### InDependent Diabetes Trust Newsletter



**December 2020 Newsletter, Issue 107** 

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his is the final Newsletter of 2020 and what a year it has been for all of us. At the time of writing this Newsletter, none of us know what Christmas and New Year will be like and they may well be different across the country, and indeed, the world.

2020 has been a difficult year for us all with sadness, difficulties, fears and unknowns. If people have not been directly affected by Covid-19, then they may have been affected by not receiving the health checks they need, by not receiving help and information when they need it or by being on a long waiting list for surgery. Our Trustees and Staff are not excluded from these same worries but our thoughts are with everyone facing these difficulties.

Despite Covid-19, Christmas and New Year are times when we think of others and the Trustees and Staff would like to send all our members and readers our best wishes. We would also like to thank you for your help, support and generosity throughout the year – they are very much appreciated at a time when the economic climate is uncertain for us all as individuals and for charities.

IDDT continues to try to reach people with diabetes through publicity and requests for our booklets are still coming in not only from people with diabetes, but also from health professionals to give to their patients. We are glad to help and this is the time when I have to thank IDDT's Staff. It has not been an easy year for them either. We have had to make our building as safe as possible – moving offices around, wearing masks in corridors and all communal areas and drinking our morning coffee outside to be able to chat to each other!

We can only hope for better things for all of us in 2021.

However, in the meantime, I have no doubt that we will celebrate Christmas this year even if it is differently from usual. It will be a time for presents and celebratory food. If you or a member of your family has diabetes, it can also be a worrying and stressful time too, especially if it is your first Christmas with diabetes. We hope our FREE booklet "**Diabetes at Christmas**" will be of help as it offers help and advice about managing diabetes at Christmas and a range of recipes and ideas about food and eating, hopefully allowing you to enjoy Christmas and still manage your diabetes. For your copy, give us a call on 01604 622837 or email enquiries@iddtinternational.org

# anniversary of insulin in 2021

Next year, 2021, is the 100th anniversary of the discovery of insulin - described as one of the most ground-breaking discoveries in the history of medicine. Before this discovery, the prognosis for people with Type 1 diabetes was very poor.

Initially patients were told to eat larger portions to make up for the loss of glucose and calories excreted in the urine. However, in 1870 doctors saw an improvement in the symptoms of diabetes during fasting and from then, the management of diabetes consisted of restricting carbohydrate and/or calorie intake. Patients were malnourished and fatigued but managed to live for months and sometimes years.

Canadians Banting and Best carried out the first experiments to isolate insulin from beef pancreases and used dogs in their trials. Professors MacLeod and Collip also worked on the development of pancreatic extract so that it was safe enough to administer to humans. For this, they all agreed to share in the Nobel Prize for Medicine in 1923 actually awarded to Banting and MacLeod.

#### The first injection

Leonard Thompson at the age of 14 was the first human to receive the extracted insulin at Toronto Hospital in January 1922. He first received Banting and Best's extract but this gave little improvement and 12 days later he received the extract developed by Collip. This time, there was an improvement in symptoms and blood glucose levels. The team could not produce enough insulin for all the patients that needed it and they made an agreement with Eli Lilly to enable mass production of insulin. This meant that children on the brink of death from starvation and ketoacidosis recovered quickly after receiving insulin. It seemed like a miracle - patients and their families had futures, could have jobs and families.

#### But the costs...

It is worth remembering that Banting and Best wanted their discovery of insulin to be free for everyone with diabetes but this didn't happen and many companies manufactured insulin. Gradually,

as we know, these companies were bought out or taken over by the three major manufacturers, Lilly, Novo Nordisk and Sanofi Aventis. They now control not only insulin production, new developments but importantly the costs. In the UK, insulin is free on the NHS but not so in many other countries and in low to middle income countries, the cost of insulin is unaffordable by many people. However, over the last decade the increasing costs of insulin have affected many countries, including the US, a high-income country! Here are some examples:

#### **INSULIN SUPPLIES IN IRAN**

Reported in September 2020, Novo is charging Iran twice as much as the UK for its advanced insulin products and more than five times the production cost. International organisations and experts are accusing Novo of unethical profiteering in a country marred by sanctions and widespread poverty. Researchers and international NGO's defending access to medicine think that a different business conduct would be appropriate when dealing with a country like Iran. Health Action International is one of these organisations and Margaret Ewen, their senior projects manager says, "It is not acceptable for pharmaceutical companies to make such massive profits, especially on essential medicines like insulin". She advocates that Novo reduces its profit in Iran.

#### IN THE US

More than 34 million people the US have diabetes and 7 million people need to use insulin. Insulin costs continue to rise and have led to desperate actions from some people with diabetes over the last 10 years.

In the US insulin prices are more than 8 times higher than in 32 high-income similar nations combined. A study compared how much different types of insulin sold in the US would cost if bought at prices in other countries. The average price per unit across all types of insulin in the US was \$98.70 but other countries would have paid a fraction of this for the same insulins. The US prices were:

- 3.8 times higher than in Chile,
- 6.3 times higher than in Canada,
- 5.9 times higher than in Japan,
- 8.9 times higher than in the UK,
- 27.7 times higher than in Turkey. (RAND Corporation Study, October 2020)

Drug price legislation has been held up during the Covid-19 pandemic but 7 states have brought in insulin payment caps of less than \$100 per month and in March, a Medicare test project limited seniors' monthly out-of-pocket costs to \$35.

Note: the situation with insulin pumps is different. Under Medicare, the cost of insulin is about 50% higher for beneficiaries who use insulin pumps compared to those who inject insulin. Apparently,

this is due to different classifications by Medicare-insulin delivered by syringe or pen is classified under 'drug benefit' and insulin via a pump is classified under 'durable medical equipment'. This situation was worsened by the overall increases in prices of insulin. (Journal of Diabetes Science and Technology, September 2020)

#### And finally...

To this day, we all have to be grateful for the discovery of insulin and the lives it has saved but despite the development of many different insulins, we still need improvements in insulin. We need insulins that will give more stable blood glucose levels with less hypoglycaemia and of course, we must remember that we still need a cure – insulin is a treatment, not a cure.

### Just to remind you...



### 2021 Diabetes Everyday Diaries still available!

Last year we published our Everyday Diary for anyone who lives with diabetes, whether you have diabetes, your partner has diabetes or your child has diabetes and this proved very popular, so we have published a similar Diary for 2021. Each page is divided into two columns, the left column is headed, "Diabetes Diary" for recording blood glucose tests, mealtimes, medication and so on. The right column is headed "Everyday Diary" for recording things like medical appointments, social events and family occasions.



#### **IDDT Shopping List**

This Shopping List is new this year. It has a magnet on the back to attach to your fridge door for easy jotting down and so it will not get lost! On one half of the page you plan your meals for each day and on the other half you write down the items you need to buy. This is a tear off section to take to the shops with you or to order your online shopping. It works well with the 28day meal planner in IDDT's FREE booklet, "Diabetes Everyday Eating".



#### **Christmas cards**

We would like to thank everyone who has already bought Christmas cards from us and remind those who haven't that we still have cards available, they are £3.25 per pack of 10 plus 80p per pack p&p.

Take a look at the leaflet included with this Newsletter entitled 'Thinking about Christmas' for gift ideas and support IDDT!



# REMINDERS & WARNINGS

#### **NHS** system launched to prioritise patients on waiting lists

Many people, and no doubt many of our members, were on waiting lists for elective surgery before the pandemic. They are still on those same waiting lists and wondering when they will be seen. Below is how the NHS is going to deal with this.

In October, a letter was sent to health providers and bodies stating that a digital solution has been commissioned for use to support Trusts and Primary Care to clinically prioritise patients on waiting lists. This online system, called the NHS e-Review, has been developed to support clinicians to record the clinical priority of patients on a waiting list and to identify alternative pathways for patients if required.

The software will be used to review all patients on waiting lists and to prioritise those with greatest clinical need and identify which patients may need to receive treatment in independent sector hospitals. All Trusts were required to complete a clinical validation of patients on an admitted patient care pathway by 23rd October and for it to be captured in the NHS e-Review.

#### Flu vaccinations

On 22nd October 2020, the NHS announced that over 30 million people are to be vaccinated this year to protect the vulnerable from flu and support the NHS. They stated that GPs, NHS trusts and pharmacies will be able to order supplies and this will be the most comprehensive flu vaccination programme in the UK's history.

Millions of doses of Flublok® have



been authorised by the Medicines and Healthcare products Regulatory Agency (MHRA) after it met the standards of safety, quality and effectiveness. The NHS announcement reassures us of the safety of this and other vaccines. Flublok® has been used in the US for the last 3 winters. A physically and biologically similar vaccine, Supemtek, was recommended for approval by the European Medicines Agency in September 2020. All vaccines undergo 3 stages of clinical trials and are assessed by the regulator for safety, effectiveness and quality before they are given to patients.

A free flu vaccine is available to:

- people aged 65 and over
- pregnant women
- people with some pre-existing conditions
- all school year groups up to Year 7
- household contacts of those on the NHS shielded patient list

Once vaccination of the most 'at-risk' groups is well underway, the department will work with clinicians to decide when to open the programme to invite people aged 50 to 64.

The NHS will contact people directly, including information about where to go to get the vaccine.

#### **OTC** medicines substitutions on home deliveries

The Royal Pharmaceutical Society has written to the British Retail Consortium to express concern that substitutions of medicines as part of supermarket home deliveries are putting customers at risk. Some over-the-counter medicines included in online shopping, such as paracetamol, are being substituted with other medicines if they are out of stock. These substitutions have on occasions contained different or additional ingredients to those originally ordered. Without clear and explicit messaging to explain this to customers, such substitutions could cause a serious risk to health, especially amongst those who cannot tolerate or may be allergic to a specific ingredient.

The Royal Pharmaceutical Society is calling on all retailers to review their systems and staff training to ensure that only like for like substitutions are made in home deliveries.

If you order over-the-counter medicines with your online shopping, then it is worth checking that you have the right one.

### Are the elderly being overlooked?

We recently received the following from one of our members and his wife:

My wife (83) and I (85) both have Type 2 diabetes and I have been taking insulin twice a day for 20 years. We were both due out annual reviews in July but our surgery told us we must wait until September. Two weeks ago, we attended the surgery for blood samples to be taken. This meant waiting outside of the surgery in the rain. When we asked about the actual reviews, we were told to expect a phone call, and that is what we got. We were told that blood tests were satisfactory and that it was not possible to carry out any further review matters. So, nothing else has been checked! Surely checking of blood pressure is important as are the other items listed on your last magazine issue. I also need attention to my hearing aids but that department is seeing nobody.

I know the NHS has big problems but I am of the opinion that (in Wales) they are now happy to overlook elderly people! As things are, I have not seen a GP for several years as all work here seems to be in the hands of nurses. Should I see a doctor at some point?

At a conference last year, a UK professor urged the healthcare profession to make older people with Type 1 diabetes a "priority and not an after-thought".

Professor Ketan Dhatariya of the Norfolk & Norwich University Hospitals NHS Foundation Trust, wants to raise the standard for the over 60s with Type 1 diabetes in a bid to reduce diabetes-related hospital admissions. He pointed out that the number of old people with Type 1 will increase with time and "a strategy must be developed to ensure long-term survival is not invariably accompanied by a fall in standards of care. It's crucial that carers and clinicians working with older people have the knowledge required to identify those at risk and to ensure safe management of this vulnerable group. This means simplification of insulin regimens, ability to recognise the early signs of hypoglycaemia, and knowledge of how and when to adjust insulin."





#### The National Institute for Health **Protection (NIHP)**

On 18th August, Matt Hancock announced the formation of this new organisation, the National Institute for Health Protection (NIHP) which will replace Public Health England. It will have a single purpose: protecting people from external threats to this country's health, threats such as biological weapons, pandemics and infectious diseases of all kinds.

Mr Hancock goes on to say that the NIHP will be a national institute that works locally by working with local directors of public health and their teams. It will also work closely with the devolved administrations, taking on existing UK-wide responsibilities and supporting all 4 Chief Medical Officers. The NIHP will report directly to ministers.

What happens to Public Health England? We have yet to learn more, but at the time of the announcement, it was said that the other functions of Public Health England, such as the obesity strategy and prevention of Type 2 diabetes, will be incorporated into NHS England.

#### Pregnant women with Type 1 diabetes eligible for CGM

In January the NHS ten-year plan pledged that all pregnant women with Type 1 diabetes would be offered continuous glucose monitoring (CGM). The proposed start date for this was April this year but this was delayed by the pandemic. Professor Kar, National Specialty Advisor for Diabetes for NHS England has now confirmed that the NHS can now offer CGM to all pregnant women with Type 1 diabetes which will result in improved in neonatal outcomes and that women can relax more during their pregnancy.

#### New rules on the sales of stimulant laxatives

Medicines and Healthcare products Regulatory Agency (MHRA) has taken action to reduce abuse and overuse of these products and new packs will begin to appear over the summer. Additional label warnings make clear that stimulant laxatives do not help with weight loss.

Stimulant laxatives include bisacodyl (Correctol,

Dulcolax), sennosides (Ex-Lax, Senokot), castor oil and the plant cascara. The active ingredient in stimulant laxatives triggers muscles in the bowels to contract, moving stool through.

Anyone with regular bouts of constipation is advised against the long overuse of stimulant laxatives because this can cause damage to the digestive system, including chronic constipation and damage to the nerves and muscles of the colon. Instead, the advice is to talk to a healthcare professional or your doctor about trying alternatives, such as diet and lifestyle changes but also switching to bulk laxatives which work in a similar way to fibre.

The new guidelines restrict the use of stimulant laxatives sold in retail outlets to patients over the age of 18 whereas pharmacists will be able to sell stimulant laxatives for use in children aged 12 and over.

The head of BEAT, the eating disorder charity, welcomed the new legislation because laxatives can prove attractive for people affected by eating disorders but they also have the potential to cause serious health problems. Many of those who abuse laxatives bought them over-the-counter and 66.7% said they had developed a dependency on them. It is hoped that these new regulations will make it more difficult for people to obtain them.

#### NHS steroid emergency card launched

As a result of 4 deaths and more than 300 incidents with steroid replacement therapy in patients with adrenal insufficiency between July 2018 and July 2020, patients at risk of adrenal crisis will be issued with a steroid emergency card.

The emergency cards are designed to increase awareness of the need to start steroids promptly in patients at risk of an adrenal crisis. From 18th August 2020, all adults with primary adrenal insufficiency (AI) will be issued an NHS steroid emergency card to support early recognition and treatment of adrenal crisis by prescribers, including community pharmacists. All eligible patients should be issued with a steroid emergency cards by 13th May 2021.

Al is an endocrine disorder, such as Addison's disease, and omission of steroids in patients with AI, particularly during physiological stress such as an additional illness or surgery, can also lead to an adrenal crisis.



During these difficult times, many people have spent more time on the internet, often using blogs to provide them with information. However, when it comes to diet, a cross-sectional study presented at the European Congress on Obesity last year showed that of the most popular UK weight management blogs only one of 9 met criteria for transparency, evidence-based references, impartiality and adherence to nutritional guidance. The researchers concluded that the majority of blogs could not be considered credible sources of weight management which were often presented as facts when really, they are only opinions! This is potentially harmful.

Researchers analysed information from nine influencers behind popular weight management blogs, published between May and June 2018, using 12 credibility indicators. They also selected the last 10 recipes from each blog and analysed them for energy, carbohydrate, protein, fat, saturated fat, fibre, sugar and salt content. These were evaluated against Public Health England's "One You" calorie-reduction campaign and the UK Food Standards Agency's traffic light rating system.

- 7 of 9 blogs provided nutrition and weight management advice but 5 blogs failed to provide evidence-based references for nutrition claims or presented opinion as fact, according to researchers. 5 influencers failed to provide a disclaimer.
- 3 blogs claimed that recipes met the Public Health England and Food Standard Agency's calorie targets but none of the recipes met such criteria.
- Of the advice-based blogs, only a degree-qualified blogger, registered on the UK Voluntary Register of Nutritionists, passed overall, with 75%.
   The lowest compliance, at 25%, was from an influencer without nutritional qualifications.

Currently, no standards exist to assess the credibility of influencers' blogs. However, considering the fact that information about weight management and physical exercise are actually medical advice if you use blogs on social media, beware that the information may not be reliable, or even correct.

#### FreeStyle Libre 3 gets CE Mark for distribution in Europe

Abbott has received the CE Mark for its next generation FreeStyle Libre 3 system so it is now approved for use by people living with diabetes in Europe. This version provides continuous, realtime glucose readings automatically delivered to smartphones every minute, offering 14-day accuracy in the smallest and thinnest sensor design at the same price as previous versions of the device.

Like previous versions, the sensor is easy to apply with a one-piece applicator and is worn on the back of the upper arm. The system also includes the FreeStyle Libre 3 mobile app, so users view their smartphone to view their real-time glucose levels, glucose history and trend arrows showing how their glucose is changing.

Good news for Europe but what about the UK? The Libre 3 will be launched in Europe over the coming months but clearly, those of us in the UK are still asking where the Freestyle Libre 2 is, let alone Version 3! Abbott has confirmed that its focus in the UK remains on delivering FreeStyle Libre 2 and is working with NHS England to achieve this - hoped to be approved by the NHS by the end of 2020 but it is a process which has been slowed due to the pandemic.

The first version of the FreeStyle Libre is the only one available in the UK and it does not have alarms. The FreeStyle Libre 2 includes alarms and alerts via its Bluetooth technology so long as the

sensor, reader or phone are in range. Whether or not the Libre 2 will be at the same price in the UK is not yet known and is part of the ongoing discussions with NHS England.

Note: also newly introduced is the Libre Sense - a version of the FreeStyle Libre aimed at sports people, not people with diabetes. It is intended to help athletes and other sports people to maximise their 'fuelling' in order to achieve a greater performance. It will not be on prescription but will be available for sale to those who are interested in using it to find out what their blood glucose profile is while they are training and competing.

For more on the original FreeStyle Libre sensor, visit www.freestylelibre.co.uk

**LATE NEWS** – just as I write this, news has just come out that the FreeStyle Libre 2 will be available in the UK from World Diabetes Day, November 14th 2020.

#### New procedure to remove the need for insulin in some people with Type 2 diabetes

A new procedure could eliminate the need for insulin for some people with Type 2 diabetes by restoring the body's ability to produce and regulate insulin naturally. The procedure is called duodenal mucosal resurfacing, or DMR. It is an outpatient procedure which involves inserting a catheter into the duodenum (the



first part of the intestine) and then destroying, mucosal cells that have changed in the process of the person developing diabetes. Destroying these tissues allows the mucosa to regrow new, healthy cells. In a new pilot trial out of the Netherlands, researchers said 75% of insulin-dependent people with Type 2 diabetes no longer required insulin 6 months after and 58% a year after the DMR procedure was conducted. (Presented at the United European Gastroenterology meeting, October 2020)

### Remote monitoring for people with diabetes

A new device by Roche was announced this year at the 56th Annual Meeting of the European Association for the Study of Diabetes (EASD).

The device was developed to help people with diabetes who require more regular interaction with their doctor and hopefully will help people to self-manage their condition. In addition, it can support those at high risk of developing diabetes complications.

Healthcare professionals can enrol their patients into the Remote Patient Monitoring programme and personalise the solution for all their needs, such as programme length, frequency of data upload, hyperglycaemia trends or standard deviation. Based on the person's shared data, as well as the predefined rules and patterns, the care team receives alerts on any irregularities to their diabetes that may incur. The care team is able to monitor the persons' health and record observations or directly communicate treatment adjustments with them via a secure and private messaging service. This provides care and advice when and where it is needed.

People with diabetes can choose to request support or share additional information and alerts remind them of their treatment plans and it supports them through their daily management.

### Experimental insulin could lead to once weekly injections for Type 2 diabetes

Findings from a phase 2 trial involving 247 Type 2 people not previously treated with insulin showed that those who underwent once-weekly treatment with insulin icodec experienced a

decrease in HbA1c levels similar to patients who took once-daily insulin glargine U100 (Lantus). The insulin, made by Novo Nordisk and is still in development. According to the researchers, the once-weekly treatment with insulin icodec could potentially "improve treatment acceptance and could facilitate management in Type 2 diabetes patients needing basal insulin". (NEJM, September 2020)

Note: there is also an ongoing trial in people with Type 1 diabetes and the results of this will be interesting as clearly a once-a-week injection of long-acting insulin has got to be good!

### Improving diabetes care for people with diabetes undergoing surgery

The IP3D project (Improving the Perioperative Pathway of Patients with Diabetes) was designed to improve the perioperative (pre-operation) pathway of diabetes care among people undergoing surgery. This is now being rolled out to 10 hospitals and if successful, it will be rolled out across the country.

The project was developed at Ipswich Hospital in 2018 and has shown to significantly reduce complications and the length of stay for people with diabetes undergoing elective surgery.

Much of IP3D is about empowering the person with diabetes so they know what to expect when they are admitted and feel reassured that their diabetes is going to be well-managed during their hospital stay. In addition, healthcare professionals play an important role because they need to take time to assess and listen to each patient to ensure they fully understand the complications that having diabetes can introduce when having surgery.

As part of the project a Diabetes Perioperative Nurse is employed and the team developed a Perioperative Passport, which has become a vital part because it contains everything that is relevant to the person who is being admitted for surgery.

Note: Many of us know that improvements for hospital stays are very necessary! Don't forget that IDDT has had a Hospital Passport for several years not just for elective surgery but any visit to hospital. This is available by contacting IDDT on 01604 622837, by email enquiries@iddtinternational.org or by writing to IDDT. PO Box 294, Northampton NN1 4XS.



#### The T:slim X" Insulin Pump

The T:slim X2 insulin pump is designed for continuous insulin delivery and management in people with Type 1 diabetes. The flat insulin cartridge holds up to 300 units of insulin and the pump can be customised to deliver different rates of insulin. It has a builtin bolus calculator which helps with insulin dosing. It is up to 38% smaller than other insulin pumps, has an aluminium case and shatter-resistant touchscreen.

For people who use the Dexcom G6 continuous glucose monitor (CGM) system, there is an additional feature called The Basal IQ technology. This predicts and helps to prevent low blood glucose levels without the need for a finger-prick test. It uses values from the Dexcom G6 CGM to predict low blood glucose levels to 30 minutes ahead and it will pause insulin delivery if levels are expected to fall below a certain level. Blood glucose levels are evaluated every 5 minutes and the pump automatically resumes insulin delivery when glucose levels begin to rise again.

The pump costs £3,150 to purchase, associated consumables cost £1,588 per year. The Dexcom G6 CGM system is an additional cost of £2,696 per year. For more information please visit: https:// www.tandemdiabetes.com/en-gb/home

This new system is being considered by the NICE Medical Technologies Evaluation Programme.

# **IDDT** News

#### 50 years on pork insulin!

In September 2020, Sabine Hancl was awarded the Mehnert Medaille 2020 for more than 50 years living with diabetes. Sabine lives in Germany and the medal was presented to her by the German Diabetes organisations, the Deutsche Diabetes Hilfe which works together with Deutsche Diabetes Gesellschaft DDG.

She has been using pork insulin for 57 years. Like many people in the 1980/90s, she had severe adverse effects from synthetic human insulin. She played a huge part in ensuring that pork insulin remained available for people in Germany and internationally. At the present time, there is no problem in obtaining Hypurin porcine insulins, although it does take 3 weeks. Thank you and congratulations to Sabine!





# Sadly, no further donations of insulin to developing countries

As members and readers are aware, IDDT is the UK arm of Insulin for Life, an organisation based in Australia that collects unwanted, indate insulin and other diabetes items to help developing countries where people are too poor to afford the insulin they need. Sadly, since the pandemic due to the regulations in the various countries, we have been unable to send any insulin or items to help people who need them.

Our fridges are full and we have not been able to accept the kind offers of insulin for some months and unfortunately, we have no idea when this situation is going to change. So please don't send us any insulin for the foreseeable future. It is a very sad situation and a dreadful waste of insulin that people need but there is nothing we can do to change this. We will keep you informed when the situation changes.

### Annual Report and Accounts for 2019

Our Annual Report and Accounts for 2019 were externally audited for the first time and due to the pandemic and people working from home, this has taken longer than usual. Added to this, we have had to cancel our Conference and Annual General Meeting. However, for the people who are interested, the Annual Report and Accounts are available on our website but if you would like a paper copy, then we are very happy to send one to you – just give IDDT a call on 01604 622837.





### Update from Dr Pendsey at Dream Trust

I would like to thank all your sponsors of children at Dream Trust and especially for the extra donations of £1550.00 which will be utilised for Covid-19 affected families with Type 1 diabetes children.

Covid-19 is progressing fast in India with a high number of cases and deaths. At our clinic, Dr Sanket looks after the cases and hospitalised patients (non-Covid). I bring senior citizen seats in my room and do nagging, administrative work and give many webinars. The clinic staff works only from 9am to 1pm and with half the number.

We have 11 districts in Vidarbha where the majority of our Dream Trust children come from. Until last month there was no public transport available and a lot of permissions were required to travel. Since this month things have improved and a lot of children have started to come for collections of insulin. From March to September they had to purchase insulin and keep the bills for reimbursement by Dream Trust. Currently, we are issuing insulin for 5 months instead of 3 months.

The majority of the families of our children are in a deep economic crisis so as per our Advisory Board decision taken in June, we are providing Rs. 15,000/- to each family for 300 to 400 families. Only two of our children have been COVID positive and they were treated at home.

We have tremendous moral support from people like you and our friends from Europe, Japan & Australia.

### From our own CORRESPONDENTS



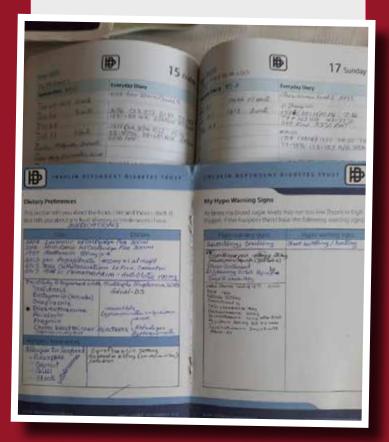
#### My three important tools

Dear Jenny,

It has been a while since I communicated with you! Since July 2018 I not only have Type 2 diabetes but also multiple myeloma. I am sending you some pictures of the three most important tools in my life – the IDDT Everyday Diary, my Chemo Book and My IDDT Hospital Passport. I find the Diary very useful with enough space being given for recording insulin injections, physical activity, meter readings and medication notes. I find physical activity, communicating with others around me and keeping a positive attitude has helped me. I am still maintaining a good balance.

Thank you for your help and stay well and stay safe.

Mr L.N. Dorset



#### Can you help?

Dear Jenny and IDDT,

I greatly appreciate the work you are doing, as well as that I am still receiving your (always very informative) newsletter, despite the fact that I live outside the UK.

I have one question regarding early morning high blood sugars in older people with Type 1 insulin-dependent diabetes like myself (I'm just over 60). A friend of mine with Type 1 diabetes in the same age range also started having the following symptoms. Despite a low early morning starting blood sugar of between 4 to 6 mmol measured between 6 and 7 a.m., the blood sugar shoots up to unusual highs of 14 to 17 around mid-morning, despite the normal insulin injection (I use Hypurin Neutral and Isophane).

I am aware of the Somogi effect and dawn effect, but the sharp rise and high levels of the blood sugars are rather unsettling. I must say that I had to start taking blood pressure medication two years ago and it seemed to me that in general, my blood sugars started to go haywire after that.

I have tried injecting my morning insulin 1 hour before eating breakfast as well as supplementing a few units of fast-acting insulin during the morning and sometimes in the afternoon to try to keep the sugars low and steady. My current diabetologist's only answer for this was to switch the slow-acting Isophane to synthetic Tresiba degludec (SIGH!!!) which has not had much significant effect.

If any of your readers have experience of this I wonder if they could get in touch through IDDT.

Keep up the good work.

By email Switzerland

Note: Hypurin Neutral and Isophane pork insulins are still available in Switzerland, BUT for several years now, the health insurances no longer cover the costs of insulin because it is no longer on the Swissmedic list and no pharmaceutical distributor or pharma company bought or renewed the rights/licence. Fortunately, one international pharmacy in Zurich is still ordering it, but the few patients who need it have to travel to Zurich to pick it up personally with a doctor's prescription and pay the full cost of the medication themselves.

#### Memories!

Dear All at IDDT,

Just a note about the letter by Karen (September 2020 Newsletter) being changed from animal to synthetic insulin. I can only echo every word. Many like myself suffered horrific reactions after being forced to change to synthetic human insulin in the 1980's.

From 1964, I was on one injection a day of beef lente zinc suspension and it suited me fine, I grew up with it and I never had severe reactions. Then in the 1980s, I went to the diabetic clinic where all my insulin was taken off me and I was given human insulin. Soon after my insulin was changed, one morning I fell on the floor as if I had been shot. I dragged myself to my bag and got food as if this was an inbuilt survival instinct. This kept happening without any warnings and sometimes it happened in the night when my Mum and Dad had to call an ambulance and I was given a glucagon jab.

The doctors wouldn't even discuss the original animal insulins but the diabetic press was full of articles about low blood sugars and hypos that never used to happen. We had to go on courses to

learn about hypos!!! From being diagnosed I was aware when I was low and my parents could see by my facial expressions when I was low or high.

After these reactions I went back to the hospital but was told I would get used to it! I didn't and I kept falling over! By chance my Dad spoke to a relative who was on the hospital board at the Royal Hallamshire Hospital in Sheffield. Their diabetes consultant, Professor John Ward, was known as one of the best doctors in the country and he immediately agreed to see me. The first question he asked me after he had studied my notes was why they had not put me back on to animal insulin, the very first question!!!!! He changed my prescriptions and immediately there was an improvement.

Karen's story brought so much back to me. People should have more choice of insulins so they have the ones that suit them and if this is animal, so be it. What about doctor's training? Is it too complicated to cover a selection of insulin treatments not just have a 'one size fits all' insulin, which is what it feels like?

Mr R.S



### Recycle Your Ink Cartridges and Help Support The InDependent Diabetes Trust

Did you know that you can help us raise funds simply by recycling your ink cartridges via our Recycle4Charity programme?

For each inkjet cartridge recycled via the programme we will receive a £1 donation, meaning you can help the environment whilst raising money for the InDependent Diabetes Trust!

To start, all you need to do is go to the address shown below and sign up for your free account.

Register now at - www.recycle4charity.co.uk/Register/C6505

#### **How It Works**



#### Sign Up & Select Your Charity

Sign up for your free account and select which charity you would like to support



#### Order Freepost Recycling Materials

Order recycling bags or boxes depending on how many cartridges you have to recycle



#### Post Us Your Ink Cartridges

Pack your cartridges up and send them to us for free



#### We Send Money To Your Charity!

Your charity of choice will earn for each cartridge received from the wanted list Pancreatic exocrine insufficiency and diabetes

As we know, the pancreas produces insulin which is secreted directly into the blood and this is part of the endocrine system. Insulin controls blood glucose levels. The pancreas also produces digestive enzymes which are secreted into the gut via ducts and this is part of the exocrine system.

The digestive enzymes break down the food (fats, proteins and carbohydrates) that is eaten so that it can be absorbed from the gut into the bloodstream. Pancreatic exocrine insufficiency (PEI) occurs when the pancreas does not produce enough digestive enzymes to digest the food properly so the body does not get all the nutrients it needs, especially fat-soluble vitamins. If left untreated PEI can lead to malnutrition which in turn may lead to bone weakness (osteoporosis, osteopenia) and deficiency of fat-soluble vitamins, A, D, E and K.

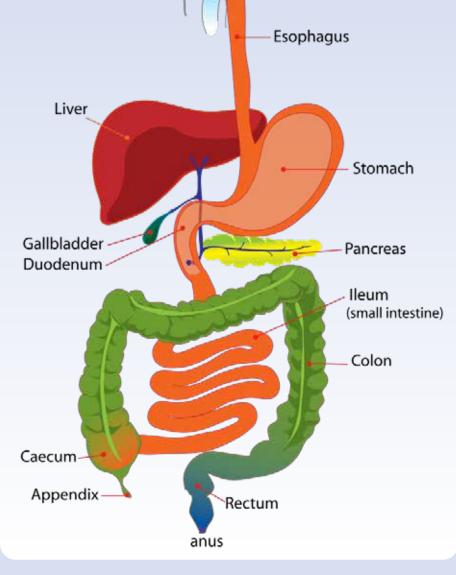
#### Who is at risk?

People may be at particular risk if they have or have had:

- surgery to the pancreas or stomach,
- · acute or chronic pancreatitis,
- · cystic fibrosis,
- pancreatic cancer.

#### **Diagnosis**

PEI is diagnosed by testing a stool sample for an enzyme called faecal-elastase-1. The symptoms are as follows:



Tongue

**Epiglottis** 

- Bloating
- · Excessive wind
- Abnormal discomfort

Salivary Glands

- Diarrhoea
- Fatigue
- Oily and pale stools
- Weight loss in severe cases.

### How are people with diabetes affected by PEI?

PEI may be responsible for variable blood glucose control.
The doctor will want to exclude other conditions that have similar

symptoms and may be associated with diabetes such as diabetic neuropathy, coeliac disease as well as conditions not associated with diabetes such as irritable bowel syndrome.

### Treatment of pancreatic exocrine insufficiency

The treatment is pancreatic enzyme replacement therapy (PERT), replacing the enzymes that are not being produced by the pancreas, usually in capsule form. To work properly, these enzymes should be taken each

time you eat or have a milky drink, including meals and snacks. They should be taken just before starting to eat or with the first few mouthfuls for them to work.

- The capsules should be swallowed whole with a cold drink because hot drinks will stop the enzymes working properly.
- For people who are unable to swallow capsules or you have been prescribed granules, open them carefully and mix the granules, without crushing them, in a spoonful of soft acidic food or drink such as yoghurt or apple juice.
- Do not chew them. Swallow immediately as PERT may cause irritation to the tissue inside the mouth. Follow this with a cold drink to wash any residue away.
- Everyone should eat a healthy diet but people with PEI should eat a nutrient rich diet.

In someone without PEI, the pancreas produces around 720,000 units for a 300 to 600 kcal meal. In someone requiring PERT, the starting dose is 50,000 units with meals and 25,000 units for snacks. For people taking insulin and measuring the dose in units, this may seem alarmingly high but this is because it aims to produce the enzymes the pancreas is unable to produce.

If you have any of the above symptoms, you should discuss them with your doctor or healthcare professional. Having said this, it can be easier said than done because many of these symptoms can feel embarrassing and not easy to discuss with anyone. Nevertheless, it is important to overcome these feelings to obtain the necessary treatment and feel better.



# THE IDDT'S LOTTERY DRAW WINNERS

We are delighted to announce the winners of our latest monthly lottery draws.

They are as follows:

#### Winners of the August 2020 draw are:

1st prize of £584.16 goes to Anon. from Exeter

2nd prize of £438.12 goes to Patricia from Waltham Abbey

3rd prize of £292.08 goes to Anon. from Hereford

4th prize of £146.04 goes to Anon. from Baschurch

#### Winners of the September 2020 draw are:

1st prize of £570.72 goes to Anon. from Bournemouth
2nd prize of £428.04 goes to Gerry from Huntingdon
3rd prize of £285.36 goes to Geoff from Bristol
4th prize of £142.68 goes to Ruth from Gloucester

#### Winners of the October 2020 draw are:

1st prize of £566.40 goes to Neville from Holmfirth
2nd prize of £424.80 goes to Colin from Andover
3rd prize of £283.60 goes to Patricia from Swindon
4th prize of £141.60 goes to Claire from Bristol

Note: The winners of the draws for November and December 2020 and January 2021 will be announced in our March 2021 Newsletter and on our website.

A huge 'Thank You' to everyone who supports IDDT through the lottery.

If you would like to join in for just £2.00 per month, then give us a call on 01604 622837 or email jo@iddtinternational.org

## RESEARCH NEWS

**December 2020 Newsletter** 

Issue 107

#### New test better predicts which babies will develop Type 1 diabetes later

Researchers at the University of Exeter and the Pacific Northwest Research Institute in Seattle have developed a new approach to predicting which babies will develop Type 1 diabetes later. This approach moves a step closer to routine testing for newborns and this could avoid lifethreatening complications.

Scientists at seven international sites have followed 7,798 children at high risk of developing Type 1 diabetes from birth, over nine years, in The Environmental Determinants of Diabetes in the Young (TEDDY) Study. Scientists used the TEDDY information to develop a method of combining multiple factors that could influence whether a child is likely to develop Type 1 diabetes. The combined risk score approach incorporates genetics, clinical factors such as family history of diabetes and their count of islet autoantibodies, which are biomarkers known to be implicated in Type 1 diabetes.

The research team found that the new combined approach greatly improved the prediction of which children would develop Type 1 diabetes, potentially allowing better diabetes risk counselling of families. Importantly, the new approach doubled the efficiency of programmes to screen new born babies to prevent the potentially dangerous condition of ketoacidosis. At the moment 40% of children diagnosed with Type 1 diabetes have ketoacidosis, which is life threatening.

Identifying the highest risk children will also benefit clinical trials on drugs that are showing promise in preventing the condition.



The researchers said the findings suggest that the routine heel prick testing of babies done at birth, could go a long way towards preventing early sickness as well as predicting which children will get Type 1 diabetes years later. They believe the combined approach can also be rolled out to predict the onset of other diseases with a strong genetic component that are identifiable in childhood, such as coeliac disease.

This test is being trialled in Washington State and the researchers hope that ultimately it will be used internationally. (Nature Medicine, 10th August 2020)

#### Type 1 diabetes could start in the womb

It was thought that babies under 6 months old only developed neonatal diabetes caused by a genetic change affecting the beta cells in the pancreas but not by Type 1 diabetes where the beta cells are destroyed by the immune system. However, research published in October 2020 has studied children under 6 months who

developed diabetes but who did not have any of the genetic mutations known to cause neonatal diabetes.

- Children diagnosed under 6 months without confirmed neonatal diabetes had a higher genetic risk of Type 1 diabetes, more autoantibodies and lower insulin producing capacity than children with neonatal diabetes.
- They concluded that this combination suggests Type 1 diabetes in children under 6 months and it is the first time an autoimmune condition that it isn't caused by a single genetic change has been seen in children this young.
- Children with this very early onset Type 1 diabetes had a lower than average birth weight, the lower the birth weight, the earlier they developed Type 1 diabetes. Those diagnosed after 6 months had a normal birth weight, suggesting that low birth weight was a specific feature of early onset Type 1 diabetes.

These new findings raise the question of whether the immune attack causing Type 1 diabetes could start before birth in some babies. The researchers want to further study very early onset of Type 1 diabetes to try to understand why the immune system can start to go wrong.

#### **Exposure to maternal diabetes**

It has been recognised for some time that exposure to maternal diabetes in utero may increase the risk of neuro-behavioural



disorders, such as AHDH (attention deficit hyperactivity disorder) in their offspring.

Using electronic medical records, researchers investigated whether this risk in children exposed to maternal diabetes was greater with the severity of diabetes. They followed 333,182 children for 4.9 years after the age of 4, which is the recommended age for the diagnosis and treatment of ADHD. Of the total population of children, 11.4% were exposed to diabetes in utero

- 522 to Type 1 diabetes,
- 7822 to Type 2 diabetes,
- 29,534 to gestational diabetes.

#### THE RESULTS

17,415 children were diagnosed with ADHD during the follow-up period.

- 9.2% of children exposed to Type 1 diabetes developed ADHD,
- 6.2% exposed to Type 2 diabetes developed ADHD,
- 4.8% exposed to gestational diabetes developed ADHD.
- These figures compare with 5.2% of children not exposed to maternal diabetes.

Note: Although ADHD was not associated with exposure to gestational diabetes or with gestational age at diagnosis of gestational diabetes, children exposed to gestational diabetes were much more likely to be diagnosed with ADHD if their mothers received anti-diabetes medication compared with children whose mothers did not.

The limitations of this study were that it did not take into account glycaemic control during pregnancy and the researchers recommend further studies to include glycaemic control. (Diabetes Care, November 2018)

#### Type 1 diabetes and intense exercise

A question that regularly arises is why blood glucose levels go up after exercise when it could be expected that they would go down, risking hypoglycaemia. However, it depends on the types of exercise undertaken and two recent studies have explained what happens with exercise.



Long-interval, high-intensity exercise is defined as activity over 10 minutes at greater than 80% peak rate of oxygen consumption and this is different from moderate-intensity exercise in terms of glycaemic effects in people with Type 1 diabetes. Intense exercise causes a rise in glucose but there is a reduction with moderateintensity exercise in people with Type 1

In high-intensity exercises glucose utilisation is lower than glucose production initially and in someone without diabetes this leads to an increase in glucose. This in turn leads to a significant rise in insulin for 40 to 60 minutes to restore glucose levels. However, in people with Type 1 diabetes this response is not present so causes continuous high glucose levels (hyperglycaemia).

One of the studies showed that 10-second sprinting just before a moderate-intensity exercise did not lower glucose level. This indicates that for people with Type 1 diabetes 10-second sprints completed immediately before a moderate-intensity exercise, prevents glucose from falling during early recovery from moderate-intensity exercise.

Taking carbohydrates during moderateintensity can lessen hypoglycaemia during the exercise and therefore, it is possible that a combination of repeated sprints and taking carbohydrates before exercise may lead to hyperglycaemia.

However, a second study concluded that in spite

of what was expected, there was no evidence to show that an intake of carbohydrates in combination with repeated sprints before moderate-intensity exercise leads to a significant rise in glucose levels during and after exercise.

#### This suggests that:

- Intense exercise causes a rise in glucose rather than a fall, seen with moderateintensity, in people with Type 1 diabetes.
- Repeated sprinting prior to moderateintensity exercise resulted no significant rise in blood glucose.
- The combination of pre-exercise carbohydrate and intermittent sprinting during moderate activity does not cause hyperglycaemia in those with Type 1 diabetes

#### An immunotherapy drug currently being trialled in Type 1 diabetes

The findings of this study could eventually lead to a drug becoming available to protect insulinproducing beta cells from the immune attack which causes the Type 1 diabetes. Protecting beta cells from the immune system is key to slowing or preventing the development of Type 1 diabetes and combined with a way to replace or regrow beta cells, it could one day lead to a cure for Type 1.

The drug is abatacept which is already used by people with rheumatoid arthritis, also an autoimmune condition. However, research has found that it is hard to predict its benefits in people with Type 1 diabetes as some people benefit a lot but others don't benefit at all.

A test to predict who will benefit from abatacept could make it possible to trial the drug in these people and eventually it could be a treatment for Type 1 diabetes.

In 2014, research demonstrated the role that a type of immune cell (called a follicular helper T cell) plays in causing Type 1 diabetes. Now this latest research shows that these same immune cells could be used to predict which people may benefit from abatacept. The researchers said that by analysing these T cells and looking at the markers they express it could make it possible to make predictions about how well people will respond to abatacept.

### Ways you can look after your feet

While correct professional help at the right time is essential for the care of your feet, there are ways to take care of them at home to help you to prevent problems arising. Here are just some ways that can be useful.

#### **Diabetes-Friendly Socks**

Our Comfort Socks have been developed for use by people with diabetes, vascular disorders and other circulatory problems. No elastic is used in the top of the sock, relying only on the gentle control of the rib for support. We also produce a Fuller Fitting Longer Sock for people who find it difficult to wear ordinary socks.

These are made with a large circumference top and are suitable for people who may be suffering from oedema, for example.

Both socks come in a range of sizes

- The Comfort Sock comes in small [4-7], medium [6 1/2-8 1/2], large [9-11] and x-large [11-13].
- The Fuller Fitting Sock comes in small [4-7], medium [61/2-81/2], large [9-12].

Both are manufactured as a unisex sock from a high quality cotton blend. They both come in a range of colours - grey, navy, white, black and beige.

The Comfort Socks retail at £8, the Fuller Fitting at £12 per pair including p&p and can be purchased from our website shop, http://www.iddt.org/shop or by phoning IDDT on 01604 622837.

#### neuropad®







neuropad® can detect early complications of the feet which can lead to foot ulcers and even amputation. The test is completely painless and is an early warning system for your feet. Diabetes can result in the sweat glands not producing enough moisture, leading to dry and cracked feet.

A neuropad® is stuck to the sole of each foot like a small sticking plaster and left in place for 10 minutes. The pad is blue to start with and should turn pink in the presence of moisture from sweating. If the neuropad® patch stays blue, or if it turns a patchy blue/pink, this indicates that you may have some level of diabetic peripheral neuropathy and your sweat glands are not working properly.

Two test pads cost £14.99 and can be purchased from our website shop, http://www.iddt.org/shop or by phoning IDDT on 01604 622837.





### InDependent Diabetes Trust



#### **SNIPPETS**

### Walking with purpose makes a difference

A study has found that when people walked with a purpose, such as to work or to go food shopping, they generally walked faster and considered themselves to be in better health than those who walked casually. People who walked to work moved at an average speed of 2.7 miles per hour but people taking a casual stroll walked at 2.55 mph. (Journal of Transport and Health, August 2020)

### Smartphone to detect Type 2 diabetes

Researchers have developed a deep-learning algorithm that is able to detect Type 2 diabetes using photoplethysmography data gathered solely with a smartphone's flashlight and built-in camera. The algorithm was able to detect about 80% of the 53,870 people in the study who had Type 2 diabetes. Its potential for further accuracy was improved when it was combined with other basic patient information such as age and BMI. (Nature Medicine, August 2020)

### Weight loss reduces the risk of Type 2 diabetes and hypertension

People with obesity who lost an average of 13% of their body weight reduced their risk of Type 2 diabetes by about 40%, their risk of hypertension by 18% to 25% and the likelihood of developing sleep apnoea by 22% to 27%. The study included more than 550,000 people in the UK and also linked the weight loss to a 20% to 22% lower risk of dyslipidaemia (lipids such as triglycerides, cholesterol and/or fat phospholipids in the blood). (Virtual European and International Congress on Obesity, September 2020)

### Microwave sensor for tracking blood glucose levels

Still in the early stages, researchers have developed a portable, non-invasive planar microwave sensor that could quickly and accurately track a person's blood glucose levels just by placing their fingertip on to the sensor. According to the researchers, the sensor uses a four-cell complementary split ring resonator in a hexagonal configuration and is a "developmental platform towards radar-driven wearable continuous blood glucose monitors," (Scientific Reports, September 2020)

### A connection between traffic noise and obesity.

Researchers from the Universities of Oxford and Leicester found that long-term exposure to road traffic noise, such as living near a motorway or on a busy road, was associated with an increase in body mass index and waist circumference.

While the difference was not great, the study did show an association between those living in high trafficnoise areas and obesity - around a 2% increase in obesity prevalence for every 10dB of added noise. This association persisted even after taking into account a wide range of lifestyle factors, such as smoking, alcohol use, physical activity, diet, and socioeconomic status of both the people and the overall area. (Environmental Research, Sept 2020)

#### **Travel survey**

In August 2020, the results of the National Travel Survey were released showing that walking trips were down by 5% for the year 2018-2019 (pre-Covid). The number of primary school children walking to school is also down from 51% in 2018 to

47% in 2019. This is the second drop in walking to school rates. Unsurprisingly, a quarter of the cars on the road at the morning peak are on the school run.

The restrictions during the pandemic have meant that many more people have appreciated the value of walking and cycling on mental and physical health, so let us hope that this continues.

# People with Type 1 diabetes would still use telemedicine after the pandemic

During the pandemic, many people have used telephone consultations with their doctors and healthcare professionals. A study has found that among the surveyed 7,000 patients with Type 1 diabetes from 89 different countries, 86% thought the telemedicine appointments they have had during the pandemic were useful. The findings also showed that 75% of the respondents would consider using remote appointments again in the future. (Endocrinology, Diabetes & Metabolism, September 2020)

### Type 1 and Type 2 diabetes linked to higher falls and fracture risks

This study found that people with Type 1 or Type 2 diabetes have 33% and 19% respectively higher risk of falls compared with the general population. Those with Type 2 diabetes had a higher risk of fractures at the hip and femur, humerus, radius and skull or face, while people with Type 1 diabetes had higher risk of fractures only at the hip and femoral region compared with the general population. (European Association for the Study of Diabetes Meeting, September 2020)

A charity supporting and listening to people who live with diabetes

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