Insulin Dependent Diabetes Trust

December 2012 Newsletter

Registered Charity No 1058284 - Issue No 75

SEASONAL GREETINGS TO ALL OUR READERS

The Trustees and staff of IDDT wish all our members a Happy Christmas and a healthy New Year. We would also like to thank you for your help and support throughout 2012.

In many ways 2012 has been a very successful year for IDDT – our membership has increased by 20%, we have had more requests for our booklets and leaflets than ever before from members, non-members and from health professionals who are giving them to their patients as part of their education package.

Our telephone helpline has been busy with many calls from people who need help, support or who just need to talk to someone, so we are fulfilling one of our primary aims – we listen.

One of the big issues raised with IDDT by you has been the change in the driving regulations. Yes, they were confusing and yes, while improvements have been made by the DVLA, they still are confusing. While I am pleased to say that quite a lot of people who have had their licences revoked because of the confusion over hypos have had this decision overturned, it is an ongoing problem. We had very productive discussions at our Annual Conference and we will be taking up the points raised with the DVLA in the coming months.

As we look forward to 2013, you will have noticed that we have changed our name to the '**I**n**D**ependent **D**iabetes **T**rust' but as you can see we will be keeping our acronym '**IDDT**'. The change in name does not mean there is a change in policy or a change in what we presently offer but it better reflects the work we do in offering help, support and a listening service to all those who live with diabetes.

The change in name also reflects our position compared to other charities in that we are independent and possibly the only independent diabetes charity in the world. We do not accept money from the pharmaceutical industry so that the information we provide is not biased or influenced by such funding sources. We are only influenced by the needs and views of people living with diabetes.

Our independence is particularly important in the wake of the publicity surrounding Dr Ben Goldacre's recent book about the practices of the pharmaceutical industry. He provides evidence that industry suppresses unfavourable clinical trial results, and by this and other ways, knowledge about the efficacy of drugs is distorted. This is harmful to patients and prevents genuine decision making. He asserts that not only do drug regulators and the research community collude in these practices but that health charities sometimes allow themselves to be used by the industry.

The charity sector is forming a response to these accusations but IDDT is in the enviable position of not having to justify our position as we have absolutely no conflicts of interest. To IDDT, it has always seemed hypocritical for charities and others to argue that patients should have informed choices of treatments and involvement in decision-making when it is well recognised that the practices of pharma industry prevent genuinely informed choices by patients and by doctors and health professionals.

It seems that charities and the other organisations are forgetting that industry does not give away large sums of money without something in return, even if that something is simply keeping quiet and allowing the status quo to continue...

Please Pick Up The Phone

With today's technology, there are so many different ways to communicate – email, blogs, chat rooms and texting.

The development of these various ways of communicating has certainly made life easier in many ways – a text to say "I'm going to be late" is so useful if you have someone at home expecting you – they can stop worrying that something has happened to you. They are also useful when you don't really want to talk.

Emailing an order for goods is a lot easier in many ways and can be done at midnight if you want. Emails can keep you in touch with family and friends around the world.

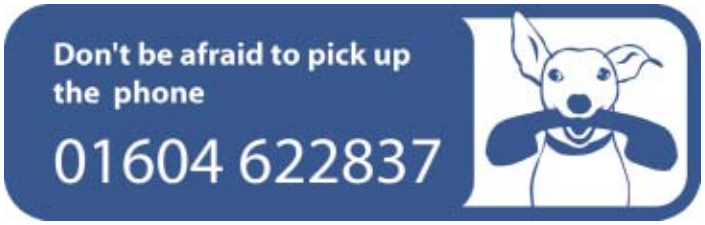
But holding a conversation by texting or emailing can result in numerous messages going backwards and forwards when perhaps a phone call would have been easier!

Mobile phones, ipads and ipods with their Aps keep children and teenagers quiet on a long car journey but it can be a fairly silent journey missing out on the fun games, and the communication, we used to have on such journeys.

Let's not forget the gift we were given – talking!
All forms of communication are important and have their place but it is important to appreciate the value of a phone call. Hearing someone's tone of voice gives us so many clues about how they are feeling – happy, sad, lonely, depressed. We can't pick these feelings in texts or emails and if we try, sometimes we get it wrong.

Our Helpline demonstrates too that by making a call about a specific topic, the conversation often takes a different direction and people express their feelings or worries about other things that matter to them. Maybe this is even the subconscious reason for ringing in the first place. By holding a conversation, we can show we are listening to each other and this isn't possible with texts and emails. It is always good to know that we are being listened to and sometimes this is enough to make us feel better.

How many times do we feel frustrated because no one is listening – it sometimes happens at the diabetes clinic or at the GP surgery. The doctor who looks at his/her computer nearly all the way through the consultation, may actually be listening but he/she is not showing they are and you, as the patient, don't feel heard. We shall regularly remind you of the importance of picking up the phone, with this symbol – we will listen.



Latest On Retinopathy

A link between myopia and retinopathy

Diabetic retinopathy is damage to the retina at the back of the eye which results in new blood vessels being formed and leaking of blood vessels. Myopia is being short sighted, where people cannot see in the distance and should not be confused with what people often refer to as being short-sighted, the inability to read without glasses when they are in their mid forties.

Interestingly observational studies carried out in Australia looking at 7230 people from 1960 to 2012 have shown that people with diabetes who are myopic could be as much as 60% less likely to develop retinopathy than people who are not myopic. The authors recommend that further studies are carried out to find out why this happens. [Clinical and Experiment Ohthalmology, Sept 7, 2012]

A link between diabetic retinopathy and long-term coeliac disease

Coeliac disease is an autoimmune condition that damages the small intestine so healthy parts of food are not absorbed. People have to eat gluten free diets. Gluten is found in wheat, rye and barley as well as other foods.

It is known that coeliac disease can increase the risk of the development of Type 1 diabetes and there is a school of thought that adults and children with Type 1 diabetes should also be tested for coeliac disease.

Researchers in Sweden set out to investigate whether coeliac disease affects the risk of diabetic retinopathy in people with Type 1 diabetes. They found that:

- People had a lower risk of diabetic retinopathy in the first five years after being diagnosed with coeliac disease than people with Type 1 diabetes without coeliac disease.
- When people had coeliac disease for more than 10 years, their risk of retinopathy increased and the risk was greater still on people who had coeliac disease for 15 years or more.

So the researchers concluded that coeliac disease in people with Type 1 diabetes does not appear to affect the risk of diabetic retinopathy for 5 to 10 years but those with long-standing coeliac disease may have a higher risk of developing retinopathy than those without it.

One flaw in the study was that the researchers did not comment on how well people stuck to their gluten free diet, so it could be that those who were less rigid about cutting out gluten from their diet were more at risk of diabetic retinopathy. Coeliac disease can also happen

with no symptoms, so people continue to eat gluten products and this could increase their risks of developing retinopathy.

The message from the study is to ensure that your eyes are regularly checked for any signs of retinopathy as early diagnosis is important to try to prevent it becoming a serious problem. [Diabetes Care, Sept, 2012]

Christmas Tips

Christmas is a mixture of many things – presents, excitement for children [and adults] and a busy time for everyone. But if you or a member of your family has diabetes, Christmas can be a worrying and stressful time too, especially if this is your first time with diabetes. Celebrating Christmas is not just a time for presents but also about food! We all eat a lot more than we should and we tend to eat much more of the sort of food that is not exactly ideal for children or adults with diabetes.

It doesn't matter whether you are taking insulin for Type 1 or Type 2 diabetes or tablets for Type 2, you can't take a day off from it but it is important to remember that it is a time to be enjoyed with family and friends.

Send for IDDT's Christmas Tips, call IDDT on 01604 622837 or go to the Homepage on the website **www.iddtinternational.org**
You will find:

- Cooking for Christmas by Consultant Dietician, Dr Mabel Blades – Christmas Dinner, Christmas Pudding and Mincemeat and some different recipes to set the taste buds going.
- Information about treating a Christmas Hypo
- Alcohol and diabetes
- And more...

Remember!

- Excitement tends to lower blood glucose levels, this especially applies to children with Type 1 diabetes.
- Stress tends to raise blood sugars.
- Eating more than usual can raise blood sugars.
- Exercise lowers blood sugars, so a walk after a big Christmas dinner will help to lower them.
- Try to keep meal times as near as possible to your usual times but if meals are later, then remember to have a snack.
- Avoid keeping extra food around as this will tempt you to eat what you want, when you want.
- Maintain your blood glucose testing routine as far as possible and test more often if you're eating frequently or at irregular times.
- Stay active - exercise reduces stress, burns excess calories and helps control blood sugars.
- Pamper yourself – whether this is taking a relaxing bath or curling up with a book, make time for yourself as this can help to prevent holiday stress from building up. Get plenty of rest to prevent holiday tiredness.
- Planning – make sure that you have enough insulin and other medications to cover the Christmas and New Year holidays.

Don't let diabetes spoil your day – enjoy it!

A Different World - Diabetes In 1956 At 5 Years Old

Kevin was 5 years old when he developed Type 1 diabetes. He was very ill for months before his GP discovered it. He remembers his mum taking him to and from the doctor who one day asked Kevin to wee in a bottle and then said to his Mum, Kevin has diabetes. While Kevin didn't understand, he remembers only too well being rushed into Queen Mary's Hospital in Carshalton.

He lived in the hospital for about 2 years as his Mum, 2 brothers and 2 sisters all had very bad asthma and his Mum couldn't cope with diabetes as well. From the age of 8 to 13 he lived in hostel, Palingswick House, for children with diabetes and only went home for school holidays, when he was not supposed to tell anyone that he had diabetes.

He can still picture the inside of the building, dormitories/ bathrooms, wardens office/staff room/ kitchen/ dinning room/ TV room and stairs at the back going down to the room where they did their urine tests.

Kevin at the front – with tattoos drawn on his body out of boredom!

Kevin hated being at Palingswick House and he ran away with two other children. They knew enough about managing their diabetes to break into the medical room and take insulin and syringes for the three of them!

They slept in Richmond Park for a couple of nights, but gave themselves up two days later as they found it difficult to get food.
However, there were highlights for Kevin - a famous footballer called Rodney Marsh who played for QPR actually played a game of football with them in the courtyard and when he was about 11, the BBC made a documentary on Palingswick House and how they managed their diabetes and it was actually shown on TV!

While Kevin hated being at Palingswick House, he acknowledges that he learned a lot about his diabetes and believes he would probably not be alive today if he had not gone there. He studied at college for many years and qualified as an electrical engineer. He and his wife Heather have 6 children and 11 grandchildren.

He would love to hear from anyone who was also at Palingswick House during his years there – just get in touch with IDDT and we will put you in touch with him.

And we also heard from Paul...
Paul has had Type 1 diabetes since 1960 when he was 9 years old. He too was sent to Palingswick House and recalls that there were between 50 and 60 children there at any one time from the age of 8 to leaving school. He too describes it as a lifesaver for most of the children but of course, he says he has many changes!

How times have changed and what a lot we have to be grateful for!

Food Labelling To Change

As we all know from experience, there has been a mixture of food labelling according to who manufactures the products and this makes it difficult for us to understand and compare different food products. In October 2012, following a 3 month consultation with food manufacturers, retailers and others, the Government announced that there will be a consistent system of food labelling by summer 2013.

The system will include traffic light colours [red, green and amber], text [high, medium or low] and percentage Guideline Daily Amounts [% GDAs]. It remains to be seen if all the manufacturers will follow this recommendation by next summer.

The answer to a Parliamentary Question on this stated that nutrients that can be declared on pre-packed foods are defined by law. From 2016 all pre-packed foods will be required to carry nutrition labels on the back including energy values, the amounts of fat, saturates, carbohydrate, sugars, protein and salt.

The new EU Regulation 1169/2011 additionally allows that energy

value only or energy value plus amounts of fat, saturates, sugars and salt may be voluntarily repeated on front of pack. The regulation does allow nutrition information can be provided on an 'as consumed', i.e. cooked basis, as long as the manufacturer gives full instructions as to how the food is prepared. The Department of Health will be considering our approach to this with industry and others.

Welfare Reform Bill

In February 2011 the Welfare Reform Bill was introduced by Parliament. IDDT has put together a summary of the Bill in relation to current income related benefits to help make the transition as easy as possible for you to understand.

Universal Credit
Current income related benefits for people of working age such as Job Seekers Allowance, Employment and Support Allowance, Housing Benefit, Income Support, Working and Child Tax Credit will be replaced with one Universal Credit (UC). The UC is designed to be an easier system, with computers linked directly to the tax office so each month they will know if your income has changed and their payments will change accordingly. This means you will not be spending time making lots of phone calls reporting changes of circumstances.

At the moment people have to go to several different offices to claim benefits – Local Authorities for Housing and Council Tax Benefit, HMRC for Tax Credits, Jobcentre Plus for Job Seekers or Employment and Support Allowance. The new Universal Credit should be one application for all, making the benefit system simpler. This claim will be made through the Department of Work and Pensions. The exception to this rule is the Council Tax Benefit which will not be included but will instead be handled in a separate claim through your Local Authority.

Pension Credit is not directly affected. However, at the moment it can be claimed as soon as one person in a couple reaches the qualifying age. Under the new rules, both members of the couple need to have reached the qualifying age to be able to claim. They will remain on the Universal Credit until this time.

The Universal Credit is due to start coming into force from October 2013 for new claims only. However, existing claims will take time to transfer across and it is planned that this should happen between April 2014 and October 2017.

Personal Independence Payment
In addition to the major changes to the income related benefits, there will also be a huge upheaval in the benefit currently know as Disability Living Allowance (DLA). It will be replaced by the new Personal Independence Payment (PIP).

The PIP will have two components (similar to the DLA) - a Mobility Component and a Daily Living Component. Each component will have two ratings – a standard rate and an enhanced rate dependent on how severely the claimant's ability to carry out daily tasks is affected. Most claimants will be expected to attend a consultation (the medical that currently happens). This will give the claimant the opportunity to explain face to face how their impairment affects their daily life.

As of June 2013 all new claims made by adults aged 16 – 65 will be for the PIP and not DLA. Current DLA claims will be reassessed when they need renewing or have a change of circumstances reported. There may also be some people who are called for reassessment between autumn 2012 and 2016.

These changes are intended to make life easier. If you have any queries, you can obtain further details from the organisations listed below:

Universal Credit to replace current benefit structure
http://www.direct.gov.uk/en/NI1/Newsroom/DG_191344
Wellfare Reform Bill unveiled
http://www.direct.gov.uk/en/NI1/Newsroom/DG_194774

Welfare and benefits - Spending Review

http://www.direct.gov.uk/en/NI1/Newsroom/SpendingReview/DG_191799

Looking After Your Insulin In Very Cold Climates

IDDT is usually asked how to look after insulin in very hot climates but from time to time we are asked about looking after in very cold climates – visiting the arctic or Chicago in winter when the temperature can go below – 6. The risk is that insulin will freeze and freezing damages it. In these circumstances the best way to find out about the insulin you are using is to telephone that insulin manufacturers and ask.

Searching for information about very cold temperatures came up with the following:

There is no product that can stop insulin from freezing in very cold environments. The safest thing is to keep the insulin close to your body to prevent it from freezing.

Blood glucose meters and test strips also become inaccurate in these very cold climates so similarly, your strips and meter can also be protected by your body temperature by keeping it close to you.
If you are sleeping in sleeping bags, take your insulin, meter and strips in the sleeping bag with you.

IDDT News

Newsletter in plastic envelopes

From 2013 onwards, the Newsletter will be sent out to members in clear plastic envelopes rather than paper envelopes as this will save us a considerable amount of money each quarter. It already goes to the healthcare professionals in this way.

As I explained in the last Newsletter, we are having to make savings wherever we can and this is just one way of doing so. If anyone has any difficulties with this, please do let us know and we will try to make other arrangements.

Thanks go...

- To Simon Taylor for raising £87.00 for IDDT, it is very much appreciated.
- Thanks to all our members who have signed a regular standing order to IDDT to help our financial position. This ongoing support is a tremendous help to us and helps to enable us to continue to help people with diabetes.
- Thanks too to all of you who have agreed to have the Newsletter electronically. It won't help the Royal Mail but it will help IDDT a great deal.

Thank you for buying our Christmas cards!

Many thanks to those of you who have supported IDDT by buying our Christmas cards – your help is much appreciated. **If you still have not bought your Christmas Cards, give us a call on 01604 622837, or order them direct from the IDDT website! http://www.iddt.org/?page_id=3364**

While talking about Christmas...

If one of your presents is a new mobile phone, don't forget to donate your old one to IDDT. Just give us a call and we will send you a recycle bag and a donation will be made to IDDT.

Shop at IDDT

Cool boxes for carrying insulin from IDDT

IDDT is offering these cool boxes for carrying your insulin at the special price of only £15.00.

This hard backed zip up personal insulin pen pack carrier has a dark navy cover, net zip up pouch inside to hold cooling gel pack, a divider to keep gel pack off medication and elasticised loops for holding pens.

- Keeps insulin at 2 - 8 degrees for 8 hours at ambient temperature 35 degrees
- Comes with Soft Gel pack
- Fits into a jacket pocket or handbag.
- Great when travelling in hot climates, and for going out and about

Order online from our shop at **http://www.iddtinternational.org/?page_id=2135** Phone IDDT on 01604 622837 or write to IDDT, PO Box 294, Northampton.

Comparison Of Pumps, Testing And Continuous Glucose Monitors

New technologies in managing insulin-requiring diabetes means that people have more choices. However, we do need unbiased information to help us make those choices, especially as they may be expensive. They may also be heavily marketed which does not necessarily mean they are the best!

Continuous glucose monitors [CGM] generally give blood glucose readings every 5 minutes by a sensor attached to the body which send the results to a display usually worn on a belt. CGM does not replace finger prick testing so people using CGM still need to finger prick test up to 4 times a day.

Insulin pumps administer insulin continuously through a catheter under the skin around the middle. Research has now been published which looked at 33 trials comparing continuous glucose monitoring [CGM] with pumps and injecting and finger prick testing in children, adolescents and adults. [Annals of Internal Medicine, 10.07.12] The results were not necessarily what we would expect:

- Insulin injections control blood glucose levels just as well as pumps but most people got better results by combining insulin pumps with continuous glucose monitoring devices.
- People who used CGM to monitor their blood glucose levels had better results than people who used finger prick testing alone but the two methods were equally effective at stopping blood sugars from dropping to dangerously low levels, hypoglycaemia.
- In most studies pumps were not more effective at controlling blood sugars than multi-dose regimes with meal time injections.
- Insulin pumps with CGM combined with continued glucose monitors gave better blood glucose control than injections and finger prick tests alone.

As the study found that insulin pumps and injections are just as effective as each other at controlling blood sugars, the researchers concluded that which method to use should include patient preference and quality of life.

As we know, some people love the idea of an insulin pump while others really do not want something attached to them all day. In the UK, to a large extent the choice of which devices to use is also influenced by what is affordable, with some local authorities funding insulin pumps

and even continuous glucose monitors, while others will not. While this study gives us unbiased information, it also might make funding of insulin pumps more difficult because it suggests that they are only superior to multi-dose insulin regimes when in combination with continuous glucose monitors.

IDDT's Annual Conference 2012

On Saturday 13th October we held our annual conference at the Kettering Park and Spa Hotel. Entitled "Diabetes is More than Medication", the event was very well attended, with more applications to attend than ever before. As usual we asked for feedback from those who attend so that we can find out how to improve the event for future years.

Given our current focus on expenditure, we were pleased to see that everyone felt that the conference was good value for money. Most people were also very complimentary about the facilities offered by the venue and although the queue for lunch seemed to go on forever at times, we tried to compensate for this by allowing plenty of time.

As ever, the group sessions proved very popular with people variously describing them as helpful, informative and welcoming the chance to share experiences and knowledge. The most popular groups were Living with Diabetes, Fun and Food, Driving and Neuropathy. I am sure you will all join me in thanking those who led the groups as well as those attending and making them such a success.

Each of the speakers too received praise for delivering clear, easily understandable and informative presentations in each of their respective areas, whether they were more traditional or reporting on new developments and innovations.

We had a few more information stands at this year's event and these generated a lot of interest. It was something of a shame that we had to break down the stands early but this was unavoidable this year as the room had been booked for an evening function. However, comments from the stand holders, as well as delegates were all very positive and people particularly liked the new stands. With this in mind, we will try to be increasing the number of stands at future events.

We like to try to ensure that there is a fun element to the day and in previous years we have held a general knowledge quiz. This year we decided to do something different and Tony, who presented the Tai-Chi session, certainly brought a breath of fresh air to the proceedings. As usual, we also ask for suggestions of topics you would like covered in the future and we endeavour to meet these requests either with the development of information leaflets, discussion groups/workshops or formal presentations. There were lots of varied and interesting suggestions this year and they can be roughly split into two groups. The first group is requests for information on diabetes in relation to other medical conditions/ complications including retinopathy, neuropathy, Addison's disease, eating disorders, skin integrity, medication and insulin resistance. The second group is requests for information on diabetes in relation to more practical issues of daily living such as travel, insurance, dealing with health professionals and residential care. This list is not exhaustive but contains the most popular requests.

One final element proving the success of the day is that every person offering feedback, without fail, said that they would come again, so I am sure you will join us in saying a big thank you to Rita, whose time, effort and hard work made the day such a success.

Don’t Forget To Have Your ‘Flu Jab

People with diabetes are advised to have the ‘flu jab as they are in the high risk category. This is because any illness can affect blood glucose levels which can lead to high blood sugars and the risk of diabetic ketoacidosis [DKA], especially in those people taking insulin. There are three types of ‘flu virus:

- Type A which is usually the more serious type. The virus is likely to mutate into a new version that people are not resistant to. This is what happened with the H1N1, swine ‘flu strain. Previous pandemics have been type A viruses.
- Type B generally causes less severe illness and the outbreaks are usually smaller. Type B usually affects young children.
- Type C usually only causes mild illness, similar to a cold.

One or two strains of Type A circulate most years in addition to Type B.

How do we know which viruses are going to circulate each year?
The World Health Organisation [WHO] makes an assessment in February each year of the most likely strains of ‘flu viruses to circulate during the next winter in the northern hemisphere. WHO recommends 3 ‘flu strains the vaccines should contain for the next year and this is usually two type A and one type B virus.

How does the ‘flu vaccine protect you?
The vaccine causes the body’s immune system to make antibodies to attack the ‘flu virus. Antibodies are proteins that recognise and attack germs or viruses that have entered the blood. The antibodies gradually decrease over time and this is another reason why you need a ‘flu jab every year.

If you have had a ‘flu jab, it may take up to 10 to 14 days for it to be effective. ‘Flu vaccines don’t usually cause side effects but there may be mild fever or muscle aches for a day or two afterwards.

News From NICE

A change of heart - NICE publishes rapid review of Lucentis for macular oedema

We reported in our September Newsletter that one lady with diabetic macular oedema was about to be charged £1500 per injection of the drug Lucentis. The reason was that NICE guidance, November 2011, concluded that the expenditure on Lucentis was not a ‘wise use of NHS funds’. Since then, NICE has conducted a rapid review of the original guidance because the manufacturer submitted a revised Patient Access Scheme along with updated analyses, including the drug’s superior effect in a sub-group of people with diabetic macular oedema.

Lucentis [drug name, ranibizumab] will be recommended as an option for treating diabetic macular oedema under the following conditions only.

- The manufacturer provides Lucentis with the discount agreed as part of the Patient Access Scheme as revised in November 2012.
- People have a retinal thickness of 400 micrometres or more. People with severe retinal thickening due to diabetic macular oedema do not respond well to laser treatment. In clinical trials there was improved vision in those treated with Lucentis and this was the greatest in patients with the greatest retinal thickness. So compared to laser treatment. Lucentis is more cost effective in the group of people with greater oedema.

It is hoped that in the near future there will be more evidence from research on vision and quality of life to support the use of Lucentis in people who do not fit into the NICE recommendations, such as those where laser treatment fails.

People currently using Lucentis who do not meet these standards will be able to continue treatment until they or their consultant think it appropriate to stop.

The final guidance is expected to be published in February 2013 and until then local NHS bodies must make decisions on the funding of

specific treatments. Assuming these recommendations do not change, once NICE issues its guidance on Lucentis, all local recommendations across the country will be replaced.

End blacklisting of NICE-approved drug
The Department of Health has announced that from April 2013 all NHS organisations such as PCTs and Clinical Commissioning Groups, should publish information setting out which NICE technology appraisals are included in their local formularies. Local formularies are the lists of drugs each area will allow to be prescribed on the NHS. This decision has been made after reports that in order to cut costs, not all local formularies include all of the NICE appraisals. This leads to a postcode lottery whereby in some areas people can obtain particular drugs and in others they can't.

The NHS organisations have also been told that they should not duplicate NICE assessments, carry out local evaluations or challenge the NICE recommendations. Once the drugs are in the formularies, there should be no further barriers to drugs or technologies being used or prescribed.

Lest We Forget – Secondary Diabetes

All too often we refer to there being two types of diabetes – Type 1 and Type 2 diabetes and IDDT is guilty of this too, but we do not mention a third type and that is secondary diabetes.

This is when diabetes is caused as a result of another condition such as pancreatitis or the use of certain medications – steroids being the most common cause. Secondary diabetes is rare and affects about 2% of reported cases of diabetes. It is sometimes confused with Type 2 diabetes and blamed on obesity or family history but secondary diabetes is caused by outside factors.

Conditions that can cause secondary diabetes:
There are many conditions including hyperthyroidism, Cushing's syndrome, cystic fibrosis, hemochromatosis or any other damage done to the pancreas, hepatitis C, fatty liver disease, coeliac disease, alcoholism and cancer of the pancreas, liver, lungs, intestines or stomach.

Drug causes include:
Drugs taken to help various diseases can also cause secondary diabetes and these include some taken for high blood pressure, beta blockers, diuretics, immune system suppressants, any hormone replacements such as steroids and oestrogen, birth control pills, antipsychotics, antidepressants, and anti-seizure, HIV and chemotherapy drugs. Any of these drugs could affect the body's ability to produce insulin properly and lead to secondary diabetes.

Surgery can also be a cause:
Any surgery involving the pancreas runs a high risk of causing secondary diabetes, as does the removal of the testes. Radiation therapy to treat cancer can also cause secondary diabetes.

So secondary diabetes is caused by another illness and generally these conditions are either hormonal, genetic, malignancies or caused by chemicals or drugs.

And could there be evidence for Type 3 diabetes?
Research carried out at Washington University adds weight to the evidence that an unhealthy diet can lead to Alzheimer's disease. The Washington study showed that even if the pancreas produces enough insulin to balance sugar levels in the rest of the body, a condition, being called 'Type 3 diabetes', stops the brain getting enough insulin. This means that the brain can be damaged in the same way that as other cells in the body. Patients who were given a nasal spray of insulin were better at remembering, had longer attention spans and were more independent.

It has been known for a long time that a diet high in fat and sugar has

been linked to a higher risk of people developing Alzheimer's. This latest study supports the theory that it could be shortage of insulin in the brain that is responsible for this. The researchers are planning a further trial on volunteers showing early signs of dementia.

Diabetes Is Not Being Seen As A Priority

The Public Accounts Committee Report into the management of adult diabetes

On November 1st, the Public Accounts Committee [PAC] published its report on the management of adult diabetes and the Chair, the Rt Hon Margaret Hodge MP, highlighted some depressing facts about the care of people with diabetes.

- 24,000 people die prematurely every year because their diabetes has not been managed effectively, and many more develop avoidable complications such as blindness and kidney disease.
- The NHS spends at least £3.9 billion a year on diabetes services and around 80% of that goes on treating avoidable complications. [Avoidable complications are complications that develop as a result of people not receiving the care and treatment they need, when they need it.]
- In 2001, the Department of Health set out minimum standards for diabetes care in the National Service Framework for Diabetes. This included the nine basic checks for the early signs of avoidable diabetic complications. These were reinforced in 2011 by the NICE Quality Standards for adult diabetes, yet over 10 years later, fewer than half of people with diabetes are receiving all nine tests.
- To add to this, fewer than one in five people with diabetes have the recommended levels of blood glucose, blood pressure and cholesterol, leaving an unacceptably high number at risk of developing complications, being admitted to hospital and costing the NHS more money.
- There are variations across the country in the level of progress towards meeting these targets. This results in an unacceptable "postcode lottery" of care, whereby the quality of diabetes care varies dramatically across the NHS.

The PAC Report can be found at: **http://bit.ly/SSZdfA**

People with diabetes have been let down and are still being let down!
Strategic Clinical Networks

These Networks were set up to improve health services for specific patient groups or conditions in 12 geographical areas with the additional intention of reducing variations in services across the country. They are hosted and funded by the National Commissioning Board and will exist for 5 years. The first Clinical Networks are for the following conditions:

- Cancer
- Cardiovascular disease
- Maternity and children's services
- Mental health

Is there a place for diabetes? NO

Unbelievably diabetes was not included as a separate condition in the Strategic Clinical Networks. It is part of the cardiovascular clinical network along with stroke and renal disease. So despite the Department of Health and other decision-makers knowing the failure of services for adults with diabetes and knowing the increasing numbers of people with diabetes, they did not see fit to make diabetes a priority with a separate Strategic Clinical Network.

Why not? And does it fit with cardiovascular disease?

If diabetes is not to have its own Clinical Network, a case can be made for Type 2 diabetes fitting into the cardiovascular category because of the association of blood glucose, blood pressure and cholesterol levels and the risk of heart disease. However, Type 1 diabetes is an autoimmune condition affecting all ages from babies to adults, so this really does not fit into the Cardiovascular Disease Network. Does it mean that Type 1 diabetes will be put on the back burner even more than it already is?

‘NHS Diabetes’ is to close at the end of March 2013

NHS Diabetes has helped to educate all the professionals who look after people with diabetes. As diabetes care has increasingly moved to GPs and their staff, there has obviously been a need to help increase their knowledge to help them to help us, those living with diabetes. Importantly, NHS Diabetes has provided evidence of the need for improvements needed in hospital in-patient care. Here are some of the key actions by NHS Diabetes:

- Launched the first ever National Diabetes Inpatient Audit in 2009, which resulted in 193 NHS Trusts providing information about the clinical care and experiences of over 12,000 people with diabetes. This provided evidence about diabetes in hospitals to enable improvements to be made.
- Produced the Safe Use of Insulin e-learning module, which has attracted more than 90,000 registrations.
- Organised the first ever national Hypo Awareness Week in August 2012 in 160 hospitals mainly in England.
- Developed a comprehensive series of printed commissioning guides covering every area of diabetes with an accompanying online resource.
- Launched a series of specialist clinical networks to ensure effective two-way sharing of the most up-to-date guidance, tools, best practice and resources.
- Commissioned a range of clinical guidance which has been hugely welcomed by the diabetes healthcare community.

Despite all this and the even greater need for their work in the future, NHS Diabetes is being closed down at the end of March 2013. Diabetes is being moved to ‘NHS Improvement’, a body that looks to improve services and patient outcomes throughout England for specific conditions. But once again there is no category for diabetes and it looks like it will have to fit into the general category of ‘Long-term Conditions’, although this yet has to be made clear. Once again, ‘diabetes’, a condition that is costing the NHS £3.9 billion a year and is still failing patents, is not being seen as a priority by the Department of Health and its advisers.

Where does the blame lie?

The PAC Report highlighted the failures of the Department of Health.

- It has NOT provided strong leadership.
- In giving local NHS organisations freedom to decide how to deliver diabetes services, it has NOT provided mandatory performance targets as it did for cancer, stoke and heart disease.
- It has failed to hold commissioners of diabetes services to account for poor performance.

Clearly the blame lies well and truly with the Department of Health, the planners and the advisers, or is it simply the money men or a mixture of all? One thing is clear, the doctors and health professionals involved in diabetes care and treatment are doing their best in a system that is letting them down and letting people with diabetes down.

And most worrying of all - what about the future? Margaret Hodge reported, “We have seen no evidence that the Department of Health will ensure that these issues are addressed effectively in the new NHS structure.”

If there was ever a time for patients, doctors, healthcare professionals and diabetes organisations to pull together for the future of diabetes care and the health of people with diabetes, it is now. IDDT will be expressing our views to Ministers and others – somebody has to!

Drugs For Painful Neuropathy

One of the complications of diabetes is neuropathy [nerve damage]. The most common form is nerve damage affecting the legs and feet and this is why it is so important for people with diabetes to have regular checks of their feet, one of the 9 yearly essential checks.

The symptoms of neuropathy affecting the feet include the following:

- Tingling or buzzing in the feet which are often worse at night

making sleep difficult.

- Pins and needles which can become intense pain or an intense burning sensation, described by some people as a painful numbness. It can be intermittent or constant according to how much nerve damage there is and which nerves are affected.
- Muscle pain - this is different from the above as it is more diffuse and more like cramp.
- Loss of temperature perception – the hands and feet are less sensitive to heat and can be very sensitive to cold.
- Exaggerated sensitivity in the skin – just wearing socks or tights can be very irritating to the skin. It seems like an allergic reaction but there are no changes in the appearance of the skin and nothing to actually see but just minor damage to the skin can be very painful.

There are various treatments for neuropathy but it does seem that what works for one person does not necessarily work for another. Recent research into drug treatment for people with both Type 1 and Type 2 diabetes has looked at high dose treatment with 3 drugs that reduce pain - amitriptyline, duloxetine, and pregabalin. However while all the drugs reduce pain, they have different effects. The research showed that:

- all three drugs improved pain compared to no treatment,
- pregabalin improved sleep continuity but was associated with more adverse effects,
- duloxetine increased wake and reduced total sleep time but despite this negative effect on sleep, it improved central nervous system arousal and performance on sensory motor tasks,
- although it was a short study, there was no reported improvement in quality of life even with pregabalin and its improved sleep continuity.

[Diabetes Care, Sept 2012]

Note: Neuropathy can affect different parts of the body, and if you would like more information about neuropathy and/or looking after your feet, you can obtain a leaflet from IDDT. Call IDDT on 01604 622837, email enquiries@iddtinternational.org or write to IDDT, PO Box 294, Northampton NN1 4XS.

Sick- Day Guidance For Type 1 And Type 2 Diabetes

It is important for everyone with diabetes to have a ‘sick-day plan’ because all illnesses can affect blood glucose levels and you need to know what to do before it happens. Your doctor or nurse can draw up a sick-day plan with you for you, your child with diabetes or the person with diabetes that you care for. This will help you:

- to know what blood glucose levels to aim for when you are sick,
- if you take insulin, to know how to adjust your insulin dose and timing, or what to do about your medications if you have Type 2 diabetes, assuming you have access to testing your blood sugars,
- to know how often to test your blood sugars and to test your urine for ketones,
- to know when to call a doctor.

You should keep your plan in a convenient place. If possible, other members of the family should know where it is and it should include contact details for your doctor and/or your diabetes nurse day and night times.

Note: IDDT’s Hospital Passport is very useful to keep with your sick-day plan as it contains details of your insulin or other medications and many other details about you that are important if you are taken into hospital. To obtain a copy, call IDDT on 01604 622837, email enquiries@iddtinternational.org or write to IDDT, PO Box 294, Northampton NN1 4XS

Why is a sick-day plan important?

Any illness, such as a cold, ‘flu or an infection can upset diabetes control and usually blood glucose levels rise, even a minor illness can cause them to rise dangerously high. With illness the body reacts by releasing hormones to fight the infection but these hormones also raise blood glucose levels at the same time. This can lead to diabetic ketoacidosis [DKA] or a hyperosmolar state.

It is therefore important for people with Type 1 and Type 2 diabetes to continue to take their insulin and/or tablets. [Metformin is usually stopped if there is a significant risk of dehydration eg with vomiting and diarrhoea.]

DKA is a serious complication of diabetes caused by a lack of insulin in the body. It usually occurs in people with Type 1 diabetes and the lack of insulin means that the body cannot break down glucose so the blood glucose levels rise very high. As the body cannot obtain energy from glucose, it breaks down fat to provide energy. During this process, ketones are produced and these cause breath to smell of pear drops or a fruity smell. [See our September 2012 publications for further information on DKA.]

Although DKA is usually considered to be associated with Type 1 diabetes, it can occur as a complication of Type 2 diabetes and is usually triggered by severe illness or infection.

Hyperosmolar state is less common than DKA and more commonly occurs in people with Type 2 diabetes who have an illness that leads to reduced fluid intake. Once this state has developed, it can be difficult to recognise it from the original illness. The signs and symptoms of a hyperosmolar state are:

- hyperglycaemia [high blood sugars],
- dehydration
- altered mental state but without significant DKA.

It is essential that the original illness, which is usually an infection, is diagnosed and treated. Many people respond to treatment with fluids alone but it may be necessary to treat with intravenous insulin alongside the fluid replacement.

General guidelines to take during illness

The same rules apply to people with Type 2 diabetes on tablets but they don't have the flexibility of altering their tablets.

Continue to take your insulin or if you have Type 2 diabetes, your tablets even if you are vomiting and having trouble eating or drinking as your blood sugar may continue to rise because of the illness. If you cannot eat or drink, then call your doctor and discuss whether you need to adjust your insulin or your tablets.

Try to eat the foods you normally eat as part of your diet and to drink extra fluids to prevent dehydration, such as water or carbonated drinks – a minimum of 200mls of sugar-free fluid every hour. You could also try foods that are gentle on the stomach such as crackers, apple sauce or custard.

It is advisable and often easier to take food gradually throughout the day rather than the whole amount at once, so meals and snacks should be replaced with 10gms of carbohydrate every 1 to 2 hours. Below are some 10gm carbohydrate 1 – 2 hourly meal replacements to try.

- Lucozade or similar glucose drink - 50ml/2fl oz
- Fruit juices [natural, unsweetened] - 1 small glass 100ml/4fl oz
- Coke or Pepsi [ordinary varieties] -1 small glass 100/4fl oz
- Lemonade or similar [sugary] fizzy drink - 1 medium glass 150ml/6fl oz
- Milk 1 large cup 200ml/8fl oz
- Soup [thickened] -1 large cup 200ml/8 floz
- Drinking Chocolate - Horlicks/Ovaltine 2 heaped teaspoons made up with milk
- Milk pudding - 1 bowl
- Natural yogurt - 1 pot 150g/5fl oz or ordinary fruit yogurt - 1/2 pot 75g/2.5fl oz
- Plain ice Cream -1 scoop
- Sugar or glucose power - 2 teaspoons
- 3 glucose tablets

Check your blood sugars at least every 3 to 4 hours and more often if it is rising quickly, even through the night. If you are taking insulin and your doctor / nurse has told you how much extra to take in these circumstances, then take the appropriate amount, but if you have not

been told, then check with your doctor or nurse first. The aim is to bring blood glucose levels down to between 4 – 10 mmol/l.

If you take insulin, test your urine for ketones every 4 hours, especially if your blood sugars are around 16mmols/L or above. Call a doctor if you have more than 2+ or moderate ketones in your urine. In children, ketones should be checked every 4 hours, even during the night. The aim is to bring urinary ketones down to 'small, a trace, or negative'. [This assumes that you have been provided with Ketostix to test for ketones.]

If you have a temperature and your breathing rate and pulse are increasing, contact a doctor.

Do not take non-prescription drugs without talking to your doctor and they can affect your blood sugar levels.

When to call a doctor
This is often a difficult decision because we 'don't want to be a nuisance' but it is better to be safe than sorry. When children with Type 1 diabetes are ill, even with minor illnesses, very high blood sugars can happen quite quickly and lead to possible emergencies. It is especially important that a doctor is called if you or your child have the following:

- Symptoms of diabetic ketoacidosis [DKA] - stomach pain, vomiting, rapid breathing, breath smelling fruity or severe drowsiness.
- Symptoms of dehydration – a dry mouth and very yellow or dark urine. Dehydration is particularly dangerous in children and may be caused by vomiting and diarrhoea.
- Low blood glucose levels that continue.

Although it may not be necessary to call a doctor every time you have a mild illness, if you are concerned, worried or don't know what to do, then it is better to seek medical advice and especially under the following circumstances:

- Your blood glucose levels is higher than around 13mmols/l after taking increased doses of insulin according to your sick-day plan.
- If you have Type 2 diabetes treated with tablets and your blood sugars are 13mmols/l before meals and stay high for more than 24 hours.
- Your have 2+ or moderate ketones in your urine.
- You still have a fever or are not better within a few days.
- You are vomiting or have diarrhoea for more than 6 hours.

If you are at all uncertain then you must ring your on call Diabetes Specialist Nurse or GP!

Winter Is Here And So Are The Colds!

We can all expect colds, especially through the winter months. Apart from the discomfort of coughing, sneezing, headache and a sore throat, they are usually harmless and last about a week with the worst of the symptoms normally lasting 3 or 4 days. Colds are common, especially in children and they may have between 6 to 10 colds a year as they pick them up at school. Adults have between 2 and 4 colds a year.

What is the common cold?
It is an infection of the nose and throat that develops over a few days and is usually caused by a virus. Symptoms of blocked or runny nose, sneezing, coughing and headache start within a few days. Sometimes people may have a fever. As with other types of infection, people with diabetes may find that their blood sugar levels rise.

You can have other conditions at the same time as a cold including:

- Sinusitis – infection of the sinuses which can cause headaches.
- Laryngitis – infection of the larynx [voice box].
- Tonsillitis – infection of the tonsils which are either side of the throat.
- Bronchitis or pneumonia – infections that affect the lower respiratory tract, bronchi are the tiny tubes in the lungs.

No cure but you can ease the symptoms
Viruses that cause colds change quickly over time so having one cold does not protect you against having another. This is also why there is no treatment or cure for the common cold. The body will normally fight off the common cold without any help.

There are various remedies that may help to relieve the symptoms:

- inhaling steam, rest, chest compresses, zinc products or herbal remedies eg echinacea but none of these have been proved to work, although certain Echinacea products may relieve symptoms.
- There is better evidence that paracetamol relieves symptoms of a sore throat but not that it speeds up recovery.
- Drinking plenty of fluids is often advised but there is no evidence that this helps recovery, so there is no need to drink more than is comfortable.
- Antibiotics only work against bacterial infections and not against viral infections such as the common cold. They also have side effects so it is sensible to let the cold get better on its own. Sometimes a bacterial infection develops at the same time, in which case antibiotics may help.
- People often take Vitamin C to prevent colds or take them at the start of a cold. However, research has shown that only in exceptional cases can it prevent colds and taking it at the start of a cold neither relieves symptoms or shortens the duration of the cold. It is worth noting that taking high doss of Vitamin C can cause side effects such as diarrhoea which can be a worse problem than the cold itself, especially in children and older people.

Note: the Medicines and Healthcare products Regulatory Agency [MHRA] has warned that children under 12 years old should not use oral herbal products containing Echinacea due to risks of severe allergic reactions. This follows advice from the European Herbal Medicinal Products Committee and the UK Herbal Medicines Advisory Committee.

The MHRA say this is not a serious safety issue but parents need to be aware that children under 12 could have a low risk of developing allergic reactions, such as rashes. Children 12 and adults can use Echinacea products because they are less likely to have allergic reactions as they weigh more and generally have fewer colds.

What is the difference between a cold and ‘flu?
The types of viruses that cause cold are usually different from those the cause ‘flu. Most people who have had ‘flu say that you know when you have ‘flu because you feel so ill! Basically the symptoms of a cold and ‘flu are the same but for ‘flu they are more severe. ‘Flu usually starts quite suddenly and lasts longer, with fever, shivering and aching of muscles and joints.

Should you see a doctor?
It may be necessary if:

- you have a fever [temperature over 38 degrees Celsius],
- your symptoms are getting worse,
- you have pain, especially in your chest,
- you have breathing difficulties.
- Your symptoms are not better within about a week.

Limiting spreading a cold
Colds are spread to other people very easily. Every time someone with a cold sneezes or coughs lots of droplets containing the virus are spread in the air. If you then touch something on which a droplet has landed then touch your mouth or nose you can easily be infected. So if you are in contact with someone with a cold, it is important to wash your hands with soap frequently.

From Our Own Correspondents

Happy to help
Dear Jenny,

In response to your article about raising funds for IDDT, I find I am able to support IDDT through loose change collection. I don't miss the small change and it is surprising how it soon mounts up, enabling me to submit a donation a few times a year. I wonder if this is something lots of members might be able to do for IDDT without feeling the squeeze on their household income. You do a great job and it is important to reach out to as many people as possible whilst staying loyal to your roots.

Many, many thanks.

By email, Marie
Parent to Lauren with Type 1 diabetes

Knowing what you want
Dear Jenny,

When it was suggested that I try insulin, I researched them all and found that the one that might suit me best was porcine insulin. This was dismissed out of hand and I was started on Novomix 30. I put on over a stone and struggled with my weight, but eventually, after ten months, I got basal/bolus, Levemir and NovoRapid. Over the next two months I noticed new symptoms developing: palpitations, sweating, runny nose which caused post nasal drip and kept me awake with coughing, memory problems, nausea, a slight rash on my arms, dizziness, pains in my legs, swollen feet, fatigue and the peripheral neuropathy in my toes was becoming worse.

I did more research and as advised by Jenny, I armed myself with my list of symptoms and reasons to try animal insulin. I also took evidence to my consultant that the analogue insulins were doing harm to me. To my relief, he said I could try Porcine Isophane and Porcine Neutral. A month later, everything is much better. Even the pains in my legs are becoming a distant memory, and the peripheral neuropathy has improved no end. I've even lost weight, five pounds! Thank you, Jenny, you inspired me to push for what I wanted, and I got it.

M.M by email

More on high carb diets...
Dear Jenny,

I would also like to add my comments on your article 'Is a High Carb Diet Poison to Diabetics'. The short answer has to be yes!

I was diagnosed twenty years ago with rapid onset Type 1 Diabetes which is, I was given to understand, rare for someone in their forties. I was horrified by the obesity that I saw at my first clinic and equally horrified by the diet that was suggested. It just didn't make sense to me to eat large quantities of carbs.

Over the years I have discussed the matter with several diabetic specialists as well as my G.P. and to my surprise, they all seemed to agree with me that the high carb regime needs re-examining. I suspect changing the views of the medical profession will take time as the theory of a high carb/low fat diet is deeply entrenched.

I am now 63, 5'4" tall, weigh 8 1/2 stone, I swim, walk and pursue many interests, which include three grandchildren, and I am also extremely healthy. My surgery tells me I am a model patient - might this be down to my diet?

I apologise if this sounds too pleased with myself, I may be struck down tomorrow! I am merely making the point that low carbs, healthy eating and exercise have kept me really well and would love other people with diabetes to benefit too.

Keep up the good work.

By email M.T.

Being caught out!
Dear Jenny,

After reading the IDDT Newsletter, specifically the article about insulin and hypoglycaemia, I began an insulin reduction strategy of reducing carbs and insulin. The strategy is working but it is a slow and measured process and not without misjudgements and unexpected results.

One day I experienced an event which I had not foreseen and I decided to investigate. It involved a bowl of bran flakes for breakfast, no other carbohydrate except for semi-skimmed milk, then a period of moderate physical activity gardening. I then had one plain bagel about 2 hours after breakfast.

Within a two and a half hour period my blood glucose more than doubled its breakfast time value of 8mmols/l to 22mmols/l – not an expected result. I reviewed my food intake:

- 25gms of bran flakes, carbs 30gms of which 5gms were sugar.
- Bagel, 45gms carbs of which 5gms were sugars.

I was amazed that I had eaten 65gms of carbs and 10 gms of sugar in just over 2 hours – so I don't eat bran flakes or bagels any more. Since that episode my wife and I have been scrutinising all manner of food products and the sugar content of some products is alarming – some cereals, commercially made dough, soups, baked beans et al. Diabetes is hard enough to manage on a daily basis without the complication of 'hidden sugar' in familiar foods.

When I realise that I have been consuming hidden sugar in addition to the carbohydrate I consciously eat, it's no wonder that my diabetic control is not ideal. Furthermore, it is no wonder that people get fatter and heavier without knowing why when all manner of foods are laced with hidden sugar!

A salutary lesson indeed.

Mr C.G.
NorthWest

Note: A study carried out by Spanish researchers found that people who read food labels tend to weigh less than those who don't and this applies particularly to women. 58% of men spend time reading nutrition labels compared to 74% of women. They also found that people living in cities and those with a high-school or college education are more likely to read labels. [Agricultural Economics, 17.09.12]

And finally……

Where were you?

Dear Jenny,

It was good to see a photo of the staff in the last Newsletter and to see who we are talking to, but where were you?

By email

Jenny – Here I am. I hate having my photo taken, so I tried to avoid it!

Obituary

Professor Arthur Teuscher
9TH August 1926 – 23rd August 2012

It was with great sadness that I learned of the death of Professor Arthur Teuscher earlier this year. Many people have written to me to express their sadness at Arthur's death and they have also said that they owe their lives to him.

I could write about Arthur's many achievements throughout his life, but he will be remembered by us for his work in recognising that GM 'human' insulin caused serious problems, and even death in some people. He recognised that the new 'human' insulin caused adverse reactions, especially loss of warnings of hypoglycaemia in some people. When many doctors in countries across the world were disregarding patients and the lack of science to support the use of 'human' insulin, Arthur stubbornly fought against the tide of medical opinion in carrying out research comparing animal and 'human' insulin. He fought governments and authorities to ensure that there was access to animal insulin and in doing so, he helped people with diabetes all over the world.

His book, '**A Voice for Choice**', has left us not only with information unavailable elsewhere, but a poignant memory of Arthur. IDDT members consider it a privilege that Arthur attended our Annual Conferences to listen to his informative talks, his ideas and his plans to maintain animal insulin and at the 2011 Conference, it was our privilege to present him with a plaque as a small token of appreciation for his work for people with diabetes, his care, commitment and kindness.

We offer our sympathies to Arthur's wife and family who I know have been comforted by the many letters from patients and colleagues from across the world.

Note: 'A Voice for Choice' by Professor Arthur Teuscher is available from IDDT, just call us on 01604 22837, write to IDDT, PO Box 294, Northampton or order online **http://www.iddtinternational.org/?page_id=2135**

Research News

TB vaccine research causes controversy

The results of a small study by Dr Denise Faustman and her team are causing controversy among the diabetes research community – but this is not the first time.

The results of the study, published in PLoS One, suggest that the use of a TB vaccine that has been available since 1921, causes the regeneration of beta cells. Beta cells are the cells that produce insulin in the islets and it is the destroying of these cells by the body's autoimmune system that leads to Type 1 diabetes. The TB vaccine attacks the autoimmune T cells that destroy the islet cells.

In reports, Dr Faustman says:

- This simple, inexpensive TB vaccine attacks the autoimmunity underlying Type 1 diabetes.
- Even low doses of the vaccine could transiently reverse Type 1 diabetes and this was even seen in people who had Type 1 diabetes for 15 years and this lasted for about a week.
- We think we are seeing early evidence of effectiveness [of the TB vaccine].

There is no guarantee that the results from this early, small study will be shown in larger studies which are now being carried out. Some researchers are criticising the the Faustman team for claiming as evidence what could be observed effects but there are others who acknowledge that we now know that there are preserved beta cells many years after the diagnosis of Type 1 diabetes, contrary to what the past belief that all the islet cells had been destroyed by the time someone was diagnosed.

In 2003 the Juvenile Diabetes Research Foundation [JDRF] rejected Faustman's funding application and even circulated a letter casting doubt on her work and apologising to people with diabetes for "having their expectations cruelly raised" by stories about her research. However, this latest research caused the following comment from the JDRF Chef Executve, "It's certainly interesting and worth further

investigation, but it's really important to be careful how we interpret the results." Our comment would be that this is true of all research.
[PLoS Clinical Trials, 8-15-2912]

Type 1 diabetes linked to viruses and toxins
Researchers in Australia have reviewed every new case of Type 1 diabetes over 25 years found that the condition is on the increase and rising at 2% per year. However, they also found that Type 1 diabetes appears to be rising among Australian children every 5 years. So although it is on the rise, it was doing so with an even flow of peaks and troughs and in some cases there was up to a 20% difference between the peak years and the low years.

The last peaks were 2002 and 2007 suggesting that 2012 will be another peak year for diagnosis.

The researchers said that while there must be a reason for both the increase and the 5 year pattern, it was not yet understood what this was. They suggest that there must be triggers and probably multiple triggers such as environmental factors, viruses and toxins. There have also been increases in allergies over the same time which could reflect similar underlying causes. They also said that the peaks could be caused by cycles in which viruses are dominant in a similar way to cold and 'flu viruses being different strains year by year.

The Australian researchers compared their pattern with other countries and found it almost identical to the situation in northern England despite the fact that the climates and demographics are very different. Research is now being done to monitor babies who could be at risk because their parents have Type 1 diabetes to track what made them develop it. However, this s complicated by the fact that 80% of children whose parents have Type 1 diabetes do not develop the condition, despite a common misconception that Type 1 diabetes is inherited. More research is needed before it will be clear that viruses are the cause as it could be things like chemicals, environmental pollutants or many other factors.
[Diabetes Care, August 2012]

New hydrogel could mean twice-yearly injections
According to researchers from Cambridge University, a new hydrogel which can provide sustained drug release for up to 6 months, could cut the number of insulin injections required to 2 a year. The easily produced gel is made up largely of water and contains cellulose polymers with barrel shaped molecules that can be loaded up with protein or other therapeutic drugs. The loaded molecules protect and hold the proteins in place so that they can remain active for longer. They then release the protein in controlled, small doses through gaps in the gel which are constantly opening and closing. The research is at the early stages but if successful, saounds promising.

New sensor to avoid finger-pricks
Researchers at Purdue University have developed a new glucose sensor designed to check glucose in body serum, such as tears, saliva and urine. If successful, in the future this may allow people with diabetes to use saliva and remove the burden of finger prick testing of blood glucose.

It may sound a bit technical for most of us but the sensor is based on petal shaped sheets of stacked grapheme that have glucose oxidase enzyme and platinum nanoparticles deposited on the surface. As the glucose converts to hyprogen peroxide, a signal is generated at the electrodes where the platinum particles are. The challenge is going to be correlating the saliva or tear glucose levels with those in blood in the same person.

Link between sleep apnoea and diabetic neuropathy
Researchers at Birmingham University have found a link between obstructive sleep apnoea and diabetic peripheral neuropathy in people with Type 2 diabetes. Obstructive sleep apnoea is having five or more per hour episodes of abnormally slow or shallow breathing while asleep.

The link between sleep apnoea and Type 2 diabetes has been known for some time but this new research has shown an association between peripheral neuropathy and sleep apnoea and that the severity of

neuropathy correlates with the degree of sleep apnoea. This does not mean that sleep apnoea causes neuropathy. However, there is now sufficient evidence to investigate this link further research including whether using continuous positive air pressure to keep the airways open has any effect on the development of neuropathy and other diabetic complications. While this may not seem like ground-breaking research, it is important because no one really knows what causes neuropathy which is why there is no satisfactory treatment. [American Journal of Respiratory and Critical Care Medicine, July 2012]

NHS News

NHS 111 no better than GP out-of-hours
A Department of Health funded report by Sheffield University suggests that NHS 111 is a waste of money. After looking at the first four NHS111 to go live, it found that the service is no better and no cheaper that NHS Direct and GP out-of-hours services. Patient satisfaction was high but the new serviced failed to improve care or make savings for the NHS. These were supposed to be pilot trials, so why not leave things as they were?

Consultation on prescribing unlicensed drugs
The Medicines and Healthcare products Regulatory Agency [MHRA] is considering allowing drugs to be prescribed before they are licensed because the approval process is taking too long. Apparently the idea is not to speed up approvals but to give doctors the opportunity to prescribe drugs still in the final stages of trials before they are approved, as long as patients understand and assume some of the risks of using unlicensed treatment.

The pharmaceutical companies have been making it very plain that they consider the approval process to be too long, so is this to appease industry, is it of real benefit to patients or does it put patients at risk?

PCTs still restricting cataract ops
Despite a government order that PCTs are not to ration treatment on the basis of cost alone, a study by Imperial College London has shown that nearly half [47%] of the 120 PCTs ration cataract surgery. This is despite evidence of clinical and cost effectiveness. To make matters worse, 92% of the 'rationing policies' used criteria that ignored national guidance or clinical evidence.

The researchers pointed out that only offering cataract surgery to people with extremely poor vision may exclude other people who could benefit greatly by having surgery and they gave the example of people with 50% vision loss who feel extremely disabled by this loss. [Journal of Health Services, Research and Policy Online 2012]

So what if you are a patient being refused cataract surgery? IDDT's advice is to ask 'Why?' If you are not happy with the answer, then take the matter up with your GP and then if necessary, with your local PCT.

Is Type 1 Diabetes Being Sidelined?

It certainly seems that way, although not by IDDT! The figures, and even some research bulletins, all too often refer to 'diabetes' making no differentiation between the two types of diabetes. This is not to mention the public perception that 'diabetes' is all down to being overweight or obese people with Type 1 diabetes must have been fat or eaten lots of sweets when they were young! In some ways this is understandable because Type 2 diabetes is very common and Type 1 diabetes is relatively rare.

Nevertheless this misunderstanding makes people with Type 1 diabetes and the parents of children with Type 1, angry and frustrated. This is one of the reasons IDDT produced our booklet 'Understanding Your Diabetes' in the hope that it would provide a better understanding of the types of diabetes.

But there is more to it than this...

There is the care that people with Type 1 diabetes receive. The care of people with diabetes has shifted to primary care, GPs and practice nurses and either by accident or design, people with Type 1 diabetes have been carried along with this. Some of our members who have received specialist care for many years have been shifted to their GP. It is remarkable and to the credit of primary care staff that they have developed understanding and competence in diabetes in a relatively short time. However, have they developed an understanding of the problems and issues facing people with Type 1 diabetes? As stated earlier, Type 1 diabetes is relatively rare and affects 0.4% of the population, about 250,000 people. So a GP practice with 5000 on its list will only have around 20 people with Type 1 diabetes. An article in Practical Diabetes [Vol 29 No 8] suggests that this is not enough for GPs and their staff to get a feel for the problems people with Type 1 diabetes experience. This is not a criticism of GPs and their staff, it is just a fact.

Does moving people with Type 1 diabetes away from specialist care make sense?

It can certainly be argued that it doesn't both from the patient's perspective or the specialist team's perspective. The specialist team consists of doctors, specialist nurses, dietitians and podiatrists, all of whose daily job is working with people with Type 1 diabetes. They have developed expertise and understanding of people with Type 1 diabetes and their treatment and emotional needs. From the patient's perspective, is it the best option for them to be moved away from this specialist team when:

- they may be developing complications,
- they may have depression or 'burn out', being fed up of the day to day burden of having Type 1 diabetes,
- they may have frequent hypos and hypo unawareness,
- there may be emergency admissions with diabetic ketoacidosis [DKA] or severe hypoglycaemia,
- there may be the normal happenings of life, such as surgery or pregnancy but for people with Type 1 diabetes, these require specialist care.

Is shared care an answer?

In some areas this actually happens, people with Type 1 see their GP once a year and their specialist team once a year, which means that with proper planning, they are actually seen 6 monthly.

However, people with Type 1 diabetes have often had it many years and have a great deal of experience so understandably, they have little trust or faith in health professionals who know less than they do. At IDDT we hear comments along these lines quite a lot. The best example has to be that GP practices cut down the number of test strips on repeat prescriptions, as they do for people with Type 2 diabetes – this shows a lack of understanding that people with Type 1 diabetes test 4 or more times a day, a lot more than this if they have an illness and if they drive a car. As one of our members who was refused strips reported to us, "Because I'm old they think I have Type 2 diabetes and don't need to test"!

Is the present system working?

Well, the evidence from the National Diabetes Audit published in 2011 would suggest not as the 9 care processes that are supposed to be carried out for people with Type 1 diabetes are only carried out in 38.5% of them in England and Wales. Hospital admission rates for DKA are rising, the numbers with kidney problems are rising and so on...

There is some evidence that people with Type 1 who attend specialist teams do better than those who don't and they are more likely to benefit from newer treatments.

So where does this leave people with Type 1 diabetes?

- In need of better communication between primary care, GP surgeries and secondary care, hospital specialist care.
- In need of clarity of roles and responsibilities to ensure that all 9 care processes are carried out regularly.
- In need of greater awareness that people with Type 1 diabetes do need to attend specialist team care to ensure that their diabetes is being properly looked after and managed.

Some of all this is about the system of how doctors get paid – GPs build up points for the tests they do on people with diabetes and this brings in a significant income for their practice. But this is not our problem, our concern as people living with diabetes is that we receive the care and treatment that we need. The government is forever telling us that patients are at the centre of care and that they have the right to choose where they receive their treatment. With no disrespect to GPs and their staff who largely deal with people with Type 2 diabetes, is it time for those with Type 1 who are not being seen by a specialist team, to stand up and demand that they are seen by specialists with experience and understanding of living with diabetes?

Air Traffic Controllers With Insulin-Treated Diabetes

In August 2012, pilots and air traffic controllers with insulin-treated diabetes and other medications that significantly lower blood glucose, may now be considered for medical certificates by the UK Civil Aviation Authority (CAA). This should allow more of them to continue operational duties safely.

Until now, only a limited number of medications for the treatment of diabetes have been allowed for pilots and air traffic controllers applying for Class 1, 2 and 3 medical certificates. Applicants who are granted medical certificates under the new protocol will be subject to a rigorous monitoring regime, including demonstrated stability of their condition, and regular blood sample self-testing during flight/duty. This is to ensure that an individual does not begin a flight or shift with blood sugar levels that are too high or too low and that a safe level is maintained.

Snippets

Suggestions that the 'NHS is being privatised' causes fears
The UK is the only country in the world to have an NHS where everyone receives the treatment and care they need – universal coverage. The results of a poll by the Canadian Medical Association have shown that 36% of Canadians have gone without needed healthcare because of insufficient insurance. The worst affected were women, part-time workers and people on low incomes. With facts like this, it is not surprising that suggestions that our NHS is becoming privatised makes people fearful for the future.

Workplace stress and low level job control
A study of more than 7,400 Canadians has shown that workplace stress, including low levels of job control, increases the risk of developing Type 2 diabetes in women but not in men. [Journal of the Society of Occupational Medicine, 21.08.12] The researchers suggest that employers re-look at how much control they give their employees as studies have shown that workers who have more autonomy and control over their jobs have more job satisfaction and therefore less stress, not to mention greater productivity.

Fruit and vegetables on prescription
US doctors have started prescribing fruit and vegetables to overweight patients, according to a news broadcast. The Fruit and Vegetable Prescription Program identifies overweight or obese children and pregnant women who are at risk of Type 2 diabetes and heart disease. They are then given advice on healthy eating and a $1 per day 'prescription' as a voucher to be spent on fruit and vegetables at farmers' markets.

Information from another part of the US where this scheme has been running for a year showed that 66% of families who got vouchers from their doctors to purchase produce increased the amount of fruits and vegetables they ate. It also led 38% of participants to reduce their BMI within four months.

Sensor-equipped bathmat aims to detect early signs of foot ulcers
A new kind of bathmat is being developed that would scan the feet of people with diabetes by checking blood flow to predict patterns that might signal ulcer development. If the device detects a pre-ulcer situation then an alert is sent to the patient and their doctor so that treatment can be started very early to prevent foot ulcer developing. The device takes about 30 seconds to use each day.

Healthiest nations
According a recent analysis, Singapore is the healthiest nation in the world followed closely by Italy. The UK was 21st and the US 33rd in the rankings. Health scores calculated on such things as life expectancy and causes of death and health risk scores taking into account things like smoking and immunisation, were used to compare countries.

Chocolate improves your memory – in snails anyway
According to Canadian research, feeding flavanoid epicatechin, found in dark chocolate, to pond snails resulted in them being able to remember a simple task for longer. This chemical affects the neurons that store memories but the reseachers do not know how this happens.
Obesity and Type 2 diabetes not quite a double whammy!

Research in the US has shown the opposite of what we might expect – people who are overweight or obese and develop Type 2 diabetes live longer than their thinner peers with diabetes. Having said this, it doesn't mean that thinner people with the condition start to eat high calorie foods to increase their waistline. The researchers suggest that the explanation may not be that the extra weight is protective but that lean people who get diabetes are somehow predisposed to have more health problems. There may also be another factor that the study did not take into account – were the thinner people smokers?

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

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From Your Editor – Jenny Hirst

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