly, Dr Iain Chalmers reported in the BMJ [ref4] says 'Critics of complementary medicine often seem to operate a double standard, being far more assiduous in their attempts to outlaw unevaluated complementary medical practices than unevaluated orthodox practices. These double standards might be acceptable if orthodox medicine was based solely on practices which had been shown to do more good than harm, and if the mechanisms through which their beneficial elements had their effects were understood, but neither of these conditions applies.' He went on to point out that it is thought that more than 60% of orthodox treatments have not been scientifically proved and that the aim should be to assess the effectiveness and safety of any form of treatment, whether it is orthodox or complementary.

Frank Dobson, health secretary is quoted as saying 'I believe that what works is what counts and what counts is what works'. He added that rigorous standards of efficacy and safety should be applied across the board.

So it appears that there isn't an answer to the question about any dangers involved in complementary medicine and perhaps many questions also need answering about the 60% of orthodox treatments being used that remain unproven. I tend to favour the Frank Dobson approach in the meantime. There is now greater awareness that in diabetes management control of blood sugars is the mainstay of treatment but this is not a simple matter of giving insulin and everything just falls into place. There are psychological and social factors involved, how people feel about their diabetes and how it affects their life - all of these and probably many more affect diabetes control. In other words, people with diabetes must be seen as people first and then treated as people who have diabetes.

Ref 1 Pract Diab Int; Dec97, Vol14, No7, 207-8

Ref 2 J Roy Soc Health Feb 98, Vol 118 No 1,39

Ref 3 BMJ 1998;316;1694 [6 June]

Ref 4 BMJ 1998;316:1840 [13 June]

Government Proposals

- Impotence Treatment - the government has announced its new guidelines on the treatment of impotence brought about by Viagra. The only changes that appear to have been made to the original proposals are that the categories of people allowed treatment have been widened to include people with MS and Parkinson's - people with diabetes were included in the original recommendations. The guidelines still restrict the prescribing to once a week and this IDDT objected to during the consultation period. It also means that people who have used other methods for treating their impotence will now be restricted to once a week treatment when they have previously had unrestricted treatment. Doctors are being allowed to give private prescriptions to NHS patients.

This restricted prescribing is the first time that doctors have not had the freedom to prescribe according to patient need and the first time that there has been government 'interference' with their professional rights in this respect.

- Pen Needles - at the time of writing we still have not had the government's response to their consultation document about pen needles being available on an NHS prescription. Readers will remember that this was also linked to the pens themselves being available on the NHS [something IDDT felt was not necessary because the only gain in this would be to industry]. It was also

linked to pre-filled disposable pens being blacklisted [not available on NHS prescription]. IDDT agreed with the government on this because of the extra unnecessary expense of throw away pens, and we suggested that for those who did need them, they could be prescribed on a named patient basis free of charge.

We will let you know when there is any news on this.

NB Research published in Practical Diabetes Oct 1997 [Vol. 14 No 6] showed that the total cost of insulin with a disposable pen was one and a half times more expensive than using a cartridge, twice as much when using a vial of the same 'human' insulin and two and a half times more than when using pork insulin, presumably in a vial. Clearly if you multiply this up by the number of people using insulin the cost of this is quite huge!

Christmas Is Here Again - Please Support Us!

We are enclosing the details of our IDDT Christmas card for 1999 with this Newsletter and members will receive a sample of the card, appropriately called 'Smiling Snowman'. Smiling Snowmen come in packs of 10 and cost £2.70 per pack, plus 50p p&p for each pack. Please help to raise funds for IDDT and to advertise to your friends that we exist by sending IDDT Christmas cards this year.

Please send your order to: Sue Morris, IDDT, PO Box 294, Northampton NN3 2BN.

Cheques or Postal Orders should be made to 'IDDT'. We are very grateful for any help you are able to give us and would be even more grateful if anyone could help with selling them to their friends!

Comments on the FRIO Wallets - tips for you

In the Spring 1999 Newsletter we printed details of the FRIO Wallet

for designed to keep your insulin cool for up to 48 hours and we know that several of our members have tried it. One of our members found that while the actual cooler part worked well, the inner bag stayed very damp despite drying it with a towel as recommended and the labels on the insulin vials started to disintegrate. The instructions also say that the cooler pouch should not be put in a plastic bag because it does not work so well.

Our member raised this with the manufacturer and they advised that waiting about 20 minutes after soaking the pouch would solve the problem. However, our member wants to 'soak and go!' and this seemed to spoil the idea and so she asked if she could put the actual vials in a plastic bag before putting them in the cooler pouch. This is OK and does not affect the cooling abilities of the FRIO but it is ONLY the vials that should be put in a bag and NOT the whole pouch. She can now 'soak and go' as quickly as she likes!

IDDT's Annual Meeting with a Difference

The Launch of IDDT - International

Apollo Hotel, Hagley Road, Birmingham, Saturday, 9th October 1999.

This year we are holding our AGM later in the year so that the date does not interfere with holidays and sports events such as Wimbledon, but above all we are making it a major event in our history and formally launching 'IDDT - International'. IDDT - International will act as an umbrella organisation for people with diabetes and the various patient groups around the world. It will provide a forum for those who believe in the rights of people to have an informed choice of insulin treatment and that animal insulins must remain available in order to provide that choice, especially for those who experience adverse effects with 'human' insulin.

Our speakers that have confirmed that they are able to join us include Dr Laurence Gerlis, IDDT Medical Adviser, Professor Teuscher from Switzerland and Dr Bettina Geier, who has diabetes herself and done a lot of work with self-help groups in Germany and patient representatives from Australia, Larrane Ingram, and Robin Harrison from the USA. I am sure it will be an interesting day - details of the final programme will be sent to our members in due course. We would like to meet as many people as possible on this special occasion but places will be limited and we will have to take bookings on a first come first served basis. The cost will be £5.00 each including coffee and a sandwich lunch. If you would like to attend please make a note of the date in your diary and watch for the post to send your reply as soon as possible or to be sure of a place, you could write to me now and include your payment. Write to Jenny Hirst, IDDT, PO Box 294, Northampton NN3 2BN.

Prescription Exemption Certificates

A cautionary tale - one of our trustees was caught out recently when he had to get his insulin prescription dispensed at a different pharmacy from usual.

Due to a mix up with supplies at my GP's dispensing practice I had to travel into town and use a pharmacy who do not know me. I was immediately asked to produce my prescription exemption certificate. I proudly handed it over with an inner glow of satisfaction, to think that I had carried it around for the past seven years and never before had I been asked to produce it for this purpose and still had it in my wallet. Many many times has it been used as a proof of address for various retail purposes, and still in tact it was very dog-eared indeed. After much close scrutiny the pronounced '....I am afraid it is two years out of date Sir!' at which point my inner glow cooled somewhat to an irritated frostiness. Apparently as a part of the clampdown on prescription fraud it has been a firm rule since April 1st of this year that

you must produce the certificate each time you take in a prescription. It took some pretty firm negotiation on my part to persuade him to part with the insulin without my paying.

I am sure that most pharmacists know their regulars, and probably still don't ask, however things could be different if you find yourself needing to use a new supplier particularly at short notice. Obtaining a renewal from your Family Health Trust can also involve a visit to your GP to obtain signatures on forms and then take a few days at the offices of the Trust.

The moral of this tale is - DON'T GET CAUGHT OUT, CHECK YOUR EXEMPTION CERTIFICATE NOW AND GET IT RENEWED IF NECESSARY.

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: _____

.....

From Your Editor – Jenny Hirst

IDDT welcomes the submission of letters and editorial articles for consideration of publication in future issues of the IDDT Newsletter. The editor and trustees do not necessarily endorse any opinions or content expressed by contributors and reserve the right to refuse, alter or edit any submission before publication. No part of this publication may be reproduced in any form without the prior written permission of the editor.

Insulin Dependent Diabetes Trust

PO Box 294
Northampton
NN1 4XS

tel: 01604 622837

fax: 01604 622838

e-mail: support@iddtinternational.org

website: www.iddtinternational.org