Insulin Dependent Diabetes Trust
April 2002 Newsletter
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Forgive My Anger...

IDDT has stepped up its awareness campaign through local newspapers to make people who live with diabetes aware not only of IDDT but also of the reasons we needed to form. We must not be complacent and forget these reasons. They were simple:

- to help and support people with diabetes who cannot tolerate synthetic ‘human’ insulin and need natural animal insulins
- to try to ensure indefinite supplies of animal insulins for the people that need them.

To achieve the latter, there has to be recognition that some people do experience adverse effects when using from ‘human’ insulin and that, despite what patients are all too often told, synthetic ‘human’ and natural animal insulins are not the same.

Our local press coverage has brought in many calls from people around the country. Many of them have had bad experiences with ‘human’ insulin and therefore want to support IDDT’s aims. But there are many more people that are contacting us who recount to us the clearly defined list of symptoms that were shown in IDDT’s survey in 1994 and the BDA’s research even earlier. Let us not forget these either – hypos without warnings, large unaccountable weight increase, extreme tiredness, regular infections, confusion, memory loss, behavioural changes and depression.

We thank everyone for joining IDDT and we are pleased to welcome everyone into the fold of IDDT. But ‘Welcome to IDDT’ seems inappropriate when the reasons for contacting us are so serious and are that people need help that they are clearly not getting from other sources. Nevertheless, I do say ‘Welcome’ and I hope that IDDT can offer you the understanding, support and information that you and your family needs.

I have been editor of our Newsletter from the outset in 1994 and I have to say that I have found this particular Newsletter difficult to put together because I am angry. I am angry that after all these years there are so many people that are having hypos without warnings, a stated adverse effect of ‘human’ insulin and I am angry that animal insulins are not even suggested as a possible option to try to reduce these problems. Hypo unawareness can colour every aspect of someone’s life from loss of job, loss of driving licence to ruining relationships and marriage.

I am angry that there is a failure to understand that while research shows that on average most people are treated satisfactorily with ‘human’ insulin, there is a failure to recognise that this does mean that everyone can be satisfactorily treated with it. To quote Bandolier 95, “equal on average does not mean equal for everyone” and there is a need to take into account individual needs.

But I am angry that the pharmaceutical companies are relentlessly proceeding with their discontinuation of animal insulins regardless of need. IDDT receives desperate pleas for help from people around the world whose lives are being severely affected by these commercial decisions that ignore the needs of people with diabetes – the people they rely on to provide the profits for their shareholders. My anger has been fuelled by the announcement last December that Novo Nordisk has acquired Biobras, a Brazilian company that not only supplies animal insulin but more importantly, is the world’s largest producer of insulin crystals, supplying them to other companies for their own production of animal insulins. Insulin crystals are the ‘raw’ material necessary for the production of animal insulins.

I am angry that insulin producers have been allowed to gain such a dominant market position so they control and dictate the treatment of people with diabetes. Insulin treatment is no longer controlled by doctors and certainly not patients but by three dominant pharmaceutical companies. I looked up the dictionary definition of dominant and it is *‘to control by strength, to hold a commanding position and to have the power to rule’.* Ultimately this dominant position is the reason people with diabetes are being, and will be, denied the choice of insulin that suits them best, whatever that insulin may be. The euphoria when Banting and Best discovered insulin has been eaten up by the greed of the pharmaceutical industry. True scientists like Banting and Best’s hardly exist now - they were uninfluenced and unadulterated by industry. They *gave* their discovery of insulin to the people of world to save lives and relieve suffering, But look what has happened to their gift!

My daughter ‘lost’ her teenage years to the adverse effects of ‘human’ insulin and I know just how much she fears ever having to go back on it – a fear that no one should have to endure. So readers will have to forgive me if my anger shows through in this Newsletter. But we should also remember that controlled anger can be turned into positive action. The time is fast approaching when we have to use our joint anger to resist the dominant position of the pharmaceutical companies, to use our joint anger to fight against their influence so that our needs are not ignored and to use our joint anger resist further discontinuations of animal insulins.

IDDT Research Grants

We are happy to say that IDDT is now in a position to make small research grants available. Sadly, this is largely due to legacy donations but we are very grateful for generosity and the kindness of all the people helping others in this way. This is especially welcome because IDDT has always declined to accept funding from the pharmaceutical industry so that we remain uninfluenced and unbiased by our sources of funding. For this reason the amount of money the Trust has to fund research projects is fairly limited. Initially, we are prepared to consider applications for research in the area of primary care up to £10,000 for any one project but we are willing to consider joint funding.

IDDT research objectives

IDDT formed to help and support people who are living with diabetes and their family carers, so we believe the research that we fund should be in the area of helping people that live with diabetes now. We want to fund studies that look at potential benefits for the average every day diabetic patient or their family carer, if there is such a thing! We would particularly support new ways of thinking and treating diabetes especially when consumer input and consumer experience is put as a key aspect of the research. Learning from patient experiences or patient experts was one of the main reasons the Trust had to be started 10 years ago, or perhaps it was lack of learning from patients!

IDDT realises the value of randomised controlled trials in providing evidence based treatment but we are also aware of the need to take into account patient experiences and/or auditing the effectiveness of treatment or drugs from a patient perspective. We have therefore advertised for applications in primary care but are happy to also consider applications that meet our criteria and are hospital based. We hope to broaden the areas of research we fund in the future but members can be assured that these will be in line with our aims of helping people that have diabetes now rather than future generations.

IDDT research grant application process

For simplicity and speed, the Trust has four levels of procedure for applying for funding from its Research Fund.

Stage 1 - Submission of an interim research application questionnaire (IQ) by the applicant. The IQ is simple and quick to fill in for the applicant to stop busy people wasting unnecessary time drafting a full application for research funding when their research field is outside the boundaries of the Trust's "patient centred" areas of interest.

Stage 2 - If the IQ is approved by the Trust's research group, then the applicant will be invited to submit a full research application. However, we do suggest that the applicant considers Stage 3 carefully before deciding whether to continue with a full research application.

Stage 3 - Before submitting a full research application, the Trust suggests that applicants carefully consider what potential benefits the research could have for the average every day diabetic patient as described above.

Stage 4 - Submission of the full research application.

For application forms please contact:

Beverley Sharpe

Research Facilitator, IDDT, PO Box 294, Northampton NN1 4XS

Tel 01604 622837 or e-mail bev@iddtinternational.org

Grant Application Awarded December 2001

National Service Framework for Diabetes – the effects of policy changes in quality, access and outcomes of care for patients with diabetes.

Applicants: Dr Julia Hipisley-Cox, Professor Mike Pringle

Aims:

- To establish baseline data for the quality of care for a cohort of patients with diabetes in primary care co-incident with the publication of the NSF for Diabetes in 2001 and to document changes in the quality of care over a period of 12 months.
- To determine the patients' views on the care they receive – its quality, timeliness, co-ordination including any deficiencies and suggestions for improvement.
- To determine any inequalities in the quality of care between and

within general practices according to age, sex, deprivation or ethnicity.

Grant awarded – this study has already been funded for 2 years by Trent NHS Executive R&D but the delay in the publication of the NSF for Diabetes means that an extension of the study is required. IDDT has agreed to provide additional funding.

Choice

Probably for the first time, the MMR debate has highlighted to the British public the reality that patients/consumers actually do not have a choice within the NHS system, the system for which they pay. They have realised that they have little involvement in the decisions made about their health yet they are expected to simply accept the decisions made by 'experts' who advise politicians. All the vast majority of parents want is choice but the government denies them this and then spends huge amounts of public money, on PR exercises to convince the public that they are wrong!

Researchers and scientists have moved from their labs to become part of a political agenda and into a world of receiving funding from industry so they should not be surprised that the public now question or doubt their advice and indeed, their work. When leading medical journals have had to develop a joint policy to try to prevent the hidden influence of industry in published research, the public are not alone in their concerns about the independence of scientific experts.

Successive governments have told us that we must take more responsibility for our own healthcare. But a natural consequence of this is that it is not acceptable to us to merely accept the recommendations of experts without question and convincing evidence. Diabetes is probably the best example of a condition where people take responsibility for their healthcare on a daily basis, so it has to be expected that we are more likely to require evidence to support the accepted wisdom of experts.

Has the MMR situation sounded familiar to you?

I am sure that it has! If one more so-called expert says that they have a stack of scientific evidence and they can't find any evidence of a connection between the MMR and autism, I am sure that many of us will want to scream. Not finding any evidence of a connection does not in itself mean that there isn't a connection – the experts whose advice we are supposed to follow appear not realise that "Absence of evidence is not the same as evidence of absence". But we do! These same arguments have been used by experts in diabetes and applied to 'human' insulin and its adverse effects but they didn't convince us either!

Anecdotal evidence

It is not for us to draw any conclusions about the safety of the MMR, suffice to say that there is evidence that casts doubt in the minds of the public. Apart from research of the pilloried Dr Wakefield and a few others, the DoH tell us that the evidence is only anecdotal. Does this make it any less valid? It certainly shouldn't because anecdotal reports from patients to their doctors are the very basis of the system for monitoring adverse drug reactions. So in dismissing anecdotal evidence are the experts and politicians questioning the validity of the whole system for monitoring the safety drugs?

Evidence of adverse effects from 'human' insulin has always been dismissed as anecdotal. But our case is stronger because when people change to natural animal insulin, their adverse effects disappear. Why should they disappear if 'human' insulin was not the cause? The experts dismiss this too as anecdotal and also choose to ignore the studies that do show a difference between synthetic and natural insulins.

Research

The public knows little about the studies carried out into the MMR but Professor Duncan Vere, a former member of the Committee on the Safety of Medicines has said publicly that ***“the periods for tests were too short to include the onset of delayed neurological or other adverse events”.***

Similarly the studies comparing animal and ‘human’ insulin were short, a matter of weeks or months but IDDT knows from our members, that on average the problems with ‘human’ insulin appear after 13 months and in some people it takes several years. Obviously these would not appear in the studies that lasted only a few weeks or months.

Lack of transparency in the drug approval process

On Jonathan Dimbleby’s Sunday programme, 10.2.02, Professor Taylor whose MMR research the government quotes, actually said it was *‘inappropriate’* to put his raw data in the public domain. This lack of openness adds to suspicion and distrust. In a similar way, people with diabetes have never been able to gain access to the research carried out prior to the approval of *‘human’* insulin – why not?

When the MMR situation was at its peak, we heard statements like ‘we can’t put the research in the public domain, because they wouldn’t understand it’. How patronising! We may not understand the research but perhaps the DoH should seek advice from the Cochrane Collaboration or Bandolier – they both manage to convert complex research into consumer friendly language. The DoH could do exactly this with the MMR studies and any other research where there is controversy. So why don’t they?

Responsibility

Healthcare decisions are supposed to be a shared responsibility between patients and doctors, yet here we have a situation where parents are being denied ‘shared responsibility’. If responsibility and choice is to be denied, then the DoH, the government and the experts have a responsibility to prove that their recommendations are safe beyond reasonable doubt. There is reasonable doubt when a former medical officer with DoH, Peter Fletcher, is prepared to publicly state ***“being extremely generous, the evidence of safety for the MMR was very thin…caution should have ruled the day…granting a product license was definitely premature”.*** Separate vaccines were available so why was the decision taken prematurely?

How many other vaccines and drugs does this apply to? Is ‘human’ insulin one of them? There was no need for ‘human’ insulin to be approved so quickly or prematurely because there was no shortage or imminent shortage of tried and tested animal insulin. Lack of answers to these questions just adds to the feelings of distrust and suspicion!

Similar but one major difference...

The similarity is that people with diabetes need proof beyond reasonable doubt that ‘human’ insulin is safe for them and provides them with the best treatment. If research cannot achieve this, then choice of insulins must remain available.

But the situation differs from the MMR one, in that people with diabetes are being denied an informed choice of insulins at the point of delivery of their treatment and not by government decisions. Of course this choice is further diminished by the influence and commercial decisions of the drug companies.

Sympathy must be extended to parents faced with the decision about having their children vaccinated with the MMR. They are left in the unenviable position of weighing up the risks and benefits of the MMR vaccination. But if animal insulins cease to be produced, people with diabetes will not even be in this position of weighing up risks and benefits – they will have NO choice and will have to use whatever insulin is left available. This may mean that they are less well, they lose their hypo warnings and their quality of life is reduced, but to survive they will have to use it. Not a prospect that many people would find acceptable!

Latest Cochrane Summaries

This is becoming a regular feature of the Newsletter because Cochrane Reviews are one of the best ways of assessing the evidence of the benefits, or otherwise, of various healthcare treatments so enabling us, and our doctors, to make informed healthcare decisions. Here are the recent ones that may be of interest to you:

Educating people with diabetes about foot care may help reduce foot ulcers and amputations, particularly in those at high risk
Foot ulcers are common in people with diabetes, usually caused by peripheral neuropathy [damage to the nerves], problems with the veins in their legs [peripheral vascular disease], excess weight and/or mobility problems. This review of all the trials found that educating people with diabetes about the need to look after their feet might help to prevent foot ulcers and amputations, especially in those at high risk of developing these problems. Although the research is not strong, education seems to improve people’s foot care knowledge and behaviour.

Not specific to diabetes but of interest and related:

No strong evidence that the effects of intermittent pneumatic compression on leg ulcers

Leg ulcers can be caused by a blockage or breakdown in the veins of the leg. Compression using bandages or stockings can help to heal leg ulcers but they do not always work and some people are not prepared to wear them. Intermittent pneumatic compression [IPC] uses an air pump to inflate and deflate an airtight bag wrapped around the leg. However, the review of the trials found conflicting evidence about whether or not IPC can help to heal venous leg ulcers.

Erythropoietin may help people with kidney failure and symptoms from anaemia who are not yet on dialysis
Anaemia [low red blood cells] is a common complication of kidney failure and causes some of the tiredness and problems associated with kidney failure. Manufactured erythropoietin is a hormone that increases the production of red blood cells and is used by people on dialysis to improve this. The review of the trials found that it can also reduce anaemia in people with kidney failure who are not yet on dialysis. It can increase blood pressure and it is not yet known if treatment with erythropoietin can delay the need for dialysis.

Long term antibiotic use for children to try to prevent urinary tract infections may cause more problems than they prevent
Bladder and kidney infections are known as urinary tract infections and they are common in children, especially girls, with some children getting repeat bouts. They cause vomiting, fever and tiredness and occasionally lead to kidney damage. Sometimes children are given antibiotics long-term to try to prevent infections returning but this can cause a lot of adverse reactions including vomiting. The review of the trials showed some evidence that the antibiotics did prevent some infections but there was more evidence that there were too many adverse reactions to make the treatment worthwhile. Nitrofurantoin was more effective than trimethoprim but produced more adverse reactions.

Sweet Success - Pancreas Transplant Support Group

Sweet Success: (Definition) – Enduring years of having diabetes; hypos; blood sugar swings; depression; anxiety; eating disorders; kidney failure; deteriorating eyesight; neuropathy and lack of self-esteem. Followed by a Pancreas and Kidney Transplant, resulting in no more injections; no more dialysis; fewer food restrictions and a much more ‘normal’ life!

My name is Joanne Tomlinson and I set up ‘Sweet Success’, a Registered Charity, after 23 years as a diabetic gave me no options but to agree to undergo a fairly new, and extremely daunting double

Pancreas and Kidney Transplant.

It was not until about a year afterwards, once fully recovered that I realised just how lucky I had been. Not only to have been offered this life-saving operation, not only that it had been a resounding success, but that I was no longer diabetic.

I wanted to let other people with diabetes know about this operation, to offer them hope and to support them through it. With the help of some Pancreas Transplant patients, my family and friends we set up a web site, www.sweetsuccess.org.uk, and a 24-hour telephone support line. We are gradually forging links with the various hospitals that offer this new procedure, as well as with potential Pancreas Transplant patients themselves, through organisations such as the IDDT.

Having developed diabetes at the age of nine, I suppose I defined myself subconsciously in those terms. I could not really remember any different way of life. I was taking seven injections of insulin a day, testing my blood a similar number of times, exercised, conquered my eating disorder, had become vegetarian and watched what I ate very carefully, and yet it was not enough – the damage had been done.

I don’t think people realise how difficult life can be as a diabetic. The general opinion is that you take some injections and don’t eat sweets and you’re fine. There are some very lucky people out there who achieve this, but there are thousands who don’t.

Teenage rebellion, society’s pressure to conform to a certain look, constantly thinking about food and being told to keep to such a strict regime, just don’t mix with growing up and trying to cope like everyone else, be that at school, at work, in a relationship or as a parent.

Having read many of the articles on the IDDT web site, I realise how angry I am at a world that lets people with diabetes get as ill as they do, that lets them cope with the tremendous pressure of life and diabetes. The dripping tap, as I see it - the slow erosion of all your body’s organs by an enemy that you don’t see until it is too late.

I realise that I sound very pessimistic about diabetes, but as I said before, not everybody has such difficulty coping with the routine and doesn’t suffer the same long-term health problems. But for those of us who do, there is light at the end of the tunnel. If like me, your health has been severely attacked as a result of your diabetes then a Pancreas Transplant may well be something to consider.

Good Luck and the Best of Health!

You can contact us via the web site (www.sweetsuccess.org.uk), or by email at enquiries@sweetsuccess.org.uk, or via the telephone on (01865) 450987, or write to us at Sweet Success, 50 Hertford Street, Oxford, Oxon OX4 3AL.

India - Choice Is Based On Cost Not Medical Need

In Western countries we are ‘big’ into patients having informed choices for their health decisions and indeed, one of our strong arguments for retaining animal insulin availability is so that people do have choice. But having a choice is a need not a luxury both for people who have adverse reactions to beef and/or pork insulin and for those who cannot afford the more expensive ‘human’ insulin.

At the 1997 International Diabetes Federation Conference a group of doctors from India presented an interesting poster [2578]. They looked at insulin usage in 232 people from their own centre for a period of 640 patient years and found the following:

Of the 82 initially using beef insulin

- only 4 developed insulin allergy necessitating a change to ‘human’ insulin.

- 22 changed to ‘human’ insulin for social reasons [rich or reimbursement]
- the remaining 56 people continued to use beef insulin without any problems.
- of the 3 people who reported local allergy to beef insulin, one opted for an immediate change to ‘human’ insulin and the other 2 remained on beef insulin and the local allergy disappeared.

Of the 150 people who were initially put on ‘human’ insulin [from other centres] or who had opted to change to pork or ‘human’ insulin

- 11 patients opted to change back to beef insulin because of affordability.

The authors conclude that there were medical indications for ‘human’ or pork insulin for only one of their patients because of his allergy to beef insulin and that patients’ choice of insulin in India is based more on social factors ie cost, rather than on medical reasons. Once again, this is hardly choice when the cost of ‘human’ insulin is beyond the means of many people but the paper does highlight that there is little or no medical reason to use the more expensive ‘human’ insulin. This could equally apply to countries that have health services such as ours – why does the strapped for cash NHS pay more than it has to for an insulin with no clinical benefits?

What the papers say in India

- Novo Nordisk to introduce ‘top-end’ injecting equipment in India

The Times of India,18.2.02

Novo Nordisk will introduce a range of top-end injecting equipment into India later this year. Novo will introduce ‘Innovo’ - a high-end electronic injection device and has plans for launching Induo, another top-end insulin injection system - a cellphone look a like with a dual integrated facility of Glucometer, for checking blood sugar levels and giving insulin accordingly.

Jenny’s Note: amazing when there is such a desperate need for basic insulin for people in India just to help them survive!

- **Natural insulin should be encouraged**

The Hindu, 21.12.01

Natural insulin, which is produced from animals, is a safer and cheaper alternative to the synthetic insulin, which is being promoted by certain pharmaceutical companies.

Speaking to newsmen here on Friday, Dr Arthur Teuscher, Professor of Medicine, Bern University, Switerland, Dr Philip Corfman, former executive secretary, US Food and Drug Authority and Dr N. Kocchupillai, Professor and Head, Dept of Endocrinology, All India Institute of Medical Sciences, New Delhi, said that there had been a concerted effort by MNCs to push synthetic insulin in the Indian market to replace animal extracted insulin.

The expected gains from synthetic insulin – purity, cost effectiveness and immunity to allergy, have proved to be ‘exaggerated’ and animal insulin had the advantage of longer duration of action so that sudden onset of hypoglycaemia [sharp fall in blood sugar levels] was avoided. Accidents and deaths from hypoglycaemia had seen a sharp rise in Europe and North America after the monopolisation of the market by synthetic insulin.

In India, while vials of synthetic insulin cost about Rs. 240, animal insulin cost as low as Rs. 65. Dr Kocchupillai said that the Indian Council of Medical Research recently recommended to the Government of India that animal insulin should be encouraged and promoted so that cheap alternatives were readily available in the market.

Diabetes Solution – a complete guide to achieving normal blood sugars by Richard K Bernstein, M.D.

IDDT has received many requests for more information about the low carbohydrate diet and some people have had difficulty obtaining Dr Bernstein's book. For those not able to order or obtain it from the well-known book shops, it is worth phoning Intercontinental Book Shops Inc in the US who will put it in the post. The phone number is 001201 967 5810, fax 001201 967 9830 or you can e-mail them at ibdbook@ix.netcom

If you have access to the internet much of Dr Bernstein's book is on his website www.diabetes-normalsugars.com

Trapped In My House Without A Pen!

By Carol Baker, IDDT- Canada

At a recent meeting of the Diabetes Resource Team, a former Home Care Nurse, who had joined the Novo Nordisk team, presented the latest information from Novo. She is a knowledgeable person about diabetes, and we have had some conversations at the Team meetings about animal insulins, and the need for them by some people. In her presentation, she made the statement that those people who did not use a pen were captive in their homes! She had recently completed her orientation with Novo Nordisk, and provided us with their latest information. One of her comments was that persons who use syringes consistently make mistakes in drawing up their insulin, and that the use of pens would alleviate this problem. She also stated that there were approximately 50% of insulin users who now used pens for administration of insulin exclusively, and did not have to use syringes. I muttered under my breath that these were outrageous statements, and misrepresenting the care and attention that the majority of us take with our diabetes. It seemed to me that her statements were patronizing at best, and demeaning at worst.

In Canada, the insulin producers/providers have said that animal insulin is incompatible with pens, and as a result, there have never been any cartridges containing animal insulin made available to those of us with diabetes in Canada. My personal experience has been to empty the synthetic insulin out of the cartridges that are available here, and to refill them (many times) with animal insulin. As a result of this I have used my pens while travelling, and when out for meals, and in many other situations. However, before I take any insulin, I do test my blood glucose, and in order to do that, I carry a small glucose meter. The meter comes in a small nylon pouch, and it has room for test strips, a finger poker, and a small net pouch in which you can put whatever your heart desires. On the outside of the pouch there is room for a number of syringes, and several bottles of insulin. This meter goes everywhere with me, and I mean everywhere. I have one beside my bed and I have one in my handbag.

Following the meeting, I spoke with the Novo Nordisk rep. and showed her my glucose meter in its' nylon pouch. I said that this is my "pancreas in my pocket" and that the statements that she had made were inappropriate. There were others with me during this exchange, and she had little to say in response to my comments. The purpose for my telling her this was to educate her in the realities of life with diabetes. I told her that I have never been captive in my house as a result of using a syringe, and that although I do not have functioning Islets of Langerhans, I do have the ability to test my blood glucose and administer insulin via syringe accordingly.

The question arises as to what happens when a pen fails. If you have never been taught how to draw up your insulin in a syringe and the pen that you are using fails, you are in a dilemma. What to do? One time on my travels, I dropped my pen, and the same day I sat on my glasses. Both broke. I was still able to prop my glasses on my nose, and use my syringes for the rest of my trip. Fortunately I never leave home without a full supply of syringes and bottles of insulin.

It is interesting to note that the nurse who had become the Novo Rep. is again working full time as a Home Care Nurse, and that her career with Novo was short. Did I contribute to that? I have no idea, but perhaps she was unable to live with the rhetoric that Novo had provided her. One can but hope.

No Insulin Identical To Pork Velosulin

From Margaret Pitcher

I have had some difficulty finding a satisfactory substitute for Pork Velosulin, and wonder how others have felt about having to change? How easy was it and was their quality of life affected? Have they found one of the other animal insulins to be a satisfactory substitute, or even advantageous? Or have they had to change to a human insulin or an analogue, despite the disadvantages this might entail? Would anyone prefer to change back to Pork Velosulin if it were available?

I have had to take a lot of time, do more testing, have more hypos (the 'pork insulin type') and more highs (this altered control led to nerve pain intense enough to wake me at night). As a result I have changed back to very old Pork Velosulin, but this will not last for ever. The Mims insulin action charts from 1984 to 1998 bear my experience out.

In 1998 replying to my letter, the then BDA said they accepted my point that, of the available pork insulins, neither insulin works identically to Pork Velosulin and that this may lead to problems. Although these insulins may work perfectly for many people, they do not fit with my regime, which involves using only soluble insulin. However, after 7 years experience of trying, as a vegetarian, to manage with human insulin (which included hypos which felt like a sort of mental torture, more volatile control, excessive

tiredness, and, over the years, the development of a persistent light headed or foggy feeling in my brain which did not appear to be at all linked with hypos) I do not feel that a change back to one is an option.

I feel angry that I have been given a problem I need not have. I am forced to 'go back to the drawing board', and to redesign my life style. Despite the current rhetoric of 'empowerment' I cannot choose the insulin that best suits me, and which gave me very good control.

Given that doctors, from Lawrence onwards, have recognised that those with diabetes differ in their sensitivity to insulin, and in the type of regime that may suit them. More recently, articles in various diabetes journals have said that a wide range of animal insulin products should remain available, and that a variety of insulins for the variety of patients is desirable, I find it hard to understand why those with diabetes find their choices are restricted, rather than being widened. Why should those who choose to use animal insulins have less choice than those who do not? This seems particularly odd as, outside the patient world, there is a constantly expanding choice for consumers.

I would be pleased to hear from anyone who has had to change from Pork Velosulin regarding their experiences.

Note: Margaret can be contacted through IDDT at PO Box 294, Northampton NN1 4XS

The NHS – delays are unacceptable

Many of us have been experiencing the now well-recognised tricks for delaying hospital appointments or inpatient stays:

- Cancellations through the post with the next appointment months away, the further cancellations of the same appointment.
- When you actually attend being told that there was an error when the appointment was made, so it is booked months later.
- One of the best to someone waiting over 2 years for an operation! "This letter is informing you that you will receive notification

> within the next 25 weeks of when you will receive a date for your consultation.” [Not operation!]

The statistics look good because patients have received appointments within the target times but they are not actually receiving the treatment. It takes clever administrators to work out systems like this or maybe they are trained to put the best possible gloss on things! However, these tricks have been picked up by the National Audit Office so presumably the administrators will have to work out some more.

IDDT has also received complaints about these delays - rightly so. Many of us remember feeling that the change to an ***annual*** MOT was a reduction in the care that we were receiving but now in some areas these annual checks are being postponed for several months. So the ***annual*** MOT is no longer ***annual***! In two cases reported to us the annual MOTs were postponed so many times that these people were not seen for nearly two years. In one case, despite appeals from the GP, the ‘annual MOT’ for a man with an infected toe was cancelled 3 times and by the time his appointment arrived, he had a black toe and the infection had spread to his knee. Apart from affecting the health and life of this poor man, such delays are ultimately not actually saving the NHS money or time.

In the other case, the man says:

“I am a type 1 diabetic of 58years old and have been using insulin since the age of 8, I feel these delays are unacceptable. I have written to the hospital, the Health Authority, my local MP and Alan Milburn – all without satisfaction. It seems to me that the emphasis is being put on people with Type 2 diabetes and we Type 1s are being forgotten. What can be done? Do you have reports of this in other areas?”

Well, the answer to this is, yes it is happening in other areas but the question of what can be done is not so easily answered.

Headlines in the Gravesend Reporter, 8.2.02, “I’m sick of being let down”

A man who has had insulin dependent diabetes for 28 years has had his annual check appointment cancelled 3 times. He waited 17months to see his consultant and has now made a formal complaint about the service provided by the Dartford and Gravesend Trust. Part of the Trust’s defense was “During this time he had open access to the specialist nurses if at any time he was concerned about his condition”.

Clearly the Trust is missing the point – firstly he doesn’t want to see a nurse, he wants to see a consultant and secondly, the point of the annual check is to screen for complications on the basis that early detection is essential to prevent/arrest further deterioration.

Making a complaint
If you are faced with a similar situation, then you should first contact your diabetes clinic, if this gets nowhere then complain in writing to the hospital.

However in the cases we have cited, making a complaint had no effect. Unless there are improvements, it is not difficult to foresee a time when the UK will become more like the US – patients will resort to the legal system. The gentleman with the septic toe that needed early treatment now has an increasingly ulcerated leg – negligence in any one’s language. No one wants to see an increase in litigation, it achieves little except to line the pockets of lawyers. But if the system fails to this extent, then people will be angry enough to take action - action not against the medical staff within that system, but the system itself.

Occasionally though we need to appreciate what we do have!
The services we receive may not be good enough in some areas but perhaps sometimes we do need to appreciate what we have got - we still have free care and treatment at the point of delivery, well for most things! We know that we are very fortunate compared to people in poor countries but we are also more fortunate than many people in other industrialised countries. IDDT is receiving an increasing number

of messages from people in the US who are searching for free or cheaper insulin. As one man said, he has worked all his life, paid into his insurance scheme, paid a percentage of the costs every time he received any treatment but in retirement is finding difficulty in meeting the very basic costs of insulin. And he has insurance cover, what about those without cover?

No way is IDDT suggesting that we should accept sub-standard care and or that we should forget that we are actually paying for our healthcare. We would encourage everyone to be assertive about their needs for good healthcare but sometimes perhaps it is a good idea to think about what we actually do have – we do not live with the fear of not being able to afford the insulin that keeps us alive!

Apologies For Error

Support groups for partially sighted and blind people

Page 11, January 2002 Newsletter

I referred to this organisation as the NASVI and this should have read NALSVI. This stands for National Association of Local Societies for Visually Impaired People. You will remember that we pointed out that support groups are an excellent way to learn from other people who have faced similar worries and concerns and they can be an excellent way of offering practical help from first hand experience. The NALSVI is an organisation that co-ordinates a network of support groups throughout the country for people with visual impairment.

If you would like further information about the nearest support group to you, then either contact Sue Ferguson of NALSVI on 01904 671921 or Beverley Sharpe at IDDT on phone 01604 622837.

Another Disappearance From The Marketplace

Novo Nordisk acquires Biobras

IDDT is alarmed as another insulin producer bites the dust, but we deny being ‘alarmist’.

Many of us will remember that there used to be a whole list of insulin manufacturers – Boots, Weddel, Welcome, Nordisk, Novo and so on. Gradually they disappeared through takeovers but nobody seemed to notice or care about the significance and the eventual outcome of these business transactions. The outcome is now there for all to see - there is a virtual global monopoly of insulin production by four major pharmaceutical companies, now reduced to three. This small group of companies has the power not only to control the price of insulin but also has the power to control insulin supplies. This power has enabled them to systematically discontinue animal insulin supplies in many countries because there is no competition in the marketplace, so they can do what they want!

As we know to our cost, this has denied choice to those that cannot tolerate ‘human’ insulin and makes insulin unaffordable for many people in developing countries. This is an insecure position for people with diabetes leaving them vulnerable to the commercial decisions of this powerful group whose prime responsibilities are to their shareholders. This is not nasty – just realistic.

Business is business!
This is an argument that is a bit too simplistic when it comes to the pharmaceutical industry! We have seen the reduction in the number of car companies over the years resulting in less choice of cars but having a few less cars to choose from does not put people’s health or lives at risk. Reducing the choice of insulin and controlling its price, undoubtedly does! The huge profits made by the pharmaceutical industry do not, or should not, come without a price and that price is a degree of social responsibility to the people that provide their profits – us, those that need their products. Even car companies exercise a

social responsibility in ensuring that their cars are safe for everyone.

- **It is not in doubt that there is a group of people who either cannot tolerate 'human' insulin and it is not in doubt that people in developing countries cannot afford the more expensive synthetic 'human' insulins.**

The insulin manufacturers know this too and yet they continue with their systematic discontinuation of animal insulins. Is this exercising any degree of social responsibility? No it is not and their discontinuation policy continues regardless of people's needs. The major insulin producers are not even exercising the same social responsibility as car manufacturers – they are NOT ensuring that they supply products are safe for ***everyone***! Yes, the vast majority of people can use 'human' insulin and that's fine but what happens to the people that can't and the people that can't afford 'human' insulin if this group succeed with their intention of removing all animal insulins? Are these companies free from all responsibility? Are governments that say they cannot interfere with commercial decisions free from all responsibility?

Novo Nordisk acquires Biobras

Biobras is one of the world's major manufacturers of animal insulin but more importantly, it is one of the few remaining producers of the insulin crystals - the 'raw' materials from which animal insulins are made. Biobras supply these crystals to other companies as source material for their own animal insulin. In December 2001, Novo Nordisk announced that they had acquired Biobras. At the time of writing, the bid has been accepted by the board of Biobras and is being considered by shareholders and the Brazilian competition authorities, because of concerns centred on Novo's recent policy of scaling down its production of animal insulins.

Fears that worldwide production of animal insulin could be at risk by the buy-out

It is not an unreasonable fear and was reported in the BMJ, 19.1.02. Novo Nordisk have already stated their intention of global withdrawal of all animal insulins and so the big question is, are they are going to continue to produce insulin crystals at all simply to supply other companies that ultimately are their competitors for insulin sales? For example, CP Pharmaceuticals, UK, is currently the only manufacturer still to produce both porcine and bovine insulins and one of their sources of insulin crystals is Biobras.

The BMJ quotes Novo Nordisk executive vice president, Lars Jorgensen ***"the company has no plans for the discontinuation of production of animal insulin. Nor will it halt Biobras's supply of source material to other companies that manufacture insulin".***

But as we witness their systematic discontinuation of animal insulins throughout the world, the first part of this statement clearly is not true - it is merely company speak that omits the words 'at the moment'! On December 31st 2001 Novo Nordisk animal insulins became no longer available in Germany! We have listened to these hollow reassurances for years, so how can we believe their reassurances that they will not halt Biobras's supply of crystals to other companies?

Just a note:

Interestingly on March 7, 2001 - Gazeta Mercantil reported that the Brazilian Chamber of Commerce had fixed an antidumping right over the imports of insulin from Novo Nordisk and Eli Lilly concluding the antidumping process requested by Biobras in August 1999. The report says that between June 1998 and June 1999 Novo Nordisk dumped 'human' insulin in Brazil at very low prices, so undercutting Biobras's locally produced animal insulin and gaining 70% of the domestic market. Perhaps now we know what they were up to!

So what is the net result?

Assuming that this take-over goes ahead, there are two main issues that have to concern us:

- Novo Nordisk will have the power and control of supplies insulin crystals to companies such as CP Pharmaceuticals in the UK. So if they want to stop animal insulin production throughout the world, they are well on their way to being able to achieve it.

- Insulin production and price will now be in the hands of only three companies – Novo Nordisk, Lilly and Aventis so putting the future supplies of insulin of all types in even fewer hands and giving them even greater power and control, not to mention even greater profits.

Pharmaceutical companies becoming bigger and bigger by buying out the competition has wide ramifications in healthcare generally. The control that they now have over insulin production and the treatment of diabetes is an example that should not be ignored. Undoubtedly there are many people who will not care that animal insulins are at risk of being 'extinct', especially those who have never believed patients' adverse experiences with 'human' insulin. But these people must also realise that ignoring the broader implications of these commercial decisions puts the control of treatment of diabetes in the hands of pharmaceutical giants and not the medical profession. As patients we must ask if our lives safe in their hands when the bottom line is shareholders profits? Is this a future patients and doctors actually want?

IDDT stands accused of being alarmist!
Only a matter of a couple of weeks before this announcement IDDT received a telephone call from a rather cross lady who uses animal insulin. Her diabetes nurse told her that IDDT was raising unnecessary alarm about the possibilities of animal insulins being discontinued. She said that this would not happen because Novo Nordisk has denied that they are to discontinue their pork insulin.

Oh, to have such faith and trust! It is quite enviable but something many of us lost along time ago. I pointed out to the lady that it was not a question of ***IF*** Novo Nordisk discontinue their animal insulin supplies but ***WHEN*** – as they have already announced their intention to globally discontinue all their animal insulins. However, the lady on the phone quickly retorted with 'My nurse says that IDDT is just being alarmist because CP are committed to continuing to produce animal insulins.'

This is naïve, not a matter of faith or trust! Yes, CP is committed to the ongoing production of beef and pork insulins. They deserve our praise and gratitude for doing all they can to ensure that not only do we in the UK have the animal insulin we need but they also do a great deal to help people in other countries to obtain their supplies.

But it is not alarmist to say that this leaves thousands of people who need animal insulin in a very vulnerable position – it is simply realistic. People in countries throughout the world could be entirely reliant on CP for supplies of animal insulins. With the best will in the world, the reality is that they are a relatively small company and may not be able to go on producing insulin indefinitely.

IDDT has always been aware of this and feared that once the big boys have ceased to produce animal insulins, the supply of insulin crystals could be in jeopardy but we had thought that this could simply be by lack of demand. The Novo Nordisk buy-out of Biobras was not what we expected and is actually worse – because at any time they can make yet another 'commercial decision' to cease production!

These possibilities are alarming. But if alarm bells had rung in the 1980s, we would not now be facing the present situation where some people with diabetes have to live with the fear that the insulin they need may no longer be available.

……

IDDT Moves Into Action

IDDT's duty and responsibility
Alarmist, realistic or whatever, IDDT has a duty and responsibility to its members and to people with diabetes, especially those who need animal insulins. Failure to take any action to defend the needs of this significant minority of people would be irresponsible of IDDT. Indeed,

failure to act would be irresponsible of any organisation that claims to care about the wellbeing of people with diabetes. No organisation can simply choose to ignore the needs of a particular section of their client group without being open to criticism. It may be uncomfortable for organisations that rely on pharmaceutical industry funding to stand up for the needs of their members against the decisions of the companies that help to fund them, but there is a degree of accountability to people with diabetes that they claim to represent.

IDDT steps up its actions following the Novo Nordisk buy out of Biobras

We have set out below our initial actions and will keep you informed.

Increased local publicity – we are circulating all local papers with a letter to the editor to inform readers of the adverse effects that can occur with 'human' insulin and to inform them that animal insulins are available and suit some people better. Already we have received lots of calls from people who recognise the problems and they all receive an information pack from IDDT.

Formally raised the issue with certain Members of Parliament – this will be developed and we hope that you, our members will help us with this when we ask for your support and help. Information for members is enclosed with this Newsletter and there will be further bulletins.

IDDT- International has made a formal submission to the International Diabetes Federation [IDF] – this body represents diabetes orgnanisations from countries around the world and is the obvious body to represent the interests of people who need animal insulin in both developed and deveoping countries. IDDT has therefore made the following formal submission for the consideration of the Executive Board of the IDF.

IDDT- International Submission to the IDF

1. Availability of animal insulin

The IDF should publicly acknowledge the need for the continued availability of animal insulins as an essential drug, for the following groups of people:

- Those that cannot afford the more expensive synthetic 'human' insulins and therefore suffer and/or die for lack of ***affordable*** insulin.
- People in poor countries that have a reduced standard of care and therefore need to use slower acting, less aggressive animal insulin for safety reasons, the reduced risk unheralded hypoglycaemia with animal insulin.
- There is also a need to maintain supplies of U40 insulins for similar reasons.
- Those that cannot use 'human' insulin wherever they may live, because of adverse reactions to 'human' insulin or because they obtain optimal blood glucose control with natural animal insulins. This is now widely acknowledged by government health departments and many within the medical profession.

2. Dominant position of the major insulin producers

The IDF should examine the dominant position of insulin manufacturers and condemn the virtual global monopoly that not only dictates the price of insulin but the production of insulin and its various species. The IDF should publicly recognise that if this dominant position continues unchecked then the treatment of people requiring insulin will be dictated by the pharmaceutical industry and not by patients' needs or by physicians' clinical judgement.

The recent proposed acquisition of Biobras by Novo Nordisk highlights this position. Biobras is a major source of insulin crystals throughout the world. Novo Nordisk have made a public announcement of their intended global withdrawal of all animal insulins and patients rightly fear that their acquisition of Biobras will lead to discontinuation of insulin crystal production. This will mean that globally insulin producers, whether large or small, could be forced to cease production of animal insulins.

3. Clinical benefit

The IDF should recognise that the medical reasons for changing a patient's treatment should be on the grounds of evidence of clinical benefit for the patient. As yet there is no evidence of any clinical benefits for patients from changing from animal insulins to synthetic insulins and so there are no grounds to transfer patients that are well and safely controlled on animal insulin to synthetic 'human' insulins. The IDF should condemn the present position where patients are being forced to change to synthetic 'human' insulin because of the commercial decisions of insulin manufacturers and not because of their clinical need. It is hard for patients to understand why physicians have allowed industry to erode their prescribing rights as well as the rights of their patients to the insulin treatment that suits them best.

4. IDF role

It is patients' understanding that the role of the IDF is to protect and support the best interests of people with diabetes and that this role is, or should be, paramount. In this there are no grounds for commercial considerations, divided loyalties or conflicts of interest. The IDF is, or should be, in an influential and powerful position to protect the best interests of people with diabetes in both industrialised and poor countries. From the patient perspective, it is difficult to understand why the IDF has not already taken the necessary steps to unite together to support the needs and freedom to choice of ALL people that require insulin treatment.

5. Summary

The IDF should make recommendations to support the needs of patients and these should be put in the public domain and also sent to diabetes associations and organisations of the medical and nursing professions:

1. condemning the dominant position of the major insulin producers whereby people with diabetes are suffering and dying as a result of their commercial decisions.
2. expressing the view that patients' needs are paramount and patients' right to an informed choice of treatment is an essential and integral part of best practice.
3. that animal insulins should remain available throughout the world for the people that need them for whatever reason whether these be on the grounds of economics or clinical need.

IDDT-International, February 2002

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Personal Importation Of Beef Insulin Into The US

Latest News, February 2002

People in the US are entitled to import beef insulin made by CP Pharmaceuticals, UK, for their own personal use because beef insulin has been discontinued by Eli Lilly and Novo Nordisk in the US. The importation procedure is somewhat cumbersome but necessary for the people that cannot tolerate 'human' or pork insulins. One of the importation requirements is a permit from the US Dept of Agriculture [USDA] and there have been some recent changes to this. At one point it appeared that the permit was going to be free of charge but unfortunately this is not to be, despite pressure from IDDT-US and others.

USDA now states the following:

- a permit will continue to be required for the importation of insulin for personal medical use.
- the duration of the import permit for insulin will be extended from a one year to a five-year permit, effective immediately.
- the initial cost for a personal import permit is $94.00 for a five-year permit. Renewal cost at the end of the five-year permit is $61.00.

While this is not by any means ideal because of the initial financial burden, overall it is cheaper than previously and there is added advantage of only having to apply to USDA once every 5 years.

- For further information from USDA, you can contact them by phone 1- 301- 734- 3277 or visit their website www.ahis.usda.gov/ncie/imp-prod.html
- Further information on the personal importation procedure can be obtained from CP Pharmaceuticals, Toll Free Phone: 011 800 667 55 555 Fax: 011 44 1978669230, website: www.cppharma.co.uk

e-mail Export@cppharma.co.ukmailto:Export@cppharma.co.uk

New Website For IDDT - US

All the above information is available on the IDDT-US website. This has recently been revised and now can be visited in two ways:

- www.iddtus.org
- by visiting IDDT-International's website www.iddtinternational.org and clicking on the flag of the United States.

From Our Own Correspondents

Response to Tips

Dear Jenny,

Further to the 'Tip' from Shirley Stone in the Winter 2001 Newsletter regarding how to ensure that you are given animal instead of 'human' insulin, surely the answer is simple – Take your own insulin with you. Surely you don't rely on a hotel or relatives/friends to provide your insulin when you are away from home, so why expect a hospital to do so?

Since developing IDDM 35 years ago and living in various parts of the country, having had 3 children by caesarian section, numerous eye operation etc I have never encountered any difficulty in using my own insulin. I make sure that I take enough with me to cover the duration of my stay.

WE are in control of our diabetes including our insulin supplies. The NHS is stretched far enough without having to provide what is to us routine care for its inpatients with diabetes.

C.V.
Lincs

Jenny's comment – Thanks to Mrs C.V. for pointing out that we should all take our own insulin into hospital and that this is our responsibility. She is lucky that the hospitals she has encountered have been prepared to use her own animal insulin. Shirley's past experience was that despite taking her own animal insulin into hospital with her, the hospital refused to use it because it was animal and only did so after a hard fought battle! I have to say that when my daughter had a caesarian section 2 years ago, her hospital refused to use her own animal insulin and insisted that they administered 'human' insulin. What Shirley discovered this time was that if she gave her reason for wanting to use her own insulin as being 'allergic' to 'human', then there was no argument and her own animal insulin was used – a tip worth knowing for those with less understanding hospitals!

To cut a long story short!

Dear Jenny,

When I read your copy of 'Introducing IDDT' several months ago some of the comments in the survey you carried out in 1994 made me think I was on the wrong insulin.

I was diagnosed with diabetes over 4 years ago at the age of 55. Everything was fine for a couple of years but a year ago my 'human' insulin was changed. From then on I just felt different – my weight ballooned, my temper flared up and down and I just felt OFF! To cut a long story short, I spoke to my GP first who had no objection to changing to pork insulin but referred me to my consultant. The consultant thought I was mad and kept telling me there was "no difference", so I just used your advice and replied "Well then, I'll try animal insulin for 6 months".

I then spoke to another GP at my practice and he said "Just remember it's your diabetes, not mine, not your GP's and certainly not your consultants". Fair and understanding words, I thought – for a change!

So I have been on pork insulin for the last few months and I feel fine. I'm a lot gappier with my life now that I am back in control and I am now really going to get my weight down again now.

Many thanks for all the information and Newsletters.

D.J.
Scotland

Jenny's comment – glad the advice worked! But there are two serious points here – this person had the classic 'human' insulin adverse effects but had never been on animal insulin and IDDT is hearing this more and more. So this blows holes in the theory that they only happen to people who have been on animal insulin and/or diagnosed a long time. The second point is, does the consultant actually believe that there is no difference between 'human' and animal? Surely not but the alternative thought is worse – he's not being honest!

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

Hypoglycaemia At Work

Research suggests that there is no reason for discrimination
Research carried out in Edinburgh [ref1] presented at the European Association for the Study of Diabetes [EASD] conference, Sept 2001, has been interpreted as showing that discrimination against people with diabetes on the basis of hypoglycaemia is unfounded.

The study involving 240 people between the ages of 20 to 69 with insulin dependent diabetes in employment, recorded full details of the reported hypos and glucose control using HbA1c over a 12month period. 238 severe hypos were experienced by 34% of the 240 people in the study.

- Of these 238 reported hypos, 62% happened at home, 15% at work and 23% elsewhere with half of them occurring during sleep.
- Adverse events included 29 people in coma, 20 people had seizures, 4 sustained head injuries and 5 had other injuries.
- No road traffic accidents were reported due to hypoglycaemia.

This actually means that about 81people had a total of 238 severe hypos during the year and that about 35 of these occurred at work.

- 78% of those having a severe hypo reported being treated by a relative or partner.
- 13% reported being treated by a work colleague
- 5% needed medical help.

1995 mild hypos were reported of which

- 55% occurred at home
- 30% at work
- 15% elsewhere
- 7 reported adverse events and 5% needed time for recovery.

This actually means that there were over 650 mild hypos while people were at work.

Conclusion by the author

The author concludes that this research showed that severe hypoglycaemia was uncommon at work and when it did occur, it did not cause disruption. From this he concludes that there is little reason for discrimination by employers. But we have to look carefully at the results:

- The hypos in the study were those reported by patients and it is well known that patients underestimate the number of hypos. Several years ago research carried out by Prof John Ward demonstrated that the number of hypos reported by partners was always significantly higher than those reported by patients. People with loss or partial loss of warnings cannot accurately report their hypos, especially the mild ones, because they don't know when they are having them!
- Were the 240 participants in this study a true representation of a clinic population? Or did the people who have more severe or more frequent hypos choose not to enter the study?
- The report of the study says '***only***' 34% of those studied had severe hypoglycaemia, even without taking into account under-reporting or selection bias of the participants, this is actually a third of the people in the study that had 35 severe hypos at work in just one geographical area.
- Research has shown that people do not function efficiently even with mild hypoglycaemia and there were over 650 reported mild hypos at work.

Discrimination or not?

Perhaps discrimination at work is best defined as an unreasonable and inflexible attitude of employers towards people simply because they have diabetes. There is no doubt that this occurs despite the Disability Discrimination Act and it is essential that people are looked at as individuals rather than general assumptions being made about people with diabetes.

But there is also a need to be realistic and the study did demonstrate that during a year at least a third of people with diabetes had severe hypos and 15% of these did occur at work. There were 650 mild hypos, when people may not be functioning properly despite feeling OK. We have to accept that there are certain jobs where this may be dangerous to the people themselves or to their colleagues in just the same way as other conditions prevent people from doing certain jobs. For example, people who have what is often described term as a 'lazy eye' or 'squint', are not allowed to drive fork lift trucks because they are unable to judge distances as well as people with two working eyes [binocular vision]. This is not discrimination but a health and safety issue. Unexpected hypoglycaemia can equally be a health and safety issue and not discrimination.

Clearly the vast majority of people with Type 1 diabetes do not pose a risk at work but some do and in certain jobs, this may present health and safety risks. Surely the best approach to beat discrimination is to accept that this is the case and argue that people to be judged on an individual basis. There undoubtedly is a need to dispel the myths that surround diabetes with effective public education. However, the best message is given by people with diabetes and their medical advisers by demonstrating that good control is not simply the avoidance of high blood sugars, but also the avoidance of low blood sugars!

"School ban on trips for diabetic boy illegal"

This case of Tom White being denied school trips abroad because he had a severe hypo on a previous school trip was widely reported in the papers when his school claimed that this was not a discrimination issue. His case was taken up by the Disability Rights Commission and the boy has now won the right to attend school activity trips. In a previous Newsletter, IDDT pointed out that there are health and safety issues involved here and not a simple case of discrimination against Tom because he has diabetes. Tom required attention from two members of staff and one had to stay behind with him the day after the hypo so denying other pupils the legally required number of staff to look after them. What would have happened if another pupil had an accident and the staff numbers were even further reduced – another legal case?

In September 2002 the law is to be changed to protect school children with disabilities from discrimination but it has to be hoped that increased finance for this purpose will accompany this change. To avoid being faced with discrimination litigation, for pupils with diabetes alone, schools will need to have staff training, perhaps a meeting with a diabetes nurse, a review of procedures and perhaps an extra member of staff will need to go on the school trip. All this costs money and a change in the law must be accompanied by extra funding otherwise the complexities of avoiding discrimination litigation could result in fewer and fewer school trips for everyone. It has to be remembered that the organisation of school trips relies heavily on the goodwill of teachers. Tom's parents are also suing the school, let us hope that they are equally active in campaigning for increased resources for future school trips.

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Overweight?

Cheer up, dieting gets easier with time!
A recent study [Obesity Research, Sept 2001] reported that people who lost a lot of weight found it easier to keep it off over time. There were 758 women participants and 173 men in the study and they had all lost at least 30 pounds and kept this weight off for over a year. A year after this, they all filled in a questionnaire when the average weight loss was 62 pounds and kept this off for an average of at least 7 years.

The research showed:

- The longer ago the weight loss occurred, the fewer strategies people used to maintain their weight loss.
- People who had kept weight off longer put less effort into dieting.
- People who had kept weight off longer did not find exercising, low fat meals or keeping weight off any more pleasant than people who had lost weight more recently but it took less effort for them.

This research supports other studies that have found that the longer people keep weight off, the less likely they are to regain it. A possible explanation is that the new healthier habits become ingrained and require less effort.

Use smaller plates!
Here are some helpful thoughts from the British Journal of Nutrition [Dec 2000; 84 Suppl.2]

- Large amounts of food on the plate lead most people to underestimate the amount of real energy contained.
- People with large amounts on their plates are apt to eat more.
- People who ate all the food on their plates showed a higher BMI [body mass index, the official measurement of weight] than those who left some of the served food.

So for those with a weight problem perhaps the messages here are to use smaller plates and put less on them!

Jenny's comment: this reminds me of a 'trick' I used to play with my daughter. When I knew that we were eating something she really liked and I knew she and her brother would want seconds, I used to give her less in the first helping. I thought this was quite a clever tactic but years later she told me she had always known I did it!

Useful organisations:

Weight Concern, tel 020 7679 6636, www.weightconcern.com

MAP [Medical Action Plan], tel 0800 731 7138

British Heart Foundation, tel 0870 600 6566 www.bhf.org.uk

More About Cholesterol

New cholesterol guidelines may lead to over-treatment

The US National Cholesterol Education Program [NCEP] issue guidelines meant to help to diagnose high cholesterol levels that need treatment with drugs. The most recent guidelines have lowered the level of cholesterol at which people with two or more heart disease risk factors need anti-cholesterol drugs. Researchers at Maryland University [ref1] are concerned that this may lead to a dramatic increase in the number of people using drugs to lower their cholesterol levels. They have calculated that this means that 36 million people in the US would be referred for drug treatment under the new guidelines compared to 15 million under the previous ones. This means the new guidelines are recommending an increase of 201% for people under 45 years old and an increase 131% of people 65 and older requiring anti-cholesterol drugs.

The researchers warn that this is an aggressive way to lower cholesterol and there is a need for caution because the guidelines have broad implications, especially for the elderly who may already be a range of other drugs.

Their concerns are well justified when one of the most commonly used anti-cholesterol drugs, Baycol, had to be withdrawn last year because adverse reactions to it. Other drugs in the same range now carry extra warnings and doctors are advised to be alert to adverse reactions especially when in people using a range of other drugs.

It must be remembered that there are less harmful lifestyle changes such as diet and exercise that can be just as effective at lowering cholesterol levels as drugs. We must also remember that there is a lot of money to be made from treating high cholesterol with drugs so the pharmaceutical industry has much to gain from pushing drug treatment but little to gain from lifestyle changes!

Circulation 2002;105:152-6

Low cholesterol levels increase the risk of death in older people

Lowering cholesterol is a major aim in the prevention of heart and circulatory disease with high cholesterol levels being linked with death in people under 65. But researchers in the US say that low cholesterol levels could be associated with an increased risk of death in older people. They carried out a study over 20 years in 3,572 men between the ages of 71 and 93 and found that the cholesterol levels fell significantly with increasing age. The group with the lowest cholesterol levels had the highest number of deaths. The researchers concluded that there is no scientific justification for lowering cholesterol levels to very low concentrations in older people.

The Lancet 2001;358:351-5

Regular exercise benefits cholesterol levels

Regular exercise is known to raise levels of high density lipoprotein [HDL] known as good cholesterol. This in turn helps to reduce the risk of heart disease in those who are physically fit and active. However it is unclear whether increasing the amount of exercise in someone with low HDL levels actually reduces their risk of heart disease. Researchers in Canada compared the responses of HDL cholesterol levels with a 20 week endurance exercise programme in 200 men. The results showed that in men that had low HDL, the levels only marginally increased with exercise but in men that had low HDL levels and high triglyceride levels to start with, there was a significant increase in HDL cholesterol levels with exercise. The researchers conclude that regular endurance exercise training may be particularly beneficial for men with low HDL cholesterol and high trigycerides.

Arteriosclerosis, Thrombosis and Vascular Biology 2001;21:1226-32

For The Ladies - More On HRT

IDDT receives many queries about whether or not HRT is beneficial for women with diabetes and we have written about this in previous Newsletters but it then appeared that there was little research and no firm conclusions either way. There is now some new research that sheds a bit more light on the issues involved to provide more evidence for you to consider when making the decision about whether HRT is for you or not.

What oestrogen and what does it do?
Oestrogen is a female hormone that helps to make bones strong and less susceptible to fractures. As women grow older the body produces less oestrogen and so after the menopause there is an increased risk of osteoporosis, thinning of the bones. Oestrogen also protects the heart and so the increased risk of heart attack after the menopause rises significantly.

What does HRT do?

- Hormone replacement therapy provides a low dose of oestrogen and is often given with progesterone, another female hormone as this combination may protect against uterine cancer.
- It increases bone density and is given to women to lower the risk of osteporosis.
- HRT also reduces the symptoms of the menopause, the severity of hot flushes, vaginal dryness and painful intercourse.
- It improves cholesterol as it decreases total cholesterol and LDL levels [the ‘bad’ cholesterol that furs arteries] and increases HDL [the ‘good’ cholesterol].
- HRT has the side effect of increasing levels of triglycerides including women with Type 2 diabetes.

New studies
Past studies have shown that in women using HRT there were less heart attacks and less heart disease. But this research was open to question because these women using HRT also ate better and exercised more and this could have been the reason for the reduced heart disease.

Now there are new studies that suggest that HRT does not protect women against heart disease. In the New England Journal of Medicine [July 2001] two of the physicians leading this research state that there is not enough proof that HRT prevents heart disease. So now the American Heart Association makes the following recommendations:

- HRT should not be prescribed for women with heart disease because they double their risk of heart attack within 1 or 2 years of starting HRT.
- HRT should not be prescribed for healthy women solely for the prevention of heart disease. There is a very small risk of stroke, heart attack and blood clots within the first 1 or 2 years of using it.

But what about the menopausal symptoms?
It maybe that after discussions with your doctor, HRT is right for you to help with the symptoms of the menopause and/or the prevention of osteoporosis but this latest research suggests that you should carefully consider the risks and benefits.

Understanding The Terminology

As we know insulin dependent diabetes and non-insulin dependent diabetes have been renamed as Type 1 and Type 2 diabetes. These terms are used to describe the cause of insulin dependent and non-insulin dependent diabetes respectively. Perhaps all this is easy enough to understand but what about all the other terms we come across, do we understand them?

Oral glucose tolerance test – the patient fasts overnight and a blood test is carried out first thing in the morning and this is followed by a liquid glucose drink. Two hours later another blood test is carried out and the result is compared with the one taken before the glucose drink.

Impaired glucose tolerance – this is the stage where there is impaired glucose regulation with a fasting plasma glucose of greater than 7 mmol/l and an oral glucose tolerance test at 2 hours of 7.8.mmol/l but less than 11.1.mmol/l.

Impaired fasting glycaemia – this is the stage where the fasting glucose levels are above the normal range but below those for the diagnosis of diabetes. This means that they are greater than 6.1mmol/l but less than 7.0mmol/l. If this is the case, then it is advised that an oral glucose tolerance test is carried out to exclude the diagnosis of diabetes.

Diagnosis

If the classic symptoms of diabetes are present – ie drinking and peeing a lot, weight loss and the plasma glucose levels are high then diabetes can be diagnosed without further tests. If there are no symptoms and the plasma glucose levels are high, then further fasting or random plasma tests will need to be carried out. If these are still not enough to confirm the diagnosis of diabetes, then an oral glucose tolerance test will be carried out. Diagnosis is not made on the results of urine tests, finger prick blood tests or HbA1c measurements.

A Quote Worth A Mention!

[The Lancet, vol 358: Feb 9 2002]

Donald Irvine, President of the GMC, “huge numbers of patients have excellent medical care from their doctors…Yet that has not stopped public opinion from being seriously critical and questioning of the medical profession collectively. That will only end when the message from the profession is absolutely clear: we really do put patients first.”

The DoH has admitted that there is a group of patients that are better suited to treatment with animal insulins. So why don’t doctors looking after people with diabetes, stand together with their patients and demand the continuation of animal insulins?

There is much rhetoric about consumers having power in healthcare but patients are not consumers when it comes to prescription only drugs like insulin – the consumers are the prescribers, our doctors. It is to them that industry sells their wares and they are the consumers that have the power to influence commercial decisions.

What better way for the medical profession to show us that they really do put patients first than for them to stand with us to publicly condemn the major insulin manufacturers for using their dominant market position to deny people access to the animal insulin that suits them best. This may not affect the ultimate decisions of industry because they are based on maximising profits for their shareholders with little regard to social responsibility but at least it may restore some of our faith and trust. We would no longer question why many of our doctors appear to be on the side of industry and not the side of us, their patients – an unanswered question that has hung over us all for many years!

Snippets

Research into drug to slow down progression of eye disease
A new drug aimed at slowing down the progression of diabetic eye disease in people with both Type 1 and Type 2 diabetes is about to

undergo trials Aberdeen. Let us hope that this may provide the help that people with diabetes need.

UK lags behind in health spending

The Organisation for Economic Co-operation and Development has compiled statistics that show that Norway spent £1,484 per person on health in 1999, while the UK spent £863 per person. This ranks the UK with the Czech Republic, Poland and South Korea making the UK 13th out of the 17 countries in the study.

Prescriptions for pen needles has doubled

MP Ivan Henderson writing in the Clacton Gazette, says he has learned from the DoH that the number of prescriptions for pen needles has doubled since they became available on the NHS.

Skin patches for insulin delivery – a possibility?

After nicotine skin patches for smokers, scientists are developing patches that could be used for delivering vaccines and drugs. Up to now only small molecules could pass through the skin so limiting the substances that could be used in patch form. Recent research shows that large molecules such as insulin, can be allowed through the skin using ultra sound. Separate trials are also looking into patches for measuring blood glucose levels which would cut out the need for finger prick testing.

Gene therapy to treat Type 1 diabetes in rodents

Scientists in South Korea have successfully used gene therapy to treat rats and mice with diabetes. They used a harmless virus to transplant the gene into the rodents and this led to their bodies producing an insulin substitute. They were able to produce this for up to 8 months. [Reported in Nature, November 2000]

Type 2 diabetes, a possible explanation

Scientists in the US have discovered a hormone in fat cells of mice that blocks the action of insulin. It is thought that this may explain why overweight people are more likely to develop Type 2 diabetes and it could lead to new tests to identify people at risk and to effective new treatments. [Reported in Nature, January 2001]

Gene for a sweet tooth

Two separate studies in the US have identified a gene in mice that they believe is responsible for tasting sweetness and using the recently completed map of the human genome, they have found a similar gene in people. This could be why some people have a sweet tooth and eat lots of sweet stuff and others don't. It is suggested that this discovery could help to combat obesity and diet related conditions such as diabetes and also to the development of new artificial sweetners.

Supplement could prevent Type 2 diabetes

Animal research in Canada suggests that giving a protein supplement called taurine, to pregnant women might prevent their children from developing Type 2 diabetes in their later life. Pregnant women could take this supplement in the same way as folic acid is given now to prevent spina bifida and other birth defects.

IDDT's Annual Meeting

This has been arranged for the weekend of October 12/13th 2002 and will take place at the same hotel as last year – the Comfort Inn, Hagley Road, Birmingham. Our guest speaker is Stanley Shortt, M.D., F.R.C.S. (C), an ophthalmologist from Canada who will talk about eyes and diabetes and will also give us his experiences of patients using 'human' insulin. From the patient perspective, Alison Blackburn and Michael Gibbons are also speaking about the help that is available for people with diabetic eye disease and their involvement with the NSF recommendations.

We will be sending out application forms and full details of the meeting but book the date in your diary. If you want to ensure that there will be a place for you at the meeting, you can make a provisional booking now by contacting IDDT, PO Box 294, Northampton NN1 4XS, tel 01604 622837 or e-mail meeting@iddtinternational.org

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

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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