



# Insulin Dependent Diabetes Trust

January 2002 Newsletter



## Happy New Year!

**The Trustees of IDDT wish all our members and readers a Happy and Healthy New Year.**

As I get older, the years seem to go even faster – something my mother used to say but I never quite understood until the last few years! Nevertheless, it is hard to realise that it is eight years since IDDT formed as a charity for people with diabetes and their families. The seeds of IDDT were set when four of us met in Gravesend to discuss what could best be described as the apparent lack of interest in the needs of the people who had problems using 'human' insulin. All four of us had been involved in this issue since the 1980s and all four of had very personal reasons for needing animal insulins to continue to be available. We also realised that we were not alone and

that there were many other people in exactly the same position.

The first reports of problems with 'human' insulin appeared in the mid 1980s and little effective action had been taken to protect, support and help the people that were affected. So when we met in 1994, it was obvious that this significant minority of people who suffered adverse reactions to 'human' insulin were alone, except for each other. There was great resistance to believing the reports of patients and their carers by most of the people and organisations involved in diabetes care. There was also a failure to accept that these people needed animal insulins or as the Department of Health now admits, 'some people are better suited to treatment with natural animal insulins'.

There seemed little option but to form an independent patient/carer organisation to offer help and support to people with diabetes and their families and just as importantly, to try to ensure that animal insulins

remained available for the people that need them. Eight years later we are still here and through our Newsletters, you have seen the growth of IDDT, the development of IDDT groups in six other countries and the experiences and views of people with diabetes. You also now know that despite all the denials from diabetes organisations, physicians, healthcare professionals, the DoH and pharmaceutical companies, it was known **before** genetically produced 'human' insulin was allowed on the market that it caused more hypo problems than natural animal insulins that everyone was using.

But as I look back over these years, I am sure that we did not realise that the whole 'human'/animal insulin debate would highlight many of the broader issues that affect all patients. These issues are important if people are to have an informed choice of treatment, if they are to receive the best possible treatment based on reliable unbiased evidence from research and if people are to be respected as valid partners in their own healthcare.

I well remember the words of a diabetologist in a letter to me, "I will never understand why patients who were happily controlled on animal insulins allowed themselves to be changed to 'human' insulin". Remembering that this was nearly 20 years ago, the answer is quite simple – we had too much trust and until that time, we had no reason to doubt the advice our doctors gave us. We had never needed to exercise patients' rights, I doubt that we even knew what they were, and we knew even less about research, the pharmaceutical industry and the regulatory procedures for drugs and their adverse effects.

- We didn't know that despite patients having rights to an informed choice of treatment, this right can be overridden by the doctors' clinical judgement and patients can therefore be denied this very basic right of an informed choice of treatment.
- We assumed that the prescribing of drugs was based on evidence from good quality, **independent** research and we didn't know that we weren't getting this. We didn't know about the influence of the pharmaceutical industry on the research agenda, about research bias or about publication bias where studies are not even

submitted for publication if the results do not show the benefits the funding drug company want.

- We didn't know and were never warned, that when a new drug such as 'human' insulin comes on the market, this is the real test of it's safety and any adverse reactions and not the relatively small trials that take place before it receives marketing approval.
- We didn't know that patients have little or no access to the Medicines Control Agency or the Committee on Safety of Medicines nor that the information they store on adverse reactions, although we knew that these bodies were set up supposedly to protect the interests of patients.
- We didn't realise that the relationship between the pharmaceutical industry, the Department of Health and the medical profession was quite as cosy as it is. We didn't realise just how much money is spent on marketing of drugs or the sort of techniques that are used. Perhaps naively we assumed that doctors prescribed on the basis of independent data from research.
- We didn't know that the NHS system for the pricing of drugs is based on pharmaceutical companies being allowed to make more profit if they do 'good works' for UK plc such as funding research, paying for education programmes, paying for NHS staff salaries etc etc. So we didn't realise that the government was not interested in the fact that prescribing of significantly more expensive 'human' insulin with no proven benefits to patients over animal insulin, was wasting millions of NHS pounds per year.

But perhaps the greatest misunderstanding and the greatest disappointment of all was the realisation that many of the doctors that we had always trusted didn't actually listen to us, their patients. We didn't realise that our adverse experiences with 'human' insulin would be ignored and we thought that they would stand by us and help to ensure that animal insulins remain available for the people that need them.

So as we enter yet another year, we read about the proposed changes in the NHS generally and the eventual publication of the National Service Framework for the treatment of people with diabetes. But

will the proposed changes in systems or in finance change the very basic issues and attitudes that affect our treatment and care? Will patients be listened to? Will patients have a truly informed choice? Will patients have greater access to information from the regulatory bodies? Will the cosy relationships with industry continue to have an even greater influence on research and doctors' prescribing habits than is necessarily in our best interests?

The recent 'scandals' within the NHS have now highlighted many of these issues that we discovered in our journey, so perhaps we were ahead of our time. But these broad issues raised by the 'human'/animal debate require changes in the attitudes and beliefs of those involved in all aspects of patient care. Changing organisational systems does not in itself change attitudes. Let us hope that 2002 sees greater respect for patients as equal and valuable partners in their own healthcare.

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## A Thank You From America

Being the representative of IDDT in the United States, I wanted to stop and share our gratitude with you, all of our overseas compatriots.

Since September 11, 2001 it has been a trying time for our country, to regain stability and normalcy towards all the freedoms that had been taken for granted. Fortunately, with good strong lead and direction, and supportive allies in this endeavor, the United States is well on the road to recovery.

I wanted first and foremost to share my condolences with all members of IDDT, the British, and the European Community as a whole for their losses in the World Trade Center tragedy that left many families shattered all over the world. Our gratitude goes to all that are involved in the efforts against terrorism for the safety of the people worldwide. Thank you also for the financial gifts sent, the many prayers spoken

for the people of the United States who suffered the loss of a loved one. We appreciate your support very much!

Pam Maples

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## Male Bonding

Research has shown that men with fit friends are more likely to work out!

A study of almost 1,000 university students in the US found that only 39% of the men exercised regularly but even worse, only 26% of women did so. The researchers decided to find out what motivated the people who did exercise.

**The men:** those who exercised regularly said they had a lot of support from fit friends. Those that admitted to not exercising said that they had no encouragement from friends to get in shape.

**The women:** the high level of support and encouragement from family was the most important driving force for them.

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## National Service Framework For Diabetes Delayed

The National Service Framework [NSF] for diabetes will set out the standards of healthcare that people with diabetes should expect, in the same way that NSFs have been produced for other conditions. Readers may remember that IDDT wrote to the Chairman of the group preparing the NSF for diabetes to suggest that there was insufficient representation of real live patients and their carers on his committee.

Our comments were dismissed and IDDT has had no involvement in the NSF for diabetes. Naturally, as the largest charity in the UK for people with diabetes Diabetes UK has been closely involved but there were still only two people with diabetes on the NSF committee and we remain concerned that the real needs of adults, children and their carers have been understood and addressed.

The full NSF for England was due to be published in the early part of 2001 with implementation in 2002 but this has been delayed. Now government has said that it will not be published until the summer of 2002 at the earliest with no fixed date for implementation although the likely date is thought to be April 2003.

The Diabetes UK press release issued October 16 2001, describes this delay as 'Government deals a blow to people with diabetes' and comments that 'we will have to wait another year for standards to systematically improve'. The emphasis may well be on the word 'systematically' but it is worth noting that standards can improve without an NSF and have already done so in many areas of the country. However, there are areas where this is not so and there are aspects of diabetes care that need significant improvement. But it is doubtful that this is due to a lack of knowledge of what needs to be done – more likely a lack of resources to do it! With or without an NSF, pressure from patients to ensure that standards in their locality are what they should be is an important part of ensuring that these standards are achieved. Patients need to be represented locally within the decision-making committees and they need to be vocal in to raising any difficulties or system failures that arise.

### **But is a combined NSF for Type 1 and Type 2 diabetes really feasible?**

- Is the NSF for diabetes so complex that it takes so long to produce?
- Is it going to be so expensive to implement that the delay is until the government can afford the necessary injection of cash?
- Is including Type 1 and Type 2 diabetes in one NSF part of the problem in producing workable and affordable recommendations

for everyone with diabetes?

IDDT has made the point in the past that Type1 and Type 2 diabetes are different conditions affecting different categories of people and we have to wonder if it is feasible to consider the healthcare standards for Type 1 and Type 2 in the same document. Type 2 diabetes is largely a modern lifestyle condition, Type 1 is not. Healthcare standards for Type 2 involve identifying the undiagnosed 'missing millions' who at diagnosis often already have complications, people with Type1 usually do not.

Perhaps if Type 1 and Type 2 diabetes had been looked at as the two different conditions that they really are, then an NSF for Type 1 diabetes could have been produced and implemented on time. It seems unfair and inappropriate that the huge problem of tackling undiagnosed and diagnosed Type 2 diabetes should delay improvements for people with Type 1 diabetes – children and younger people who have their whole life ahead of them!

**Note:** On November 14th 2001 the Scottish Diabetes Framework was published as planned with recommendations for new national standards for diabetes care and new guidelines for health professionals on diabetes treatment. The framework will set up an Education Trust by March 2002 to provide high quality training programmes to ensure that all patients are cared for by staff with the most up-to-date skills and knowledge of diabetes.

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## **Blood Glucose Meters For The Visually Impaired**

Regular readers know that IDDT has been concerned about the lack of availability in the UK of a 'talking' meter for people with visual impairment as a result of their withdrawal because there is only a small market! While this problem is not yet solved, there is a blood

glucose meter on sale at Superdrug that has the advantage of having large numbers on the visual display. Although this will not help people that are blind, it may be of benefit to people that are visually impaired.

The meter is called 'Superdrug glucose monitoring meter', costs £7.50 and it is to be used with Prestige blood testing strips that are available free with an NHS prescription.

Note: IDDT is not endorsing this product but providing information of its availability for people who cannot see the meters with small display screens.

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## A Date For Your Diary

The delegates from the 2001 Annual Meeting unanimously requested that future meetings should include an overnight stay because they gained so much from being able to chat informally with other people with diabetes. So IDDT's 2002 Annual Meeting will be held on the weekend of October 12/13th in Birmingham at the same hotel as last year. We hope that many of you and your partners, spouses or friends will be able to join us. More details later but please put this date in your diary!

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## Insulin For People In Poor Countries - Thank You!

The response to our request for unwanted, unopened, in-date insulin has been tremendous and we would like to thank everyone that has helped and continues to help. We started our appeal in July and so far IDDT has sent the following supplies to *Insulin for Life* in Australia for their distribution to people in need:

- 308 vials
- 392 packs of 5 cartridges
- 74 pre-loaded pens, 18 bottles of blood testing strips and other supplies.

You will be pleased to know that some of the insulin you donated has gone to help people in Rwanda. It has been sent to the Association des Diabetiques du Cong, an organisation formed in early 1999 by people with diabetes. Despite millions of dollars being donated to Rwanda by the international community, this did not reach people with diabetes because healthcare is very expensive and diabetes is not seen as an emergency. The insulin goes to a dispensary that people visit for blood and urine tests.

**World Diabetes Day 2002** – to mark this, the IDF [Internationals Diabetes Federation] and the WHO issued a press statement highlighting the problems for people in developing countries and there was considerable press coverage that made the following points:

- 13% of people with diabetes in industrialised countries are treated with insulin but this figure is only 3% in developing countries.
- In many African countries, the cost of a vial of insulin may be equivalent to a month's salary.
- Pharmaceutical companies have stoked the problem in the first place by removing cheaper animal insulins and replacing them with more expensive 'human' insulin.
- Dr Kochupillai in New Delhi has carried out research that shows that "the two types of insulin are equally good" but animal insulin only costs 1.58 dollars per dose whereas 'human' insulin costs 4.38 dollars per dose.

**IDDT is continuing to collect insulin and any other unwanted supplies, so please continue to donate by sending your unwanted supplies to IDDT, PO Box 294 NN1 4XS.**

Note: concern was expressed by one member that in winter there may be a danger that insulin will freeze in the post. This is unlikely to

happen partly because the packing in the Jiffy bag will offer protection and partly because we rarely have sufficiently low temperatures. In the unlikely event that the insulin did freeze, it would form visible clumps and we would discard it. But if in doubt, please take your parcel of insulin to a Post Office rather than putting it in a letterbox.

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## Tips From you

Calling it an 'allergic reaction' worked for me!

I recently had to go into hospital for a small operation. The doctor came round to give me the once-over before the op and asked if I had any allergies. I said that I was **allergic** to 'human' insulin and gave her my IDDT sticker saying that I did not give consent to the use of 'human' insulin. I described a few of the side effects I had when using 'human' insulin and she put the sticker in a prominent place on my notes and ensured that everyone knew of the situation.

I wonder if the key is '**allergic**' – perhaps this is more understandable and acceptable than describing a range of symptoms that doctors find difficult to understand or explain. It worked for me and maybe will work for others.

I must add that I do not believe that I am actually allergic to 'human' insulin, just that for me it causes adverse reactions and animal insulin does not.

Shirley Stone

### Pre-cooked chickens

One of my favourite meals in the evening is pre-cooked chicken and salad. We usually buy these chickens at the same supermarket but on a couple of occasions they did not have any so we bought them from a different one. On both these occasions I noticed that my blood sugars

were high the next morning. However, the next time we bought the pre-cooked chicken from the usual supermarket and my blood sugars were fine the next day. This caused me to look into the labeling and sugar content of pre-cooked chickens. I also made inquiries at the supermarkets about the method of cooking. One supermarket said there was no added sugar – just dextrose!!!! Morrisons said they use a sugar based-marinade before cooking but the ingredients of fresh products are often subject to frequent change, therefore customers may be relying on inaccurate, out of date information but Marks and Spencer's labels do state the sugar content on the labels. I also discovered that some pre-cooked chickens are even injected with sugary 'material'. Clearly the sugar content of pre-cooked chickens can be misleading and so can the labeling, so watch out for your blood sugars!

Howard Glansfield

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## What The Papers Say

Trials of novel dual acting insulin drug for Type 2 diabetes, Reuters 7.9.01 – Novo Nordisk originally in co-operation with Novartis, is starting the final phase in studies of a new drug with a dual action to target blood glucose control and dyslipidaemia [high lipid levels] in Type 2 diabetes and is an insulin sensitiser. The drug is licensed by Novo Nordisk from an Indian drug maker. The final trials are expected to take 2 years. However, on 30.10.01 The Wall Street Journal reported that Novartis have pulled out of the arrangement with Novo Nordisk. A week earlier GlaxoSmithKline stopped the development of a similar drug because of adverse side effects.

**Diabetes and Depression, The Scotsman 13.9.01** – people with diabetes are twice as likely to become depressed as people without. Research has shown that depression is associated with a reduction in blood glucose levels and an increased risk of long-term complications.

Researchers at Washington University are studying the effect of depression treatment on mood and diabetes outcome. They say that it is essential that healthcare workers take into account both the physical and psychological aspects of diabetes.

**Research in more depth needed, Central Press 12.9.01** – speaking at the European Association for the Study of Diabetes Conference Sir Steven Redgrave said “There is a need for a lot more research to be done. I would like to see a lot more information gathered and a little more in depth.” He also said that he would like to see research carried out by an independent body, not the food industry or drug companies who he said had a “vested interest”. [Very wise!]

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## Anonymous Complaint!

**Jenny Hirst**

“The IDDT Newsletter is biased and badly referenced” - this anonymous message was left on IDDT’s answerphone.

Criticism is healthy. It can lead to debate that brings forward new ideas or change policies and IDDT welcomes criticism as well as praise. But I take the view that anonymous criticisms should be ignored on the grounds that if the complaint is justified or justifiable, then the person making the complaint will leave their name and phone number. However, I thought that perhaps this one needed an answer.

**“Badly referenced” – what does this mean exactly?**

If the references are actually wrong, then I apologise. But if the complaint is that there are not enough references then I think it has to be said that most organisations do not reference articles in their patient magazines and we should understand that IDDT’s Newsletter is not a medical journal but simply a Newsletter for people with

diabetes. There is a world of difference but there is still a need to provide accurate information and IDDT is careful to ensure that the Newsletter articles making statements about diabetes, its treatment or research developments are usually referenced but always obtained from a reputable source.

**“Biased” – yes, we are!** This is not in doubt and never has been – we are biased in favour of patients and their carers. Our original aims and objectives clearly state that we represent the interests of people with diabetes and especially those who experience problems with ‘human’ insulin. We have always accepted that the majority of people are fine using ‘human’ insulin but there is a significant group of people that are not.

- We are biased in favour of recognising that synthetic ‘human’ insulins and their designer insulin successors do not suit everyone’s needs and that animal insulin is needed for this group of people.
- We are biased in favour of people with diabetes having a choice of treatment and in particular insulin treatment and we are biased in favour of people being provided with information about all insulins so that they can make an informed choice of treatment. But this we have learnt from successive governments telling us we should take greater responsibility for our own health!
- We are biased in that we will not happily accept changes in our treatment unless it is based on scientific evidence of benefit for us, the people that live with diabetes. But this we have learnt from the medical and healthcare professionals! If scientific evidence of the problems with ‘human’ insulin is necessary for them to believe that there are adverse effects with ‘human’ insulin for some people, then this same approach applies to all aspects of the treatment of diabetes.

**If being biased includes questioning or criticising systems, organisations and industry if their actions do not appear to be in the best interests of people with diabetes, then yes we are biased! IDDT has no divided loyalties – our loyalties are to people with diabetes and their family carers.**

We may understand that the NHS is strapped for cash and perhaps this is why we are denied some of the services. We need we may understand that the pharmaceutical industry's aims are profit and that may well be best achieved by removing animal insulins. We may understand that other diabetes organisations have to try look after the needs of everyone with diabetes and so are failing to fight the major insulin manufacturer's decision to remove the animal insulins that some people need, but we do not have to just accept all this without criticism.

**This is not written in anger – perhaps frustration, but not anger.**

Every year that passes brings us nearer to the disappearance of Novo Nordisk's pork insulin. Although CP Pharmaceuticals is committed to the ongoing supply of animal insulin in the UK, this one relatively small supplier will leave the people who need animal insulins in a vulnerable position, as indeed they already are in other countries. Perhaps the anonymous caller should try to imagine just what it must be like to live with the withdrawal, or the threat of withdrawal, of the insulin that keeps you fit and well. IDDT will continue to be biased in favour of supporting the needs of people with diabetes, especially those who have not been given an informed choice of treatment and those who need animal insulin.

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## What's New

Soft Sense glucose meter – this new meter was launched in the UK in November with the expectation that the lancets and test strips will soon be available on the NHS. It is hand held and has incorporated the lancet and the strip into one so a vacuum draws the sample of blood from the skin and then produces a meter reading. This is carried out in a single procedure so there is no messing with getting the blood from the finger on to the strip. It can also be used on less sensitive areas of the body where there are fewer nerve endings eg the forearms, upper arms and base of the thumb. The people that have used it claim that

it is virtually pain-free with no more sore finger ends! [A talking form of this meter would be ideal for blind people who even if they have a talking meter, still have difficulty actually getting the blood on the test strip.]

The Soft Sense costs around £225. For further information contact the helpline at MediSense on 0845 607 3247

**mhi- 500** – a Sheffield based company, The Medical House plc, has developed new technology that it claims will mean the end of daily injections for people with diabetes. The Medical House hopes that it's needle-free injection system will be available by the end of the 2001 year although when the device was announced, approval by the medical authorities had not yet been received. It works by converting insulin into tiny droplets that can be sprayed through the skin without puncturing the surface and is a new generation of the Vitajet 3 system. The device itself will cost £120 plus a weekly cost of £1 for 'consumables'.

Concerns have been expressed that the penetration of the skin may be too shallow so preventing the insulin from going far enough under the skin.

**New test strip for Glucotrend** – Roche Diagnostics have replaced the Glucotrend Plus test strips with Active Glucose test strips that are compatible with Glucotrend, Glucotrend 2 and Glucotrend Premium. The Glucotrend Plus ceased to be available from December 1st 2001.

Accu-Chek Easi-Opener – this device is similar to a bottle opener and is designed to open blood test strip pots simply and easily for people who have difficulty with hand movements. It is a hand held device with a hook at the end that fits underneath the lid and is tilted back to lift the lid off. It is available free of charge to people that use the Accu-Chek meter if you give the serial number of your meter. Contact Roche Diagnostics care line on 0800 701000. You will need to give the serial number of your meter.

# The Time Of Year For Colds

We all know what a cold is – an infection that develops over a few days causing a blocked up nose, sneezing, coughing, sore throat etc. It is an upper respiratory tract infection ie the breathing system around the nose and throat and sometimes it can be hard to tell the difference between a cold and infections of the sinuses [sinusitis], the voice box [laryngitis], the throat [pharyngitis] or and tonsil infections [ tonsillitis].

It can make you feel quite ill but it usually goes away within a week. If the symptoms do not go away in a week or they are accompanied by fever or chest pains, then it may be more serious than a cold and you should visit your GP.

Colds are very common, especially in young children who may have 6-10 colds a year and adults get 2-4 colds a year usually in winter. Flu is not the same as a cold – it usually comes on suddenly with a fever, chills and muscle aches and pains.

## How you catch colds

A cold is caused by viruses or some kinds of bacteria. Antibiotics do not kill viruses but bacteria can often be killed with antibiotics. Colds are usually spread by our hands coming into contact with the virus and then touching the mouth, nose or eyes and it can get into the nose through the eyes and mouth.

## Myths or not?

IDDT looked at the Cochrane Review of colds for some answers.

- You don't catch a cold from getting physically cold - might be a myth because colds may be more likely in colder temperatures. Colds are more likely in winter but it could be that people spend more time indoors so enabling the virus to pass between them more easily.
- Being stressed or tired can make you more vulnerable to colds – might be a myth.

## Can you prevent a cold?

There is no evidence from Cochrane Reviews about what really works but increasing your resistance to infection may help by strengthening your immune system by eating well and getting plenty of rest. Many dietary and herbal remedies are sometimes recommended for strengthening the immune system but as yet there are no Cochrane reviews on these to provide reliable evidence. You might lessen your chances of catching a cold by:

- Keeping warm
- Avoiding contact with people who have colds
- Washing your hands when you touch things that people with colds have touched
- Not touching your face when people around you have colds.

## No cure for the common cold

Colds are very common and we all want relief from the symptoms even though most of us realise that there is no actual cure for the cold itself. Your body will usually fight off the cold but there is a wide range of products on the market that may help relieve the symptoms.

## So what do the Cochrane reviews say about these?

Generally the reviews have found that the following treatments may shorten the length of your cold:

- **Zinc** - the review of zinc lozenges shows that they might help. There did not appear to be any improvement in cold symptoms in the first few days but about one in seven people in the trials had less cold symptoms after a week. Adverse effects of zinc lozenges include nausea, mouth irritation, change in taste, abdominal pain and headache. Zinc nasal sprays have been developed to try to avoid these adverse effects – no review yet but trials have shown that these were reduced but the length of the cold was not.
- **Echinacea** - is a North American plant and a member of the sunflower family but is very different from other sunflower products that are not known to prevent colds. It comes in tablets, teas, and

other forms and is thought to stimulate the immune system. The German drug regulatory authority recommends that it is not used for longer than 8 weeks at a time and that it should not be used by people with metabolic conditions such as diabetes. The evidence from Cochrane reviews is that it might be effective but there is no evidence from Cochrane reviews about who can use this herb safely, or at what dose.

- **Vitamin C [ascorbic acid]** - is found in fresh fruits and vegetables, particularly in citrus fruits and berries. Vitamin C is an important part of a healthy diet, and artificial supplementation is not usually necessary for health. Taking vitamin C supplements daily, including mega-doses has been recommended by many people, in the belief that this can prevent a variety of diseases, particularly the common cold. However, there is no evidence from Cochrane reviews that taking regular doses of Vitamin C prevents colds. Too much vitamin C can cause diarrhoea, which can be severe and be dangerous for young children and the elderly. It might also might also distort tests of glucose levels, and blood-clotting test results for people taking anti-clotting drugs.

#### **What do the Cochrane reviews say about other remedies?**

- Cough remedies – there is no strong evidence that most cough medicines work and some have adverse effects. Many of them claim to relieve the cold symptoms but there is no strong evidence to support this either.
- Antihistamines in cough medicines - do not help the cough but might help with some runny noses and sneezing.
- Antibiotics - antibiotics really only work against bacterial infections and not against viral infections. Most colds are caused by viruses and so antibiotics will probably not help the common cold. There are drawbacks to using unnecessary antibiotics for colds as excessive use can lead to bacteria developing resistance against antibiotics and also the person using them can also develop some resistance so that when an antibiotic is needed in the future, it might not work. There are several common adverse effects from using antibiotics (diarrhea, nausea, vomiting, headache, skin rash, and vaginitis).

Antibiotics require a doctor's prescription.

#### **So what can you do about the common cold?**

- Drink lots of fluids - not alcohol, as it can be dehydrating. It may be a myth that you should avoid tea and coffee when you have a cold because there is some evidence that caffeine may even help sore throats.
- Take paracetamol to relieve the discomfort.
- If you develop a high fever, serious pain or something worse than a cold then you should consult your doctor.
- If you develop a high fever, or serious pain, you may have complications or something worse than a cold, and consulting a doctor should be considered.

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## **Introducing Pam Maples From IDDT-US**

We are delighted that Pam Maples has not only joined IDDT-US but has volunteered to take on a major part of the work! But like the rest of us she has very good reasons for doing so! Here is Pam's story:

My family and I received the devastating diagnoses of Type I diabetes in February 1974. Immediately placed on beef/pork insulin with the necessary instructions needed for me to live a long adequate and sufficient life with minimal complications, demonstrated great success for the years that followed.

In 1987 and 1998, under the care of an endocrinologist, I was administered a recommended dose of the synthetically engineered 'human' insulin. The first time, within twenty-four hours I slipped in a coma only to awaken several days later being informed that for no apparent reason I had a rare, severe allergic reaction to the synthetic insulin. With a second attempt at using this so-called 'Human' insulin in 1998, I had allergic indications consisting of severe oedema,

high blood sugar levels, an extremely rapid heart rhythm, shallow respirations all accompanied by anguishing thirst. Ascertaining no success either time, I returned to my beef/pork insulin, resuming adequacy with my health, yet devastated.

In September 1997, I collected my usual insulin from the pharmacist only to discover my beef/pork insulin, lletin1, had a red label 'notification of discontinuation'. In an absolute dispute, I telephoned the Food & Drug Administration (FDA): "We don't agree with the discontinuation of a life sustaining drug, we tried to persuade them not to make this decision" and then Eli Lilly Pharmaceuticals: "This was a business decision". I immediately contacted family and friends in a quest to purchase as much beef/pork insulin that we could to allow me the time needed to figure out what to do from here. As each vial disappeared, I would feel emptiness in the pit of my stomach, the overwhelming since of desperation. The more I searched, the less results I received. I felt completely alone. Ready to accept the fact that when the last drop from the last vial was gone, so was I. I began preparing life without me for my children and my family.

November 1998, receiving the gift of a computer, I discovered Insulin Dependent Diabetes Trust, which brought a blessing from God above. Through the years I've kept in close contact with the members of IDDT as I treaded through the facts for information and the process of Importation. I was not the only one fighting this battle of diabetes and the choice we all need. In all, I felt the overwhelming desire to join the battlefield as a voice for the United States in an effort to listen and help other people going through my experiences and fears. I want to help our global team to ensure that we, the children diagnosed today and **all** people in our nation who develop diabetes, have the choice in the care and control that we need to maintain a place in society with good health and the freedom to choose.

To the people with diabetes in the United States, I ask for your support as we continue to "Fight for Survival", welcoming you and yours to join IDDT-US. I would like to hear from you about to your situations and how this disease affects you and your family. I hope that through IDDT-

US, I can offer help and support to you. I welcome your comments about IDDT-US and our website with ideas on issues that concern you. Our actions **now** are important, they not only affect my family but they involve you and yours. Join us in our team effort. I look forward in getting to know you.

**Pam can be contacted at IDDT-US as follows:**

Tel 1-800-276-2091 and 1-800-276-3531[toll free direct line] Fax 1-800-649-9645

Or by e-mail [IDDT-US@msn.com](mailto:IDDT-US@msn.com) IDDT website can be reached by visiting [www.iddtinternational.org](http://www.iddtinternational.org) and clicking on IDDT US.

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## When Alternative Becomes Dangerous!

A letter to the doctor in 'Alternative Medicine Section' of the Observer [23.9.01] asked if there were any alternative approaches to Type 1 diabetes because the writer didn't like the prospect of injections and diet. The doctor answered that he should take up chi gung, t'ai chi or both and that he should also gently press into his liver and spleen for a few minutes everyday. According to the good doctor, chanting 'huuu' as resonantly as possible, feeling the sound vibrate under the left ribs will help too – apparently it's an ancient Taoist spleen/pancreas healing sound.

This advice is both dangerous and irresponsible – Type 1 diabetes means that the pancreas no longer has the ability to produce insulin and therefore cannot be stimulated to do so by relaxation, chanting or any of his other recommendations. This sort of advice gives alternative treatments a bad reputation and it is surprising that a reputable newspaper such as the Observer is not more cautious in its advice.

## Looking At Eyes Again - Retinopathy

Our eyes provide sight which is probably the most important of our 5 senses. We covered glaucoma in the Summer 2001 Newsletter but IDDT is very aware that probably the complication of diabetes that people fear the most, is retinopathy.

There are still many misunderstandings about eyes and these misunderstandings mean that people sometimes worry unnecessarily. Sometimes this is because we don't understand the terms and language used and sometimes it may be because not enough time is spent explaining conditions of the eyes in a simple and straightforward way. Understandably many of us are quite nervous when we have our eyes examined - the underlying fear of 'bad news'. We hope that this article will provide a clear explanation of retinopathy and at the same time perhaps we can dispel some of the myths and misunderstandings that occur.

While it must be strongly emphasised that everyone should have regular, full eye examinations, it is especially important for people with diabetes. In the UK everyone with diabetes is entitled to a free eye test. Early detection and diagnosis of many eye conditions mean that treatment can start early in order to preserve sight. The following facts and statistics demonstrate why this is so important:

### Facts

- If diagnosed early enough diabetic retinopathy is a treatable condition.
- The only treatment for diabetic retinopathy is laser treatment.
- Over the past 15 years laser treatment has been shown to be helpful in either stopping the progress of the condition or in maintaining sight.
- In the UK sight tests for checking for diabetic retinopathy are free.
- There are two vulnerable groups of people susceptible to retinopathy – firstly, pregnant women and secondly, children and adolescents. In the long term children and adolescents are at

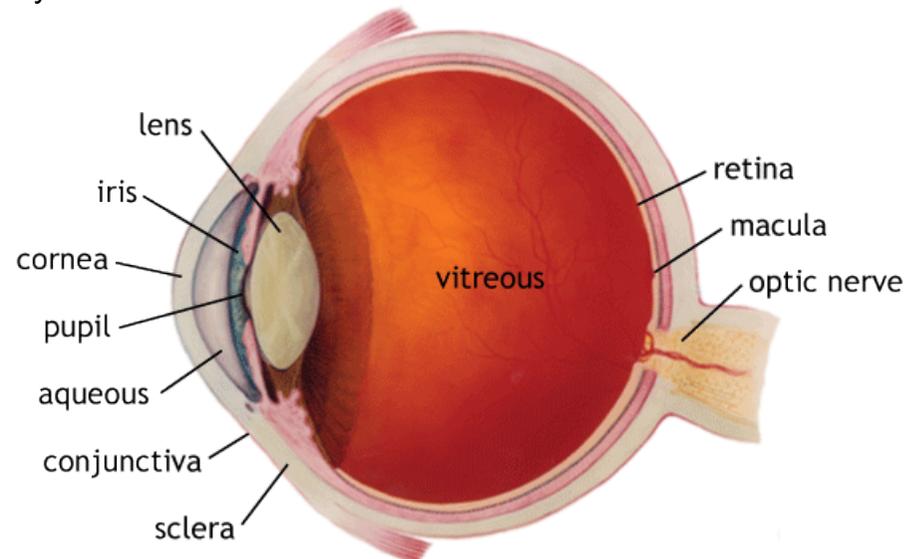
greater risk of microvascular and macrovascular complications of diabetes. It is recommended [ref1] that surveillance for the earliest evidence of microvascular disease [this includes retinopathy] should begin at puberty and after 3 and 5 years of diabetes.

- Diabetic retinopathy is the leading cause of blindness in people of working age in industrialised countries.
- It is estimated that 12% of people who are registered blind or partially sighted in the UK have diabetic eye disease.
- Twenty years after diagnosis almost all those with Type 1 diabetes and 60% of those with Type 2 diabetes will have some degree of retinopathy.
- British screening studies suggest that around 5-10% have sight-threatening retinopathy and up to 40% of people with newly diagnosed Type 2 diabetes have some retinopathy. [ref 2]

Ref 1 Endocrin Metab Clin North Am 1999 Dec;28[4]: 865-8

Ref 2 A review of retinopathy by the University of York NHS Centre for Reviews and Dissemination published in Effective Health Care, August 1999

Here is our diagram of the eye again – just to remind you of how the eye works



**LENS** - is a transparent crystalline structure behind the pupil of the eye. It helps to refract incoming light and focus it on to the retina. A cataract is when the lens becomes cloudy, and then the lens can be removed and replaced with a plastic intra-ocular lens.

**VITREOUS** – is a clear jelly-like material in the middle of the eye.

**OPTIC DISK** - is the visible portion of the optic nerve on the retina. The optic disk is the start of the optic nerve where messages from cone and rod cells leave the eye and pass along nerve fibres and so transfer all the visual information to the brain. The optic disk is also known as the 'blind spot'.

**RETINA** - is a light sensitive layer that lines the interior of the eye. It is made up of light sensitive cells known as rods and cones. The rods are necessary for seeing in dim light. And the cones best in bright light and are essential for receiving a sharp accurate image. Cones can also distinguish colours. The retina works much in the same way as film in a camera.

**MACULA** - Is the yellow spot on the retina the back of the eye with the greatest concentration of cone cells. It is the area of greatest acuity of vision such as reading.

#### **How we see:**

For sight to take place light must be able to pass to the retina at the back of the eye. The light passes through cornea and enters the eye through the pupil. It then passes through the lens and the vitreous to be focussed on the retina. The focussed light or images of what we have been looking at, are then passed from the retina down the optic nerve to the brain.

#### **What is diabetic retinopathy?**

Retinopathy affects the fine network of blood vessels in the retina and is usually classified according to its severity. This may not be the same in both eyes. There are two classifications of diabetic retinopathy:

#### **Background retinopathy**

This is the first stage of the development of retinopathy and it is thought to be rare before 8 to 10 years duration of diabetes. At this stage the vision is normal and sight is not threatened. If there are diabetic changes present such as small haemorrhages, fatty deposits [exudates] or abnormal blood vessels [microaneurysms] then this is a sign that the retinopathy is worsening and the doctor will be alerted to arrange more frequent follow ups.

#### **Proliferative retinopathy**

This is where the blood vessels [capillaries] block and starve the retina of nutrients and as a sort of compensation, new vessels grow to try to supply the retina with blood. These new vessels grow either in front of the retina on to the back of the vitreous or occasionally on to the iris but unfortunately these new vessels are fragile and may easily bleed into the vitreous. This then affects the sight and may cause floaters, dots or lines and if severe may cause clouding of the vision or loss of vision.

If the vessels grow on the iris, they can cause a rise in pressure in the eye and severe, painful glaucoma. The new vessels eventually cause scar tissue and this can lead to a retinal detachment where the retina becomes detached from the back of the eye with a resulting severe loss of sight.

If the macula is affected by these blood vessel changes then this is called maculopathy and central vision is affected making it difficult to read or recognise people's faces. This can vary from person to person but usually the wider field of vision is maintained so that vision for getting around is maintained. When maculopathy occurs, it is unlikely that all sight is lost.

#### **Who may develop retinopathy?**

- Anyone with insulin dependent diabetes, both young and old.
- People with Type 2 diabetes whether treated insulin, tablets or diet only.

- People who have well-controlled diabetes can develop retinopathy if they have had diabetes long enough.

### **Can retinopathy be prevented?**

No, but early 'good' diabetic control may slow down the rate of progression of the condition. Improving diabetic control rarely has an effect on diabetic retinopathy itself, but it can prevent further deterioration. Therefore you should:

- Always take your diabetic treatment - not doing so is harmful.
- Control your diet.
- Avoid becoming overweight.
- Avoid smoking and alcohol.
- Have regular blood pressure checks.

### **Points to remember about retinopathy:**

- If diagnosed early enough diabetic retinopathy is a treatable condition.
- The changes in the small blood vessels in the retina can continue for years without causing visual symptoms or impairment. During this period, retinopathy can only be detected by eye examination.
- Regular eye checks do not prevent retinopathy but do enable early diagnosis and early treatment and this will benefit your sight.
- In insulin treated diabetes, annual eye checks should be carried out after about 5 years of diabetes or after the onset of puberty in children and young people.
- In people with diabetes not using insulin, then eye checks should take place annually from diagnosis onwards.

### **Retinopathy and driving**

You should tell the DVLA and your motor insurers, if you have retinopathy that requires treatment, or that is affecting your vision or visual fields. It is a condition that should be declared under the item 'has there been any material change that could affect your driving.' If you were involved in an accident and you had not declared that you have retinopathy, then you may not be insured and the DVLA could take action because you have not informed them.

## **Registering As Partially Sighted Or Blind**

### **Diagnosis of retinopathy or any sight threatening condition**

As we said at the beginning of the article, sight is arguably the most important of the 5 senses that we have and any threat to this is frightening. We all know that retinopathy is one of the complications of diabetes but knowing this is a risk and actually having it diagnosed are totally different things especially if the diagnosis is of proliferative retinopathy that can threaten sight. Knowing the risk does not prevent the shock of diagnosis, the denial [this can't be happening to me], the anger, the feelings of guilt perhaps for past indiscretions with food, drink, blood sugar control or the 'why me?' feelings. Nor does it prevent the panic at the possibility of changes in lifestyle – just the simple thing of losing your driving licence can mean having to take a whole new look at your life and/or work and that of your family. It is important to remember that early diagnosis and treatment of retinopathy can slow down its progression and that achieving better diabetic control may also slow down its progression. Nevertheless, diagnosis itself can bring about this range of feelings and it takes time to adjust to the diagnosis and perhaps to looking at the future differently.

### **Depressing, but maybe we need to take a look...**

Understandably some people do not want to read about the complications diabetes because it is upsetting and depressing - perhaps especially those that may affect sight. IDDT has debated long and hard about how to address visual impairment and blindness in the Newsletter but the reality is that there are many people with retinopathy now. We cannot ignore the needs of the people that are affected – they and their family carers need information and reassurances that there is help available to them. While we do not want to upset other people, part of IDDT's role is to support and inform everyone living with diabetes and this has to mean all people.

Perhaps by looking at the help and support that is available to people who are partially sighted or blind may even help to allay some of the fears we all have. But if you find this depressing, then skip the next bit and go to the following article!

## **Registration as partially sighted or blind**

Registering is a big step and it may feel like the biggest step you have ever taken. Emotionally it means admitting that you have sight problems that are making your life difficult, but registration could provide you with just the help that you need. If you are in this situation, you may have thought about registering but don't know what the benefits are or where to start. We hope that this article will give you the confidence to seek the help you need.

## **What is registration?**

- It is entirely voluntary.
- It entitles you to certain benefits and makes it more likely that you will receive the help you need.
- Your local authority keeps a register of blind and partially sighted people in your area. The register is held by the Social Services department or the local voluntary society for the visually impaired acting as an agency for your local authority. Whoever keeps the register it is important to know that it is entirely confidential.
- The purpose of the register is to help local authorities provide people with what they need and are entitled to.

## **How you register - the first step**

If you are under an eye specialist [ophthalmologist] at the hospital then you should speak to him/her to see if your sight makes you eligible for registration. Your eye specialist will certificate you as partially sighted or blind. You should also discuss this with you GP who can refer you for further help.

## **What are the benefits for you in registering?**

Naturally if you are considering registering as partially sighted, you need to know what the advantages are from doing so. You may be entitled to more than you think. There are five main agencies involved that can give you help in all sorts of areas and these are:

## **Benefit Agencies – national, tel 0845 882 200**

**Your local Benefit Agency** – contact your local office

**Social Services** – contact your local office

**Inland Revenue** - tel 0845 605 585

**RNIB** - tel 0845 766 9999

## **How IDDT can help**

Beverley Sharpe has investigated what help is available and IDDT has put together a leaflet describing the benefits to which you may be entitled. She has also made contact with the RNIB [Royal National Institute for the Blind] and arranged for any of their large print information leaflets to be available to you through IDDT or directly from the RNIB. The following leaflets are available:

## **Benefits and information leaflets**

- Coming to terms with sight loss
- Sight problems
- Services for the visually impaired
- What is community care?
- Staying at home
- Money for pensioners with sight problems
- Registering as blind or partially sighted
- Meeting blind people/local support groups

## **Practical information leaflets**

- Shopping made easy
- How to use better lighting to make things easier to read
- Seeing at home
- Leisure at home
- Magnifiers
- Fact sheet on specialist reading services
- Keeping safe

## **Support Groups for partially sighted and blind people**

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 NASVI

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 NASVI on 01904 671921 or Beverley Sharpe at IDDT on phone 01604 622837.

If you would like to receive any of the above leaflets or the IDDT leaflet on registering, contact Beverley Sharpe at IDDT, PO Box 294, Northampton NN1 4XS or tel 01604 822837, or e-mail [beverley@iddtinternational.org](mailto:beverley@iddtinternational.org)

The RNIB details are: RNIB, 224 Great Portland Street, London W1W 5AA or tel 0845 766 999 website [www.rnib.org.uk](http://www.rnib.org.uk)

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## Implantable Glucose Sensors Prioritised For Research - Health Technology Assessment

The Health Technology Assessment [HTA] programme has listed research into glucose sensors for people with insulin dependent diabetes as a priority. This has to be good news as glucose sensors that will detect the level of glucose in the blood have to be a major step forward for people with diabetes. This is the device that people have been awaiting for years and the ramifications are huge:

- diabetes will be much easier to manage and the early, automatic detection of hypos will mean parents will be able to sleep in their beds at night and know that their child will not slip into hypoglycaemic coma or seizure, carers of adults will be the same
- violent and aggressive behaviour as a result of hypoglycaemia will be avoided and family/marital relationships will not suffer as much
- the increasing problem of hypoglycaemia unawareness will no longer be as large a problem. Yes this is what we need!

What is the HTA programme? This is a national programme of

research established and funded by the Department of Health's Research and Development programme. Its purpose is to ensure that high quality research information on the costs, effectiveness and broader impact of health technologies, is produced in the most effective way for those who use, manage and provide care in the NHS. Every year the HTA programme and its advisory panels decides which of the many suggestions received from the NHS and its users should become research priorities. The programme then issues calls for proposals and commissions research to answer those questions. Commissioning and publishing involve rigorous peer review and all projects under way are closely monitored.

**What is "health technology"?** Health Technology is an internationally recognised term that covers any method used by those working in health services to promote health, prevent and treat disease and improve rehabilitation and long-term care. "Technologies" in this context are not confined to new drugs or pieces of sophisticated equipment.

For more information about HTA, visit their website: [www.hta.nhsweb.nhs.uk](http://www.hta.nhsweb.nhs.uk)

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## From Our Own Correspondents

### Do doctors understand?

Dear Jenny,

Do doctors understand the mechanics of living with diabetes? My husband's consultant has a lovely lady as his Registrar who, despite being very nice, has been known to cause mirth with her remarks for patients and nurses alike. A typical one happened to my husband at his recent check up when she was looking at his diary of the times and results of blood tests. She was looking at a week when he was on a day shift and leaves the house at 5.15am and so does his blood test at 4.30am – he uses the 24hour clock for recording. After commenting

that his blood tests were somewhat erratic she asked why he was having his breakfast at 4.30 in the afternoon! When it was explained to her that he was having breakfast at 4.30 in the morning, she asked why he had it that early and he would be better getting up later. At this point we all had to contain our laughter at her naively not realising that some people have to go to work early in the morning. But when we pointed this out she replied in all honesty without a trace of irony that if he didn't work his blood tests would probably be better! Just goes to show what pampered unreal lives some people lead.

Mrs J.L.  
S East

### **No more hypos!**

Dear Jenny,

Just a note to thank you once again for your guidance and helpful IDDT Newsletter which has helped me take up the cudgel on behalf of my eldest son. He was on Human Mixtard and was having frequent frightening hypos and black outs. He has been on Pork Mixtard now for 18months and has only had one hypo since changing and this one was his own fault!

Once again many thanks for the interesting Newsletters. Recently I was chatting to a lady in a shop and her husband was also on Human Mixtard and is having nightly severe hypos. His doctors refuse to change his insulin to animal and he is finding it impossible to get help. I passed on IDDT's Newsletters to the lady in the hope that some of the articles give her the strength to take up the cudgel on behalf of her husband as I did for my son!

Mrs S.D.  
S.East

**Jenny's Note** – we shouldn't need such fighting talk and it is no wonder that people who want animal insulin are classed as aggressive! All Mrs S.D's son did was to change from 'human insulin to pork insulin

of the same type and his hypos disappeared! Just how many more people does this apply to I wonder?

### **From far and wide**

Dear Jenny,

I read in the July Newsletter about your "free leaflets in good old paper form!" I have no access to the internet and therefore would be grateful of you will be kind enough to supply me with the leaflets.

A million thanks to your organisation for the good service rendered to humanity over the years. I have diabetes and your Newsletters and leaflets have been of immeasurable assistance to me.

C.D.  
Nigeria

### **Low carbohydrate diet works for me**

Dear Jenny,

After listening to Ron Raab's talk about the low carbohydrate diet at IDDT's Annual meeting in Birmingham in May 2001, I decided that I would try my own version by cutting down my carbohydrates and reducing my daily insulin dose. It is working for me – I haven't had a hypo since adopting this diet and my HbA1cs are now down to 7mmols/l. Good isn't it?

Mr KM  
Oxon

**Jenny's comment** – Mr KM is not the only one who has taken up the low carb regime since listening to Ron's experiences. One of IDDT's Trustees has done the same - not only is he a slim-line version of his former self but his daily insulin intake has reduced by 50% and above all he says he feels so much healthier and 'brighter' generally.

## The truth is sometimes alarming

Dear Jenny,

Thank you for what you and your team do to help people involved with diabetes. The Newsletters are always informative and helpful and I still find some of the contents rather alarming. However, I would rather know what is going on, even if the information you provide sometimes makes me shake my head in disbelief. A perfect example is the intended global withdrawal by Novo Nordisk of pork insulin! At least IDDT readers will be aware of the future situation, even though others may again claim that they led a strong nationwide campaign to resist Novo Nordisk's actions!

Why do government and the drug companies want to make things even more difficult for people with diabetes and their families than they already are?

Please keep printing the truth!

My main worry is that at some time in the future, the only 'choice' for everyone with diabetes will be human insulin which is still not proven to be better than animal insulin and for me was awful. I tried it for 6 months and had some very hairy moments. At least I know that animal insulin is an alternative but I wonder how many people and their families think that human insulin is the only option?

I truly dread the day when I am forced to become a 'human' guinea pig again but until such times arise, I shall continue to enjoy myself. My job gives me lots of exercise, I play football twice a week and drive all over the country to watch stock car racing. I won't let my condition stop me doing what I want to do. I try to be sensible and it works most of the time!

Mr M.J.  
South East

## Intake Of Vitamin D And The Risk Of Type 1 Diabetes

This study, published in The Lancet [vol 358 Nov 3 2001], was carried out in people in Finland which has the highest rates of Type 1 diabetes in the world and is following the trend of increasing incidence in children under 5 years. Vitamin D supplements given to animals have been shown to reduce the incidence of Type 1 diabetes and the researchers wanted to find out whether or not giving Vitamin D supplements to infants would affect the development of diabetes.

The study was what is called a birth-cohort study where all the pregnant women due to give birth in 1966 in a northern area of Finland, were enrolled. A year after their birth information was collected about the frequency and dose of Vitamin D during the first year of the baby's life. Whether the supplement was below, above or within the recommended daily dose of Vitamin D was recorded. [84 children that were given daily cod liver oil were also classed as receiving the recommended dose]. A follow up survey was done in 1997 to find out how many of the then children had developed Type 1 diabetes, either as a child or as an adult.

### Results

81 of the children developed diabetes and analysis of the findings showed that giving Vitamin D supplements, irrespective of dose, reduced the incidence of Type 1 diabetes. In the children who regularly received Vitamin D the risk of developing diabetes was reduced by 80% if the child had received at least the recommended dose compared with those receiving less but even giving irregular doses compared to no Vitamin D supplement was associated with reduced frequency of diabetes.

The authors suggest that ensuring that adequate Vitamin D supplements are given to infants could reverse the increasing trends in the increase in Type 1 diabetes.

## Authors comments:

- Vitamin D acts as an immuno-suppressant and diabetes is an autoimmune disease, so the results are not surprising.
- Vitamin D supplementation is only beneficial and safe in people whose biological concentration of it is less than it should be.
- Northern Finland has less daylight than many other countries and it is daylight that produced Vitamin D in the skin, therefore Finland may not be typical of other countries.
- A Norwegian study [Diabetologia 199;42] showed that cod liver oil taken during pregnancy reduced the risk of Type 1 diabetes in their children.

### **Reduction of recommended Vitamin D allowance over the years and increase in Type 1 diabetes – coincidental or not?**

In Finland the daily allowance of Vitamin D for infants is one tenth of what it was in the 1960s. It was reduced in 1964, again in 1975 and even further reduced in 1992. The authors wonder if this reduction in dose and perhaps a reduction in compliance in giving Vitamin D supplements could be at least partly responsible for the increase in Type 1 diabetes. They do point out that Vitamin D is potentially toxic and therefore any changes in recommendations should be made with caution but they also add that health workers should ensure that all infants are receiving at least the present recommended dose.

### **Who links all these studies together?**

Some of us will remember the days when our mother's used to insist on the daily dose of cod liver oil and young children even received a cod liver oil capsule with their morning bottle of milk. Diabetes in childhood and certainly children under 5 was a rarity in those days.

But what happens to a study like this? And all the other studies that have shown associations and links that could provide explanations for the increasing numbers of adults and children that are diagnosed with Type 1 diabetes. It is well recognised that there is not going to be one single cause but it would be good to know that somewhere someone is trying to piece together the jigsaw. Or do these studies

just sit there?

Type 1 diabetes is costly in economic terms for any health provider, whatever the health system but it is also costly to the people with it. 'Normal life' is normal life with diabetes and all that this means – injections, blood tests, diet, doctors visits, perhaps a somewhat uncertain future and the risks of complications. It is essential that greater emphasis is placed on Type 1 diabetes.

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## Parents Part

Arguably the people most interested in diabetes research developments are parents of children with diabetes – hardly surprising when they have to watch their children grow up with diabetes and when most parents would rather have diabetes themselves than have it in their children. So they watch the research not just with interest but with hope that one day someone will come up with some answers for their child or for future generations. Here are some bits and pieces from research that fit into three categories – research that may affect the treatment of our children now, that provides information about causes and risks and research that may give hope for the future.

### **Research looking at treatment now**

#### **Insulin pumps work in some children and not others**

Research in Colorado tested the use of insulin delivery pumps on 56 children and adolescents with Type 1 diabetes between the ages of 7 and 23 for a 12 month period. Their control was monitored before and after treatment. Nearly 66% achieved HbA1c levels below 8.1% from 8.5% with less frequent seizures and hypos. However 20% showed an increase in HbA1cs from an average of 7.8% to 8.8%. The researchers are now looking for differences in the children to try to find out why pump treatment fails in some children.

Paediatrics Feb 2001

### **Insulin pump therapy at night time only for children**

Ten children between 7 and 10 years old were studied to compare night time only use of the pump with a pre-breakfast injection of isophane and a short acting analogue with the 3 injections a day regime. The pump group showed a reduction in fructosamine [average blood sugars], a significant reduction in the number of blood tests within the target range and a reduction in the total dose of insulin. There was also a decrease in the fear of hypoglycaemia. The authors concluded that pump therapy may offer significant benefits in selected groups of patients.

Diabetes Care 2000;23:579-582

### **Humalog and short-acting 'human' insulin compared**

884 people with Type 1 diabetes, 719 children and 165 adults were studied over 5 years. 676 were switched from 'human' short-acting insulin to Humalog while 208 remained on 'human' insulin. The patients on Humalog showed a drop in their HbA1c levels and no increase in the numbers of hypoglycaemic events compared to those on 'human' insulin. [Worth noting that there was no decrease in the number of hypos either!]

Diabetes Care March 2001

### **Children with diabetes and asthma**

Research in Norway has found that people with Type 1 diabetes may have increased risks of developing asthma. Children with diabetes in 16 European and 12 non-European countries were studied and it was shown that more children with diabetes had asthma than the people without diabetes. There was a higher incidence of diabetes and asthma in English speaking countries leading the researchers to suggest that this may be caused by genetic make up and/or early environmental exposures.

Lancet Feb 24 2001

### **Type 2 Diabetes in children**

Type 2 diabetes is now affecting adolescents particularly in the US and it is thought to be as a result of lifestyle – obesity as a result of eating the too much, the 'wrong' foods and lack of exercise. Glucophage is a drug that is used for adult type 2 people that makes the body more responsive to insulin. Research looked at adolescents between the ages of 12 and 19 with a body mass index of 30 or greater ie they were obese. They received Glucophage twice daily or a placebo. The results showed that insulin sensitivity increased in the Glucophage group with a reduction in the fasting blood glucose levels although the HbA1c results were the same for both groups. However, Glucophage caused diarrhoea in 40% of the treated group.

Paediatrics April 2001

### **Research into causes, risks and associations**

#### **Taller children at greater risk of diabetes**

Children who are taller and weigh more than their peers have a greater risk of developing Type 1 diabetes according to a 3year study carried out in Finland. 586 children with Type 1 diabetes were compared with the same number of children who did not have diabetes. Children under the age of 3 who weighed at least 10% more than their peers had a 50-60% higher chance of developing diabetes and children who were taller than average for age their group had a 20-30% higher chance. The researchers suggest that growth could stress the insulin producing beta cells by increased insulin secretion or that it could be that a genetic tendency to accelerated growth may induce hyperinsulinaemia.

Diabetes Care Dec 2000

#### **Maternal age and birth order influence the risk of childhood-onset type 1 diabetes**

Data was collected on 1,382,602 people born in Norway between 1974 and 1998. The children were followed for a maximum of 15 years and were matched with children with Type 1 diabetes diagnosed before 15 years of age.

The results showed that there was no relationship between the mother's age and Type 1 diabetes in the first born children but there was a positive association between maternal age and the incidence of type 1 diabetes for the second and later born children. The strength of the association increased with birth order. So, for example, among the fourth born children, there was a 43.2% increase in the incidence of Type 1 diabetes for each 5-year increase in the mother's age. However, each increase in birth order was associated with a 17.9% reduction in incidence among women who were 20 to 24 when they gave birth. The authors suggest that the risk of type 1 diabetes may be influenced by intrauterine factors and by early life environmental factors that can differ according to maternal age and number of siblings, such as feeding practices, neonatal care, and exposure to infections.

BMJ 2001;323:369-371

### **Type1 and Type 2 diabetes genetically linked**

Researchers in Sweden and Finland have investigated the link between the two types of diabetes by looking at 695 families with more than one family member with Type 2 diabetes. They found that 14% also had family members with Type 1 diabetes and of this 14%, 30% had more than one family member with Type 1 diabetes. They also found that the people from mixed Type 1 and Type 2 diabetes families seemed more likely to have impaired insulin production and were more often treated with insulin than people in families where only one member had Type 2 diabetes. The researchers concluded that Type 1 and Type 2 diabetes cluster in the same families and a shared genetic background with a person with Type 1 diabetes predisposes people with Type 2 diabetes to impaired insulin production.

Journal of Clinical Endocrinology and Metabolism 2001;86:574-82

## **Good News From Abroad!**

### **Good News For Animal Insulin In The Czech Republic**

CP Pharmaceuticals in Wrexham have stepped up production of their animal insulins so that from January 2001 people in the Czech Republic will be able to receive animal insulins that they have been using. This follows the withdrawal of animal insulins and replacement with the more expensive 'human' insulins by the major worldwide drug companies. Not only will this prevent people in the Czech Republic from suffering the adverse effects of 'human' insulin, but it also ensures that they will have a supply of affordable insulin.

The approach to CP came from the Czech government and they are to be commended for their immediate action, recognising that some people would suffer the adverse reactions to 'human' insulin and they also recognised that 'human' insulin would be more expensive without providing any clinical benefit for patients. They have speedily granted registration of CP insulins on the basis that there is full registration in the UK and they have co-ordinated pricing arrangements and supply agreements with wholesalers.

This contrasts very sharply with other countries such as America where the authorities insist on tests to prove that beef insulin is BSE free, despite the original insulin being extracted from US cattle and no such test is available! Little sympathy shown here for people's needs. We also have to point out that although CP insulin has been registered in Finland on the same basis, the insulin has not yet reached the people who are in need of beef insulin.

We congratulate the Czech government for their actions and congratulate CP for coming to the rescue of the people with diabetes whose needs are being ignored by the giant pharmaceutical companies.

## Good News For Beef Insulin Users In The US

As many of you have read, people in the US that need beef insulin are having to import CP Pharmaceutical beef insulin because it has been discontinued by Eli Lilly. The importation process is far from ideal and it is costly. The 6 month supply of insulin has to be paid for up-front and the importation permit from the US Department of Agriculture [USDA] has been costing \$36. To make things worse from in August 31st 2001 USDA increased this charge to \$94. This trebling of the cost resulted in some heavy and persistent lobbying.

This has resulted in complete removal of the need for a USDA permit for beef insulin importation so removing this cost altogether and making the process easier for people.

### **Instructions for people in the US importing insulin from the UK:**

The package should be clearly labeled with an accompanying declaration stating "Human pharmaceuticals, ready for use, not containing live animal or poultry viruses as the vector." It would also be helpful to include the trade name and package inserts with these documents.

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## Security On Flights update

As a result of the New York disaster, we are all aware of increased security at airports and on flights. At the time of writing this, no sharp objects can be carried in hand luggage and this clearly affects people requiring insulin. Whether syringes, pen injection devices or lancets, these are sharp objects and therefore fit into this category.

### **Flying in the UK**

Airlines have recognised the need for people with diabetes to inject on flights and a letter from your doctor will allow you to carry syringes etc in your hand luggage. The letter must clearly state that you have

diabetes and will need to inject during the flight. The letter will also need to refer to any further supplies in the baggage in the hold. Without such a letter you may not be allowed to take your medication on board. IDDT recommends that you contact your airline for its exact policy but to be on the safe side it is sensible to obtain a doctor's letter.

**The Jersey Weekly Post** [27.9.01] reports that the Jersey Diabetes Centre is issuing certificates free of charge to people with diabetes to enable them to take their syringes and other equipment in their hand luggage.

**The Stirling Observer** [10.10.01] reported that a member of the Scottish Parliament has raised concerns with the Minister of Health that doctors' letters could be forged so special 'insulin dependent' cards should be supplied by Health Boards to enable people with diabetes to take their supplies on board.

Clearly the regulations may change and therefore it is important that you check the current position with your airline, well before flying. The regulations may be different in other countries and this is important if taking internal flights in those countries.

### **Flying in the United States**

The following information applies to airports in all 50 United States and was supplied to the American Diabetes Association.

1. Because of concerns over forgeries, prescriptions and doctors' letters are not sufficient to allow people with diabetes to carry syringes and other equipment on board.
2. Passengers may board with syringes and other insulin delivery systems only if they can produce a vial of insulin with a professional, pharmaceutical pre-printed label that clearly identifies the medication. NO EXCEPTIONS WILL BE MADE. Since the prescription label is on the outside of the box, it is recommended that passengers refrain from discarding their insulin box and come prepared with their vial of insulin in its original pharmaceutically labeled box.

3. Passengers who have diabetes not requiring insulin but who need to test their blood glucose may carry their lancets on board as long as the lancets are capped and are brought on with a glucose meter that has the name embossed on the meter eg 'One Touch', 'Accucheck'.
4. Glucagon should be kept in its original pre-printed pharmaceutically labeled container.

### **Flying in Canada**

The situation in Canada is similar to the UK – a doctor's letter is required stating that you have diabetes and need to carry insulin, syringes, pens lancets etc. The doctor's letter was a requirement before September 11th but was not always adhered to previously.

Note - even prior to the increased security, many people have always carried a similar doctor's note when travelling abroad explaining their need to carry syringes or injection devices. In the past this has been to prevent any confusion with syringes and drug addiction and has, and still is, especially important for young people who are more likely to be suspected of drug misuse.

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## **Snippets**

### **The General Medical Council [GMC] has been given charitable status**

This means that the GMC will now have had to conform to requirements of being a registered charity. According to the Charity Commissions, the GMC's purpose is now to protect, promote and maintain the health and safety of the community by ensuring proper standards in the practice of medicine. They add that the GMC is there for public benefit and any benefit to the medical profession is purely incidental. Interesting that the GMC was set up to govern the medical profession but now it's primary aim is to protect patients and not it's medical members. The GMC has come in for much criticism and presumably this change reflects a change in their priorities.

### **Charity Commission Changes**

The Charity Commission has announced that the independent complaints system that has been trialed for the past year, will become a permanent fixture and will give the independent reviewer the powers to recommend payments for financial redress where appropriate. The Commission says that it is conscious of the need to be fair, open and accountable in the way it does business.

Also to enhance public confidence in charities that they are being actively regulated, the Charity Commission is introducing a new-style of review visits to charities. These will be phased in with 150 being conducted before April 2002 and 600 per year from then onwards. These visits will be primarily aimed at charities with incomes from £0.25 million and £10 million. About 8000 charities fit into this category but they receive about half of the total charity income.

### **Contradictory, or what? Drug companies sponsor American Medical Association [AMA] campaign.**

Maybe this doesn't sound too bad but just look at the subject of the campaign they are sponsoring. Be prepared for a smile – it is to promote ethical guidelines to discourage US doctors from accepting expensive gifts from drug companies!

The AMA has accepted \$600,000 from pharmaceutical companies to sponsor its \$1 million campaign. The Lancet [8.9.01] reports that the chairman of the working group that drew up the guidelines said that the support of industry was appropriate because the campaign would target sales reps as well as doctors. He also said that media reports saying that some companies are supplying doctors with lavish gifts and expensive trips have hurt the reputation of the companies as well as the medical profession, therefore the guidelines are to the advantage of the companies, as well as the doctors.

Wonderful logic here! If the companies are not buying lavish gifts for doctors, then the guidelines are unnecessary but if they are and don't like their reputations being damaged, then all the drug companies have to do, is stop giving their reps the finances for the expensive

gifts for doctors! Whatever the logic of the AMA, it doesn't quite give out the right message, does it?

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## Regular Reminder

Novo Nordisk has NOT yet announced the date for withdrawal of their pork insulin in the UK but IDDT is regularly publishing details of the pork insulins that are available as alternatives for if/when they do.

Users of Novo Nordisk pork insulins will NOT have to change to genetically produced 'human' insulin. Pork insulins are produced by CP Pharmaceuticals in vials and cartridges for pens. The nearest equivalent replacement insulins are as follows:

Novo Nordisk Pork insulins	CP Pharmaceuticals pork insulins
Pork Actrapid [short-acting]	Hypurin Porcine Neutral
Pork Insulatard [intermediate acting]	Hypurin Porcine isophane
Pork Mixatard [pre-mix]	Hypurin Porcine 30/70 Mix

**Note:** While the action profile charts for Pork Actrapid and Hypurin Porcine Neutral show that the durations of action for these two insulins are about the same, they do show that Pork Actrapid starts its peak of action sooner than Hypurin Porcine Neutral. These charts are only a rough guide and insulins work differently in different people. Some people that have already changed have noticed this difference and have had to make appropriate adjustments to their dose.

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**

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Northampton  
NN1 4XS

Name: \_\_\_\_\_

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\_\_\_\_\_

Postcode: \_\_\_\_\_

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

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## From Your Editor – Jenny Hirst

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