InDependent Diabetes Trust Newsletter



SEPTEMBER 2024 Newsletter, Issue 122

PO Box 294 Northampton NN1 4XS Telephone: 01604 622837



By the time you receive this Newsletter, the big events of 2024 will be over - football EURO 2024, Wimbledon and the General Election but at the time of writing this, we don't know the winners of any of them! The first two may not matter very much in the wider scheme of things but the last one certainly does. The contents of this issue are a little different from usual because there is no news about the NHS and whichever Party is in power, we still don't know what their policies actually are in relation to Health and Social Care or indeed, if they will carry them out!

However, we can assure our members that IDDT will be watching and waiting for improvements. In addition, we are here to help you where we can and we will continue to provide free information booklets to people living with diabetes, their families, and to healthcare professionals as well as being at the end of the phone to offer a listening ear and help where we are able. Above all, we will not give up trying to ensure that the needs of people with diabetes are highlighted and addressed – we will have lots of new MPs who can be contacted if care and treatment is not what it should be!

One good bit of news for Wales appeared the day before the Election – the BMA's consultants, junior

doctors and SAS (specialist, associate specialist, and specialty doctors) committees in Wales have all accepted the Welsh Government's pay offers after members voted in favour of the deals. In a referendum,

- 96% of junior doctors voted to accept a 7.4% additional uplift taking the total to a 12.4% uplift for junior doctors for the 23/24 financial year, which will be back-dated to April 2023.
- 86% of consultants voted to accept a revised consultant pay scale which will improve early years pay and increase career average pay to retain the senior workforce.
- 82% of SAS members voted to accept the offer which will see increases of 6.1-9.2%, as well as an additional uplift for associate specialists – senior doctors who are on closed contracts.

Let us hope that the disputes in rest of the UK can be settled so that hospitals can function better and staff feel valued for the work that they do for all of us.

Finally, following our campaign in the last few months of 2023, we are pleased to have welcomed over 3,000 new members with Type 1 or Type 2 diabetes. Sadly, many of them have not received the information they need to manage their diabetes but we know that they have been grateful for the support and information that IDDT has offered. It is 30 years since IDDT formed as a very small charity which has grown over the years. For this, many thanks have to go to our staff team for their commitment.

We can assure readers that this commitment will continue so if we can be of help to you, don't hesitate to get in touch by phone: 01604 622837 or email: enquiries@iddtinternational.org

Insulin shortages 'causing stress and anxiety' in the UK

Some people with Type 1 diabetes are being forced to endure the "stress and anxiety" of insulin shortages. The "distressing" drug scarcity, is leading to uncertainty for the 400,000 people with the condition, with some products not available again until next year amid global manufacturing shortages.

A regular and reliable supply of insulin is essential for life for people with Type 1 diabetes. As we know Type 1 diabetes is an autoimmune condition which means they cannot make insulin naturally and must inject it every day or receive it through a pump. It is vital that people with Type 1 diabetes have supplies of the type of insulin they need. In addition to the dangers of not being able to obtain their insulin, the news of shortages causes anxiety and distress for people with diabetes can significantly upset diabetes control.

It is reported that the Department of Health and Social Care (DHSC) has confirmed there are supply issues with a some insulin products and patients might find this "distressing". The NHS has tried to reassure people with Type 1 diabetes that they can use other formulations when their usual product is unavailable but some people have experienced difficulties as a result of being switching insulins.

A report published by the Nuffield Trust warned that drug shortages were a "new normal" in Britain and that Brexit had worsened the situation.

Just before going to print, IDDT was contacted by a man who has had Type 1 diabetes since the 1960s and he has been to many pharmacists but is unable to obtain the Humalog he needs and he has been told that it is unavailable until early 2025. He has adverse reactions to other insulins so Humalog is essential for him.

He was very worried and understandably angry and pointed out that in all the years he has had Type 1 diabetes, he has been through many difficulties – just a mention a few: needles that he had to sharpen, no blood glucose testing but urine testing that really wasn't accurate but never has he had to fear not having any insulin! As well as Humalog, two other insulin formulations, Fiasp FlexTouch pre-filled injecting pens and Tresiba FlexTouch pens – are also in short supply.

Neither is expected to become available again until early next year. We urgently need the Government (whoever it is) to sort out the fragile medicines supply issues.

Update from Ukraine

Thanks to the help of our members, healthcare professionals and many people who have become aware of the support we give to people with diabetes in Ukraine, we are still receiving lots of diabetes items. This includes insulin, Type 2 medications, blood glucose meters and strips, lancets, needles and pump equipment. So since the last Newsletter, we have sent two consignments of diabetes items to Ukraine.

These consignments have also included Easter eggs and thanks to the support of people in knitting circles hats, scarves and teddy bears to help children in need.

We would like to say a huge thank you to everyone who is helping to support people with diabetes in Ukraine. The situation in Ukraine may fall from the headlines but the needs of people with diabetes continue and our support is essential.



Don't forget IDDT's Get Together on Saturday, 28th September 2024!

An invitation and copy of the programme and booking form for IDDT's Annual Event on Saturday, 28th September 2024 was sent to all IDDT members in June and the final programme is enclosed with this issue. The Event is being held at our usual venue, the Kettering Park Hotel and Spa.

We start the day with our Annual General Meeting and this is the opportunity for members to nominate new Trustees. If you would like to nominate someone, then please put this in writing to IDDT along with the agreement of the person you are nominating.

We hope you will find the programme for the day interesting. It is a combination of speakers and discussion groups so should include something for everyone. We are pleased to welcome Professor Alan Sinclair, an international expert in diabetes, especially in older people. We also welcome Dr Charles Fox, again well-known and for many years the consultant physician taking care of people with diabetes in Northampton. Abban Qayyum, Senior Specialist Physiotherapist, is joining us again to help us understand the effects of physical activity on diabetes management.



Dr Mabel Blades will be leading the group to discuss diet and will be around all day for you to chat to. We welcome back Jane Cheetham and her colleague from Abbott Laboratories who will have a stand and speaking about the FreeStyle Libre 2 and will be able to answer your questions.

I am sure the discussion groups and speakers and other guests will be interesting for you. We have a lot of new members this year but whether new or a longstanding member, we hope that you will join us on 28th September 2024! Teas, coffees and a meal at lunchtime are provided. If you have any questions or would like another booking form, don't hesitate to give IDDT a call on 01604 622837 or email enquiries@iddtinternational.org

Peak cognitive performance and glucose levels

A study carried out at Washington State University showed that cognition among people with Type 1 diabetes was slower when glucose levels were not typical compared with a persons' usual levels. They also found that some people were more susceptible than others to cognition effects associated with large fluctuations in glucose levels.

The researchers said that their study showed that people can differ greatly in how their brains are affected by glucose. They observed that minimising daily glucose fluctuations is important for optimising processing speed, especially so in older people or those with diabetes complications. The study included 200 adults aged 18 and older who had had Type 1 diabetes for over a year with 24 access to a smartphone and reliable internet connection. Digital glucose sensors and smartphone cognitive tests were used to collect information – glucose data every 5 minutes and cognitive data 3 times a day for 15 days.

Results

- Cognition (thinking speed) was impaired when blood glucose levels were either higher or lower than usual and processing speeds were also affected but the person's sustained attention was not affected.
- Some people experience greater thinking slowdowns with blood sugar swings than others, especially older adults and those with diabetes complications.
- Peak cognitive performance was associated with blood glucose; levels slightly above the person's normal range but further increases led to performance dropping off. One of the commentators said that this is an important finding because people with Type 1 diabetes often report feeling better with a blood glucose level considered to be higher than in the healthy range. This could be that the brain habituated a glucose level higher than it is used to.

The next step for research is to see whether the glucose levels associated with peak performance drop down into the normal range when the amount of time of blood sugars spent above range is reduced – this can be achieved with today's technology.

Diabetes distress

The psychological burden of living with diabetes

This recently published study highlights that living with Type 1 or Type 2 diabetes requires sustained involvement with multiple self-care behaviours including taking medication, healthy eating and glucose monitoring. The ongoing demands of self-care along with a fear of complications takes a toll on these groups of people.

Diabetes distress refers to the emotional effect of living with diabetes and can include feelings of guilt, anxiety and concerns about self-managing the condition. The research identified 6 areas in relation to diabetes distress:

- treatment regimen,
- food and eating,
- future and complications,
- hypoglycaemia,
- social and interpersonal relationships,
- interactions with health-care professionals.

Although symptoms of diabetes distress can include low mood, these feelings are centred on diabetes-related difficulties. Diabetes distress is distinct from other forms of distress, such as depression, which can also be present in people with diabetes. However, despite the possible overlap with depression, diabetes distress is not considered a psychiatric disorder. Diabetes distress is common and ongoing and it is estimated that it is present in more than 20% for both Type 1 and Type 2 diabetes.

The researchers suggest that given the stigma of poor mental health in some communities, the higher burden of diabetes among Black people and South Asian people and the higher reporting of diabetes distress symptoms among ethnic minorities, distress in diabetes might contribute to inequalities in diabetes. (The Lancet Diabetes & Endocrinology, 30th May 2024)

Type 1 diabetes distress, first manage emotions

Another piece of research has looked into the most effective way to reduce the distress that comes with having diabetes, and also improve glucose control, is to focus on managing the emotional strain of living with the condition. Most people with diabetes have never heard of diabetes distress or been asked about it and don't understand that it can be alleviated.

What is diabetes distress?

The researchers first identify diabetes distress as the fears, worries and burdens associated with living with and managing diabetes which can affect up to 75% of adults with Type 1 diabetes. It is linked with poor self-management, such as missing medication doses, raised glucose levels, more incidents of low blood glucose (hypoglycaemia) and lower quality of life. This recent study published in Diabetes Care, compared three group programmes, all of which were delivered virtually, they were:

- the first focused on education about and management of diabetes,
- the second on the emotional side of living with diabetes,
- the third combined the two approaches.

All three programs yielded significant and clinically meaningful reductions in diabetes distress and HbA1cs, which measure glucose control.

However, the emotion-focused programme, called TunedIn, showed the most consistent benefits and was far more effective at lowering diabetes distress than any other programmes that have been studied. 276 people with Type 1 diabetes and raised diabetes distress took part in the study which was conducted from 2019-2022.

They were randomly assigned to one of the three programmes described above, each of which involved a series of virtual meetings over a 3 to 4 month period and included group workshops, group calls and a one-to-one call with the instructor. The outcomes were as follows:

- Half the study participants no longer had diabetes distress after using TunedIn for one year, compared to 27% of those who used the education-focused programme and 31% who used the combination programme.
- TunedIn also had the highest numbers of participants (56%) whose HbA1c declined by 0.5% or more, which is clinically and statistically significant.

TunedIn incorporates elements and strategies which foster awareness of how painful emotions and beliefs can drive behaviour that conflicts with diabetes management. This has proved effective in a range of chronic diseases.

The researchers advice

If you don't address the emotional part of living with the diabetes, you don't do well. Also that it is important that clinicians are trained on how to have these conversations with their patients with diabetes as part of normal care.

The future

One Diabetes Centre in the US has begun to use a diabetes distress screening into its practice. TunedIn could broaden access for patients nationwide, and potentially worldwide, who are unable to book treatment with clinical experts in diabetes distress. The research team's work has gained international attention through the research lead who is currently working with colleagues on implementing diabetes distress programmes in the UK and Europe.

With so few mental health specialists and psychologists trained in diabetes, virtual programmes are really needed to be able to bring this type of evidence-based treatment to patients.

Note: IDDT has a booklet, 'Stress, Anxiety and Depression', if you would like a free copy, please get in touch – phone 01604 622837, email enquiries@iddtinternational.org or write to IDDT, PO Box 294, Northampton NN1 4XS.



Metformin and Type 1 diabetes



Metformin is the commonly prescribed medication for people with Type 2 diabetes and has been used for many years. However, some experts see benefits in giving the drug to some people with Type 1 diabetes to help with conditions such as insulin resistance, excess weight and reducing the risk of heart disease. In the US and most other countries, other than France, metformin is only approved for use in people with Type 2 diabetes. For years some healthcare professionals have been prescribing it for people with Type 1 diabetes 'off label' meaning that it hasn't been approved for this condition.

- In Scotland about 15% of adults with Type 1 have been prescribed metformin.
- The UK's national guidelines recommend consideration of prescribing metformin off label to people with Type 1 who have a BMI of above 25 (23 and above in Asian people) and who want to get the best glucose control while minimising their insulin use.

How metformin may help people with Type 1 diabetes

There is increasing recognition among experts that medications originally intended for Type 2 diabetes may also support some people with Type 1 diabetes, metformin being one of these - it can help keep blood sugars in range using less insulin and lose a small amount of body weight at the same time. This is because metformin provides people with extra help to make the insulin they are injecting work a little better which in turn helps them to lose a small amount of weight, maybe 5 to 10 pounds. In some cases, it may also lower cholesterol levels. It has also been observed that in some people a nighttime dose of metformin can help people that have difficulties with overnight rises in blood sugars caused by a glucose release from the liver (the dawn phenomenon).

What does the research say?

Scientific research for the use of metformin in Type 1 diabetes is lacking even though some people with Type 1 diabetes do well when prescribed it. Metformin was originally studied in Type 2 but there is only a small number of studies for its use in Type 1 diabetes that show possible benefits for some people. Results in these studies were mixed, one study showed the following results for the effects of metformin in people with Type 1 diabetes:

- Reduction in insulin needs by 5 to 10 units a day.
- HbA1cs reduced by 0.6% to 0.9%.
- Weight loss of 3 to 13 pounds.
- Reduction in total cholesterol by 11 to 16 mg/dL.

Researchers concluded that overall metformin was linked to lower insulin requirements but not lower blood sugars.

The drawbacks to metformin

Metformin has a long track record of safety in people with Type 2 diabetes and it may be useful for some people with Type 1 but there is not enough evidence to prescribe it for everyone with this condition. However, like all drugs, it can cause adverse effects:

- Stomach upset, nausea and vomiting.
- Vitamin B12 deficiency, an issue for people with Type 1 diabetes because they are already at risk for it. It is doubtful that we will see large scale studies on the effects of metformin in people with Type 1 diabetes to provide the evidence that is needed because this type of large scale, long-term study is expensive. In addition, metformin is a generic drug so is less profitable and there is little incentive for drug companies to invest in such research.

Diabetes and Flu

Although it is still only September, the flu season is coming and people with diabetes are at increased risk of developing complications of flu and difficulties with the impact flu may have on their diabetes. Influenza, commonly known as flu, is a respiratory virus and causes symptoms such as fever, cough, sore throat, runny nose and can progress to more serious illnesses, such as pneumonia. In fact, flu is responsible for about 800,000 visits to GPs a year in England and Wales.

The flu virus infects cells at the back of the nose and throat, causing congestion and/or a sore throat. Also inflammation of the mucus membranes inside the bronchial tubes, which carry air in and out of your lungs, causing a cough. This inflammation also creates an opportunity for bacteria, normally present in our throats, to infect the lungs, causing pneumonia. This can cause difficulty breathing, a cough, and chest pain, and, if not treated, it may become deadly. People with diabetes already have difficulty fighting off various infections, so they may have difficulty mustering an appropriate inflammatory response to fight off early pneumonia and are at an increased risk of developing pneumonia from an infection. So it is very important that people with diabetes get their free flu vaccination.

How the flu can affect people with diabetes

Initially the body responds to illness in the same way whether or not diabetes is present. Any infection or injury causes a stress response by increasing the levels of certain hormones, such as cortisol and adrenaline. These hormones work against the action of insulin so as a result, the body's production of glucose increases and blood sugar levels rises, which can make you feel even worse. On top of this, high blood sugars mean that your body cannot fight infection as well as normal, so without good diabetes management, your recovery can be slower.

How to prevent Flu

These steps apply to anyone looking to prevent the flu and its complications, but they are espe-

- Get a yearly flu vaccine jab. (See below)
- Avoid physical contact with others who are coughing or sneezing.
- Wash your hands frequently.
- Flu virus can live for 24 to 48 hours on surfaces, so wash surfaces with soap or other disinfectants.
- Wear a face mask to indoor events during flu season.
- Keep tabs on influenza spread in your community, and consider staying home if cases are high.

Flu and Pneumo Jabs

We are reminding you that the flu jab is offered as a priority to people in 'at risk' groups, which includes those with diabetes, pregnant women and the elderly. People with diabetes are eligible for both the flu and the "pneumo jab" vaccines. If you are offered both vaccines it is safe to have them at the same time. The 'pneumo' jab is a vaccination to protect against pneumonia and it is available to the following groups of people:

- children under two years of age as part of the childhood vaccination programme,
- adults who are 65 years of age or over,
- children and adults with certain chronic health conditions, including diabetes.

Getting vaccinated does not guarantee that you won't get the flu but it reduces the likelihood of people with diabetes being hospitalised by 46% and of those admitted, a 26% lower risk of being admitted to intensive care.

While talking about vaccinations, a shingles jab is available for the over 65s

Shingles is a viral infection that causes a painful rash. Shingles can occur anywhere on your body. It typically looks like a single stripe of blisters that wraps around the left side or the right side of your torso. Shingles is caused by the varicella-zoster virus — the same virus that causes chickenpox. The shingles vaccine helps protect against shingles. It's recommended for all adults turning 65, those aged 70 to 79 and those aged 50 and over with a severely weakened immune system and is available from your GP.

Sick-day guidance for people with Type 1 or 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 we need to know what to do before it happens. Your 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 plan 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. If you would like 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 or 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 but it can occur as a complication of Type 2 diabetes and is usually triggered by severe illness. 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.

Hyperosmolar state is less common than DKA and most 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],
- dehvdration
- 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/nurse 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 options to try.

- 10gm carbohydrate 1 2 hourly meal replacements
- 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 powder 2 teaspoons



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'.

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 as 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' or it can be difficult to get an appointment even a phone call, but it is better to be safe than sorry so be persistent! 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 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.
- You 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.

For children

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 has 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. This is particularly dangerous in children and may be caused by vomiting and diarrhoea.
- Low blood glucose levels that continue.

If you are at all uncertain then you must call your doctor!

BITS AND PIECES

18,000 children sign up for screening trial for Type 1 diabetes

The ELSA (EarLy Surveillance for Autoimmune diabetes) study is screening children aged 3 to 13 years to find those who are at high risk of developing Type 1 diabetes. 18,000 children and their families have already signed up and taking part involves a finger prick blood test which allows researchers to look for the earliest warning signs of Type 1 diabetes.

What is ELSA screening for?

Long before people develop Type 1 diabetes, signs (islet autoantibodies) can appear in the immune system that show it is preparing to attack the beta cells in the pancreas. Usually, our antibodies help to protect us against bugs which make us ill but in Type 1 diabetes autoantibodies tell the immune system to destroy the beta cells. Screening looks for these autoantibodies in the blood. Screening means that children can be closely monitored to identify Type 1 diabetes sooner so reducing the risk of DKA making diagnosis safer.

The future

Children found to be at high risk of Type 1 diabetes through ELSA could be able access new immunotherapy treatments. These are designed to halt the immune system's attack to delay or prevent Type 1 diabetes. For example, research has shown that one treatment, teplizumab, delayed the development of Type 1 by about 3 years in people at high risk. Other preventative immunotherapies are being tested in clinical trials.

Recently a new pre-Type 1 diabetes SNOMED code was launched so once the ELSA risk is known, it is stamped in your health records and will mean people can receive earlier, more timely care and be linked up with immunotherapy trials and treatments.

What about adults?

People aged 18-70 years in the UK can take part in a similar screening study called T1DRA. Over 5,000 people have already signed up and the researchers want 15,000 more to take part. (May 2024)

Warning about non-invasive glucose readings

The FDA in the US has issued a warning to people with diabetes not to use smartwatches or smart rings that do not pierce the skin for measuring blood glucose as the readings could be inaccurate.

Those inaccurate measurements could lead a person to take the wrong dose of insulin or a diabetes medication and cause dangerously low glucose levels, which could result in mental confusion or coma within hours of the error. The FDA has not authorised any smartwatch or smart ring for measuring glucose.



There is great interest in developing a non-invasive glucose monitor, that is one that doesn't pierce the skin but could either measure glucose in the body through the application of optical energy or through analysis of a body fluid, tears, sweat or saliva. Non-invasive optical monitoring is technically difficult, and non-invasive fluid sampling results often do not match blood glucose concentrations.

Some people may remember the GlucoWatch in the earlier part of this century which was non-invasive and claimed to measure glucose levels in sweat. This was inaccurate and the manufacturers went into liquidation.

Warning about CGM use by people without diabetes

People without diabetes using continuous glucose meters (CGM) has become quite common and is promoted on social media. Athletes and sports people are increasingly using them as a tool to improve their performance and recovery. Athletes use CGM to try to maintain optimal blood glucose levels for sustained energy, endurance, and performance and to find out how their bodies respond to various types of training, the impact of stress and the effect of their diet on glucose levels.

For people without diabetes who are not particularly athletic, CGMs can provide insights into how their diet, exercise and stress levels affect their blood sugar levels, enabling more informed lifestyle choices.

However, NHS lead, Professor Partha Kar has said that there is no strong evidence that the meters help people without diabetes. In addition, unless people without diabetes are using CGMs or smartwatches that pierce the skin, the results are not accurate, so this may not be as helpful as people believe.

A company called ZOE is one of the main companies selling the meters to people without diabetes and is now offering a programme, starting at around £300. It is advertised widely including on social media but ZOE acknowledges their studies are only small and they do not have all of the evidence. Expert researchers think there are potential problems from using CGMs when there are no health reasons eg it can drive an obsessive focus on numbers which can lead to eating disorders, especially as people with eating disorders often fixate on numbers as part of their illness. The eating disorder charity Beat would never recommend the use of CGMs for people without diabetes.

Technology availability in Scotland – answers to Parliamentary Questions, 25 April 2024

Question: what percentage of patients with diabetes the Government anticipates will be offered the option to transfer to a hybrid closed loop system as part of their insulin management during the financial year 2024-25, broken down by NHS board. Answer: it is for each individual NHS Board to determine how they plan to meet the needs and priorities of their local populations. The Scottish Government is committed to increasing access to diabetes technologies. We are continuing to work with key stakeholders to determine the best way to do this and how to fund it.

Question: what progress is the Scottish Government making on achieving priority 8 of its Diabetes Improvement Plan "to accelerate the development and roll-out of innovative solutions to improve

treatment, care and quality of life of people living with diabetes".

Answer: the implementation of the Diabetes Improvement Plan is underway and supported by the Scottish Diabetes Group. Regarding Priority 8, the Scottish Government has provided £19 million of additional funding to NHS Boards to support the roll out of technologies since 2021. This Group also has a significant programme of work which aims to find new solutions, or scale up existing, and ensures dedicated focus on the delivery of Priority 8.

Question: how much funding has the Scottish Government provided to each NHS board in each of the last three years to support an increase in the provision of insulin pumps and continuous glucose monitors.

Answer: In the last three years, the Scottish Government has invested £19.6 million of additional funding specifically to increase the provision of insulin pumps and continuous glucose monitors. This funding consisted of £5.1 million in 2020 to 2021 and £14.5 million in 2021 to 2022...and was allocated based on the percentage of patients with Type 1 diabetes within each given NHS Board area relative to the Scottish population. It is important to note that this funding was in addition to and not a replacement for local budgets. The Scottish Government provides

budgets. The Scottish Government for local budgets. The Scottish Government provides baseline funding to NHS Boards, and it is for individual Boards to determine how best to utilise this funding to meet the needs and priorities of their local populations. This includes ensuring those with Type 1 diabetes have access to the most appropriate treatment and care, including diabetes technologies.

Congratulations to Stewart Hood – 70 years of living with diabetes!

Earlier this year, Stewart Hood an IDDT member from Northern Ireland received his 70 year medal and here we see him receiving his medal from Professor Julie Silvestri, Consultant Ophthalmologist Surgeon and his medal. We must congratulate him on living for 70 years with Type 1 diabetes, especially through difficult times when treatment was very different. He has seen many changes over the years. When he phoned IDDT to tell us about the medal, we





discussed some of these changes, many of which people may find hard to believe. We discussed using glass syringes with needles like pokers that had to be sharpened at home, soaked in spirit and boiled on a regular basis. There was also life before blood glucose testing when control was probably guess work but the best we had! Diet to some extent has gone back to where it was, certainly when my daughter was diagnosed in 1975, we were all carbohydrate counting and matching this with insulin doses – not a lot different from today, it's just the technology that has changed!

Congratulations to Stewart and a big thank you from IDDT for his support over many years!

News from Dream Trust

Dr Sanket Pendsey has sent us these photos of "happy faces" after receiving glucose meters from **DREAM Trust!** Also is a photo of the weekly counselling sessions in progress at DREAM Trust clinic.

India Board exams are considered to be very crucial in a student's career and recently the 10th and 12th standard exam results came out (equivalent to UK GCSE and A level) and here are **DREAM Trust** successful students with Type 1 diabetes.





As regular readers know, for many years IDDT members have sponsored children and young people with Type 1 diabetes at **DREAM Trust** clinic and helped with their diabetic and educational needs.

Dr Pendsey has asked us to share with all our sponsors the success of the following students and on their behalf, he thanks you all for your support as this has played a very important role in their success.

Is diabetes a hereditary condition – how your genes can play a role

No type of diabetes mellitus is genetic by itself, but your DNA may influence your risk of developing it. It is true that diabetes tends to run in families so it is not unreasonable for us to wonder if that means there is a genetic cause. There is not an easy answer to this as it depends on the type of diabetes and other factors such as diet, lifestyle and environmental, so we will take a look at the various types of diabetes.

Type 1 diabetes

Type 1 diabetes is caused by the body's immune system attacking and destroying the beta cells in the pancreas that produce insulin. It is most commonly diagnosed in childhood or early adulthood but it can occur at any age. The autoantibodies that attack the beta cells can be present but their presence does not guarantee that a person will develop Type 1 diabetes.

Here are some of the known facts about the development of Type 1 diabetes:

- In the US white people have higher rates of the condition than other racial and ethnic groups as
 do people who live in colder, northern climates globally. It has also been observed that Type 1
 diabetes can be triggered by viral infections.
- A study published in 2017 found evidence that being breastfed as a baby lowered the risk of Type 1 diabetes. Nutrition in infancy may also play a role in its development.
- People with Type 1 diabetes are also at a higher risk of having other autoimmune disorders, such as Graves' disease, Hashimoto's thyroiditis, coeliac disease, and pernicious anaemia.

From these points, while people who have a family history of Type 1 diabetes may be predisposed to developing it, the inheritance pattern in most cases is unclear.

Type 2 diabetes

TType 2 diabetes happens when the body doesn't use insulin properly (insulin resistance). At first, the pancreas makes more insulin to compensate for this, but in time there isn't enough to keep blood glucose at normal levels. Around 90 to 95% of all diabetes cases are Type 2 and it typically develops in people over 45 years old but it is increasing in young people.

Here are some of the known facts about the development of Type 2 diabetes:

- Being overweight or obese is a strong risk factor for Type 2 diabetes.
- People in most ethnic groups are at risk for Type 2 diabetes if their body mass index (BMI), is 25 or higher. However, people who are Black, Alaska Native, American Indian, Asian American, Hispanic or Latino, Native Hawaiian, or Pacific Islander are at a higher risk for Type 2 diabetes even if they are not overweight.
- Associated with Type 2 diabetes are cardiovascular health conditions, such as high blood pressure, low levels of HDL ("good") cholesterol, high levels of triglycerides in the blood, or a history of heart disease or stroke. So is having depression or polycystic ovary syndrome.

The influence of family history on whether people will develop diabetes is better established in Type 2 than in Type 1. People with Type 2 diabetes are more likely to have relatives who also have diabetes, obesity or other risk factors. However, it is hard to know if this is due to genes alone or a shared environment and lifestyle. For instance, it could be that what they are sharing is not a genetic variation but maybe their diet or lack of access to opportunities for exercise, depending on where they live.

Gestational diabetes

During pregnancy, women normally develop a certain amount of insulin resistance, which ensures there's enough glucose available to provide energy for the growing foetus. Most pregnant women do not develop gestational diabetes but in those who do, a combination of genes, environment, and lifestyle factors are likely to be involved as with Type 2 diabetes. Many women who develop the condition have at least one close family member who has had gestational diabetes or Type 2 diabetes. Here are some of the known facts about gestational diabetes:

- it is associated with high blood pressure during pregnancy (may lead to preeclampsia) and premature birth.
- Babies born to mothers with gestational diabetes tend to have higher than average birthweight which can cause delivery complications.
- The babies of mothers with the condition are more likely to develop low blood sugars soon after birth. Later in life, these children have an increased risk of developing obesity, heart disease, and Type 2 diabetes.
- The number of women with gestational diabetes is increasing and maternal age may be a factor.
- Half of all women with gestational diabetes will go on to develop Type 2 diabetes.

Monogenic Diabetes

In 1 to 4% of all diabetes cases, the condition results from mutations in a single gene, meaning that the condition is monogenic. This means a single gene can be identified and a test can be carried out. Two of the most common monogenic forms of diabetes are maturity-onset diabetes of the young (MODY), which usually appears during the teen years or young adulthood, and neonatal diabetes mellitus (NDM), which is most common in newborns and infants.

MODY

Some forms of MODY result in slightly high levels of blood sugar that remain stable throughout life, resulting in no symptoms or mild symptoms, and no complications. Other forms may require treatment with insulin or a class of oral medications called sulfonylureas, which increase the release of insulin from the beta cells in the pancreas. At least 10 genes have been linked to forms of MODY, the common mutations are found in the GCK gene or the HNF1A gene. It is thought that GCK mutations are responsible for 30 to 60% of MODY cases and this statistic is an example of why genetic testing can be useful. Although the person's bloods look like they have Type 1 diabetes, they actually don't need insulin because it doesn't make a difference in the treatment of the disorder. This will prevent unnecessary treatments and relatives can be tested for the gene and monitored for the development of MODY.

Neonatal diabetes (NDM)

Neonatal diabetes mellitus (NDM) is a rare condition that affects up to 1 in 100,000 infants usually during the first 6 to 12 months of life. Infants with NDM do not produce enough insulin, and the condition is often mistaken for Type 1 diabetes. They tend to be born undersized and grow less rapidly than those without NDM. For about half of babies with NDM, the condition is permanent; for the other half, it disappears but can reappear later. Most testing for NDM will look at three genes. Most forms of NDM and MODY are caused by autosomal dominant mutations, meaning they can be passed on to children when only one parent carries the gene for the disease. In these cases, the parent

who carries the gene has a 50% chance of having an affected child.

Genetic testing

Most forms of Type 1 and Type 2 diabetes and gestational diabetes are polygenic which means they involve multiple genes and a complex interaction with environmental and lifestyle factors. The usefulness of genetic testing in polygenic diabetes is limited as it is only going to reveal an association or a probability that someone might get Type 1 or Type 2 diabetes because the disease is not only caused by genetic variation. The test won't indicate with certainty whether some will go on to develop the condition and more traditional diagnostic testing, like HbA1c (a measure of blood glucose), is usually more helpful than genetic testing to find out if someone has a form a diabetes and to determine the correct treatment.

Pharma News

Discontinuation notice

To help other people, one of our members informed IDDT that he could no longer obtain some of his usual supplies. On investigation he found a formal notification that company Embecta, formerly part of BD, discontinued the distribution and sale of the BD Sharps Disposal by Mail and the Safe-Clip™ Needle Clipping and Storage Device on October 10, 2023.

New drug for severe hypoglycaemia - Zegalogue approved in Europe

Zegalogue (dasiglucagon, Zealand Pharma) is a new drug for treating severe hypoglycaemia and has been recommended by the European Medicines Agency (EMA) for patients aged six years and older with diabetes. These recommendations are subject to ratification by the European Commission. Zegalogue will be available as 0.6-mg solution for injection.

Severe hypoglycaemia is defined as having low blood glucose levels that require assistance from another person to treat. The active substance in Zegalogue is dasiglucagon, a hormone that increases blood glucose concentration by activating hepatic (liver) glucagon receptors. This stimulates glycogen breakdown and promotes the release of glucose from the liver. The EMA's Committee's decision is based on evidence from two studies involving adults and children aged 6 years or older with diabetes.

These showed that treatment of insulin-induced hypoglycaemia with Zegalogue reduced the time required to increase plasma glucose compared with placebo, with a median time to recovery of 10 minutes. More patients experienced plasma glucose recovery with Zegalogue compared with placebo.

The most common side effects are nausea, vomiting, or headache. Irritation, redness or swelling at the injection site may also occur.

UK planning laws deter investment, says drugs giant - BBC News, 1st July 2024

Dave Ricks, chief executive of the insulin manufacturer and now the obesity drug manufacturer, Eli Lilly, the world's most valuable pharmaceutical company told the BBC that the UK's planning system puts companies off investing in the country. He said that Lilly has considered building a factory in the UK in the last decade, but chose another country instead. This was due to the current planning processes being an "impediment" to building factories at speed. Eli Lilly, along with its Danish rival Novo Nordisk, has developed a considerable lead over the rest of the pharmaceutical industry when it comes to obesity medication. Its obesity drugs are in such demand that the company cannot build factories quickly enough.

The company has operations in the US, Ireland and other European Union countries including Italy, France and Germany. Mr Ricks said countries that "could present a path" in which the time taken to set up a pharmaceutical plant was reduced from five years to two was "very attractive".

"In the UK - although I love visiting, it's a wonderful county - it's not the largest market so you have to overcome that with other attractiveness, whether that be workforce, asset delivery or economic incentives," he said. "You have to be candid, say 'are we as competitive as we can be?' And to date it's been a little bit less, but I think it's not unachievable."

Drug companies are paying Australian doctors millions of dollars a year

In the first of its kind of comprehensive analysis of reports from major drug companies, it was found that drug companies paid more than A\$33 million to Australian doctors in 3 years from 2019 to 2022.

This was to fly overseas to conferences, meetings and to serve on advisory boards for these consultancies and expenses. It also underestimates how much drug companies pay doctors as it omits food and drink which drug companies in Australia do not have to declare.

How was this information found?

Since 2019, Medicines Australia, the trade association of the pharmaceutical industry, has published a centralised database of payments made to individual health professionals. Researchers analysed the data and found:

- More than two-thirds of rheumatologists received industry payments, often prescribing expensive new biologic drugs that suppress the immune system. These drugs are responsible for a substantial proportion of drug costs on the Pharmaceutical Benefits Scheme (PBS).
- The specialists who received the most funding were cancer doctors, receiving over A\$6 million. Some of the expensive new cancer drugs are great treatment advances but others offer minimal improvement on survival or quality of life. A 2023 study found doctors receiving industry payments were more likely to prescribe cancer treatments of low clinical value.
- Some doctors only had many small payments of a few hundred dollars but there were also cases of large individual payments.

The best available evidence on the effects of pharmaceutical industry funding on prescribing comes from the US government-run programme called Open Payments. Since 2013, all drug and device companies must report all prescribing payments over US\$10 in value in any single year.

Payment reports are linked to the promoted products, which allows researchers to compare doctors' payments with their prescribing patterns. Analysis of this data, which involves hundreds of thousands of doctors, has indisputably shown promotional payments affect prescribing.

Why does all this matter?

Doctors usually believe drug company promotion does not affect them. But research shows that industry payments can affect both doctors' own prescribing decisions and those of their colleagues.

We, as patients, trust doctors to choose the best available treatments to meet our health needs which are based on scientific evidence of safety and effectiveness. They don't expect marketing to influence that choice!



In the March issue of the Newsletter, we discussed the issues around the roles of Physician Associates (PA) and Anaesthesia Associates (AA), especially in relation to whether or not we, as patients, are aware of who is treating us – a fully qualified doctor or a physician associate.

As we reported previously, the government's plans to expand physician associate (PA) and anaesthesia associate (AA) roles, and to establish the General Medical Council (GMC) as their statutory regulator, came under renewed criticism in February when the House of Lords sent the draft legislation to the main chamber for proper scrutiny.

This followed opposition to the plans by the Doctors' Association UK (DAUK) and the British Medical Association (BMA). DAUK Co-chair Dr Matt Kneale said in a press release: "We've been saying all along that legislation that will fundamentally change patient care in the NHS to the detriment of the public should be properly debated and scrutinised and not rushed through on the nod".

Why is regulation needed?

This was written before the election was announced and at the time, the government intended to increase the numbers of PAs in the NHS from 3000-plus to 10,000 and the number of AAs from 320 to 2000 by 2036/37. As the aim is to relieve pressure from doctors, according to the government, the regulation would improve patient safety as well as support expansion plans.

What PAs can currently do:

- they can voluntarily register with the Faculty of Physician Associates (FPA).
- take medical histories,
- perform basic physical examinations,
- help develop treatment plans.

They cannot at present:

- order X-rays
- prescribe independently; only professions that are statutorily regulated have the right to prescribe.
- AAs can review patients pre-surgery, initiate and manage medications, fluids, blood during
 operations and help with postoperative management, but they can administer anaesthesia only
 under the supervision of a medically qualified anaesthetist. For extension of prescribing roles to
 PAs and AAs the Commission on Human Medicines would have to give approval and appropriate
 legislative amendments would be required to facilitate this.

Why are the proposals contentious?

- the BMA say that allowing the GMC to regulate PAs would "blur the lines" between doctors and nondoctors in patients' minds.
- The GMC is the wrong regulator for medical associate professionals: it is the body for regulating doctors, which these staff are not. Patients being told that the people seeing them are regulated by the same body that regulates doctors will make them think they are receiving a doctor's standard of care.
- The Health and Care Professions Council is the appropriate regulator for these roles not the GMC."
- The BMA said that doctors have complained about miscommunication, incorrect prescriptions and inaccurate assessments from PAs, as well as an expectation to prescribe on behalf of PAs solely on the basis of their assessment. Some said that having to supervise PAs had increased their workload, and they were concerned about the safety implications.

How would GMC regulation work?

The General Medical Council (GMC) view is that regulation will help to increase the contribution PAs and AAs can make to UK healthcare, while keeping patients safe. They state that to register new and existing PAs and AAs will need to show:

- they have the knowledge, skills, and experience to work safely,
- there are no outstanding concerns about their fitness to practise which includes employer references, the last 5 years employment history and a fitness to practise declaration to assure us that there are no ongoing or previous concerns about their performance, professionalism, or behaviour.
- once regulation is in place, the GMC will ensure that PAs and AAs remain up-to-date and fit to practise through a process of revalidation. PAs will still be required to work with a dedicated medical supervisor: a consultant, GP, or other senior medical personnel.

What is the process the legislation will go through?

The government announced in 2019 that it would ask the GMC to regulate PAs and AAs. Following a consultation, it laid the necessary draft Anaesthesia Associates and Physician Associates Order 2024 before Parliament in December 2023, and the House of Commons has passed the Order. The government's aim is for the GMC to start PA/AA regulation "by the end of 2024 at the latest."

Research and retinopathy

Risk factors associated with diabetic retinopathy in young people with Type 1 diabetes

This study collected information from 2005 to 2020. The researchers used macular scans and automated retinal segmentation to determine the inner and outer layers in a subset of patients. They looked for looked for correlations between the patients demographics, body mass index (BMI), blood pressure, HbA1c and retinal layer cell thickness and volume with the presence of diabetic retinopathy.

The following correlations were found with the presence of diabetic retinopathy:

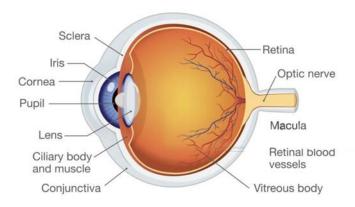
- Older age
- Longer duration of Type 1 diabetes
- Earlier onset of the condition
- Higher HbA1c
- Higher systolic and diastolic blood pressure.

The results indicated that maintaining control of blood pressure and HbA1c are key to preventing the onset of diabetic retinopathy. (Paper presented at the Association for Research in Vision and Ophthalmology annual meeting; May 5-9, 2024)

Risk factors for diabetic retinopathy in older people with Type 1 diabetes

A Danish study suggests that longer duration of diabetes and the use of drugs to reduce blood pressure appear to increase the risk of diabetic retinopathy and its progression to proliferative diabetic retinopathy in people with Type 1 diabetes. Proliferative retinopathy is the advanced stage of retinopathy where abnormal new blood vessels grow on the surface of the retina. These vessels may break and bleed into the vitreous, the clear watery gel that fills the eye, and cause severe vision loss. This stage of diabetic retinopathy typically requires urgent treatment.

Human Eye Anatomy



The researchers evaluated 16,999 patients with Type 1 diabetes with an average age, 45 years (57.5% were men) from the Danish Registry of Diabetic Retinopathy. They attended a national screening between 2013 and 2018 and had diabetes for an average duration of 16.7 years.

The degree of diabetic retinopathy in the worse eye during the first screening was used to grade its severity from:

- 0 (no retinopathy),
- 1-3 (mild, moderate, and severe nonproliferative retinopathy),
- 4 (proliferative retinopathy present or previously treated with panretinal laser therapy).

Results

- At the time of the first screening, 44.2% patients reported diabetic retinopathy, with 26.9%, 6.7%, 1.3%, and 9.3% reporting levels 1, 2, 3, and 4, respectively.
- The 5-year cumulative incidence of any retinopathy and its progression to proliferative disease were 8.9% and 2%, respectively.

The likelihood of retinopathy was higher in the younger people, those who had had diabetes longer, men, and users of drugs to control blood pressure and cholesterol. These risk factors were also associated with progression to proliferative diabetic retinopathy. (Acta Ophthalmologica. May 2024)

Note: IDDT has a booklet The Eye and Diabetes and if you would like a copy, please get in touch: Tel 01604 622837, email enquiries@iddtinternational.org or write to IDDT, PO Box 294, Northampton NN1 4XS

IDF and IAPB release joint policy for the early diagnosis, treatment and prevention of diabetic retinopathy

The International Diabetes Federation (IDF) and The International Alliance for the Prevention of Blindness (IAPB) have released a new policy brief – Diabetic Retinopathy: A Global Call for Action. It advocates for a joint approach to prevent and manage vision loss in people living with diabetes by integrating diabetic retinopathy care into diabetes policies and national health plans.

Diabetic retinopathy is the fifth most common cause of moderate to severe vision impairment and blindness globally, affecting over one in three people with diabetes over the age of 40.

It usually affects both eyes and results when high glucose levels damage blood vessels in the retina, causing blurred or distorted vision. Other symptoms include the onset of colour blindness or colours appearing faded and poor night vision. If diabetic retinopathy goes untreated or treatment is delayed, it can result in visual impairment or blindness affecting mobility, mental well-being and the ability to work.

Early detection, regular screening and appropriate diabetes management are crucial to prevent vision loss and improve the quality of life for people with diabetes. The IDF-IAPB policy brief provides the first steps to take action to tackle diabetic retinopathy and includes a series of recommendations for advocates, healthcare professionals and policymakers to prevent and manage this common and costly diabetes-related complication.

The Diabetic Eye Screening Team raising awareness for how diabetes can impact the eyes

The Diabetes Eye Screening Team (DESP) took part in a sponsored walk on Saturday 15th June 2024 to raise awareness for people living with diabetes of the impact it can have on their eyesight but also to highlight the importance for people to attend their eye screening appointments. Of course, to also raise money for The InDependent Diabetic Trust.

The Team run clinics from 10 different sites across County Durham and Darlington. The team consists of a very productive and dedicated programme manager, a clinical lead ophthalmologist, 2 optometrists, 8 retinal screeners/graders and 4 administrative staff, who together ALL play a vital part and work extremely hard to ensure they provide a friendly, effective and efficient service for their patients.

As part of this service they give IDDT booklets to their patients, not just about eyes but about various aspects of looking after or managing their diabetes because they are very aware that the better diabetes is looked after, Type 1 and Type 2, the less risk there is of diabetes retinopathy developing. IDDT is very happy to send them booklets so that more people can learn about and understand their diabetes.

Here's the Team braving the weather!

They trekked Catbells walking route, which is nestled within the magnificent landscapes of the Lake District, offering spectacular panoramic views! IDDT says a huge thank you to the whole team for supporting our charity and we are glad to hear they enjoyed the day too!



Perhaps this is an opportunity to remind you about Eye Screening

Over a prolonged period of time, having high blood sugar levels can damage the blood vessels inside a part of the eye called the retina. It causes the tiny blood vessels within the eye to become damaged, get blocked and bulge, leak fluid or bleed. Diabetic retinopathy does not usually affect the vision until it has reached an advanced stage, so early detection, diagnoses and treatment is crucial to keeping the eyes healthy.

The diabetic eye screening programme provides free eye screening for everybody who has diabetes, from the age of 12. It's a very quick and simple appointment, which involves having drops put into the eyes and having a digital photograph of the back of the eyes, this enables the team of screeners to have a more detailed look and detect any signs of diabetic retinopathy. This makes a positive difference to people's lives.

Once weekly insulin

Canada - the first country to market once weekly iodec (Awqili)

In the last Newsletter we wrote about a new once a week insulin iodec, brand name Awiqli. Now, from 30th June 2024, Canada has become the first country to make it available for adults with Type 2 diabetes. Doctors say it will "make life easier" for people living with diabetes as there will be less of a burden in terms of the number of days when insulin is needed. Its estimated annual treatment cost is \$1,085 to \$1,357.

Canada has not approved Awqili people with Type 1 diabetes or for children and those under 18 and manufacturer Novo Nordisk says it should not be used in pregnancy or breastfeeding as it has not been studied in these groups.

What is iodec (Awiqli)?

Awiqli is a long-acting basal insulin that helps to control high blood sugar levels in adults with diabetes over a seven-day period as opposed to the daily basal insulin option. The pre-filled pen can provide a dose of 10-700 units in one injection in increments of 10 units.

For people with Type 2 diabetes, Awiqli may be used along with other tablets or injections, including short- or rapid-acting insulins.

What are the side effects?

The side effects of this insulin are not any different from other types of insulin - low blood sugar, (hypoglycaemia) being the most common. Other possible side effects include allergic reactions, skin problems where the injection is given, weight gain, swelling of the ankles and feet and the forming of anti-insulin antibodies. It has to be said that most of the trials were carried out in people with Type 2 diabetes. Only one of the trials involved people with Type 1 and it found a higher risk of hypos in those that took the new once weekly insulin.

lodec position in the UK and Europe

In the UK, NICE has announced that it is assessing iodec for use in this country but this will

take some months. While not yet licensed in the EU, iodec has received a positive opinion which usually leads to licensing.

lodec diabetes not approved in US for Type 1 diabetes

The FDA panel in the US looked at 5 ONWARD trials conducted in people with Type 2 diabetes but has not publicly raised concerns about efficacy and safety in any of those trials. However, the FDA panel has voted 7 to 4 against licensing iodec for people with Type 1 diabetes because the benefits do not outweigh the risks of hypoglycaemia.

The panel looked at the evidence from the ONWARD-6 trial in Type 1 diabetes carried out by iodec manufacturers, Novo Nordisk. In the trial there were 290 people with Type 1 diabetes taking iodec and 292 people taking once daily degludec (Tresiba). At 26 weeks the results showed that iodec was non-inferior (meaning no worse) than degludec but there were significant increases in serious and severe hypoglycaemia with the greatest increases on days 2 to 4 after the injection.

Novo Nordisk's suggested the following ways around this:

- limiting the use of iodec to people who use continuous glucose monitors,
- restricting use to people with low glucose variability,
- avoiding use in those who have hypo unawareness,
- and/or using in different dosing strategies, such as reducing mealtime injections on days 2 to 4.

The panel discussed the possible advantages, such as improved adherence and convenience and whether Novo Nordisk's above suggestions would be workable in real life. Most panellists agreed that Novo Nordisk should conduct further trials.

Research

Abnormal lipid profiles linked to obesity in Type 1 diabetes

This study showed that dyslipidaemia, which means that there are too many lipids (fats) in the blood, was more common among children with newly diagnosed Type 1 diabetes vs those without overweight or obesity.

Although dyslipidaemia is a modifiable risk factor linked to cardiovascular disease among people with Type 1 diabetes, the link between obesity and lipid profile at the time of Type 1 diabetes diagnosis remains unclear.

To clarify the link between dyslipidaemia and body weight among children with newly diagnosed

Type 1 diabetes, researchers conducted a study among 186 young people between the ages of 1 and 19 years. 69% were a healthy weight and 31% were overweight or obese.

They detected no significant differences between these two groups at the start of the study and the basal was similar in the healthy or the overweight or obese groups.

- Among all of participants, 76% had at least 1 abnormal lipid test.
- Elevated tryglycerides among 60% of the overweight or obese group compared with 42% of the healthy weight group.
- The overweight or obese group vs the healthy weight group had a greater proportion of patients with abnormal high-density lipoprotein levels (76% vs 48%).
- Although the average HbA1c glycated haemoglobin level was higher among the healthy weight vs overweight or obese group, there were no in rates of diabetic ketoacidosis between groups.

Conclusions

The researchers concluded that compared to patients of normal weight, children with newly diagnosed Type 1 diabetes who are overweight or obese may be more susceptible to early cardiovascular complications. (Pediatric Endocrine Society Annual Meeting, May 2024)

The efficacy and safety of weight loss treatments in Type 1 diabetes

This research showed that different weight loss treatments provide a range of benefits for people with Type 1 diabetes but they also have some potential adverse effects.

With the increase in obesity in the general public over the last 20 years, people with Type 1 diabetes are at an increased risk of developing obesity which highlights the need to look at treating both conditions. The researchers say that although promising new medications are now available to treat overweight and obesity, there are challenges:

- Weight loss in Type 1 diabetes may reduce insulin requirements and lead to an increase in hypoglycaemia frequency and severity.
- Concerns about the adverse effects such as diabetic ketoacidosis at normal blood sugar levels, cardiovascular disease and depression.

The review looked at medical nutrition therapy, exercise and behavioural modifications for preventing or treating obesity. The researchers found that:

- Weight loss programmes can benefit people with Type 1 diabetes.
- Choosing a specific diet was seen to be less effective than a diet which is more sustainable.

- Exercise had only modest benefit on weight loss but it provided benefits for cardiovascular disease and psychological health as well as reduced risk of regaining weight.
- Studies into different insulin types, short and long, but there were only modest differences in weight loss. The new obesity treatment, semaglutide, is only licensed for use in in Type 2 diabetes.

The conclusion has to be that people with Type 1 diabetes are at risk of obesity but weight loss may improve outcomes in Type 1 diabetes especially in relation to cardiovascular health, kidney disease and mortality. However, as shown above, treatment does not come without risks and the researchers recommend more studies across all lines of treatment are needed. (Current Opinion in Endocrinology, Diabetes and Obesity, May 2024)

Chemical exposure can lead to higher risk of metabolic syndrome in children

A new study has found that pre-natal exposure to endocrine disrupting chemicals (EDCs), which interfere with the normal functioning of the hormonal system, can result in poorer metabolic health in children, which in turn can have lifelong negative effects on health. Metabolic syndrome is a combination of conditions that can increase the risk of cardiovascular diseases and Type 2 diabetes.

The study found EDCs, such as mixtures of metals, polyfluoroalkyl substances (PFAS), pesticides and flame retardant, present during pregnancy increased the risk of children developing metabolic syndrome. This can have lifelong impacts, which can appear as obesity, hypertension, insulin resistance and high cholesterol, all of which contribute to the development of cardiovascular diseases and diabetes.

Girls were more at risk from PFAS and polychlorinated biphenyls, and boys were more impacted by exposure to parabens. The research involved 1,134 mothers and their children from Spain, France, Greece, Lithuania, Norway and the United Kingdom. Initially, samples were collected during pregnancy or from the umbilical cord and the study later followed up on the children between 6-11 years old. There is a call for action in the next EU legislature to restrict EDCs. (EU-funded ATHLETE project, 24 May 2024)



From our own correspondents

What Schools Need to Know and Parents Passport

Dear IDDT,

Thank you so very much for the booklets for schools that you sent us. We are passing them around to a number of staff to highlight procedures, and also gave some to one of our students who, although diagnosed a few years ago, is struggling with her understanding and management of her diabetes.

We are very grateful and wish to reassure you that they are very informative to us and will be put to great use.

Thank you.

By email Secondary School, Surrey

Ground almond flour

Dear Jenny,
On Page 6 of the March issue of Type 2 & You, there is mention of replacing white carbs with whole grain. We make bread using 'ground almond flour', buying the almonds from the local wholefood store and grinding them ourselves leaving the skin on. We make two loaves at a time and store in the freezer or fridge. I am sure there are many recipes to be found online which may be of interest to your readers.

By email W.M.

Sharps bins, mine are free!

Dear Jenny,
I have read in previous Newsletters that some readers are having trouble getting their sharps bins emptied or they have to pay for it. I thought I would let you know that I filled in a form at my GP practice and my sharps boxes are collected regularly free of charge by a company called Stericycle UK.

By phone

IDDT looked into this and Stericycle charge for collections. The only explanation we can offer is that our caller lives in Wales where NHS prescriptions are free, so we wonder if sharps box collections are free to the users too but paid for by the NHS. If you know the answer to this, we'd love to hear from you so that we can pass the information on to our readers. Just call IDDT on 01604 622837.

Labels aren't always accurate

Dear Jenny,

I think I should draw your attention to the fact that nutrition listing on foods is not always accurate. For instance, I have been in email contact with Aldi about their Bramwells Chicken in White Sauce. The listing on the back of their tin shows that carbs are listed as 0 but it also lists various types of flour and modified starch but doesn't point out that these are carbs! I have in the past bought a similar product from other supermarkets who always seem to manage to list accurate ratios even if a slight difference in values.

As someone with Type 1, I always read food labels and have used carb counting for many years - about 30gm of carbohydrate per meal! I tried to draw this to the attention of Aldi, but the first acknowledgement was from someone who seemed to think I was referring to allergens.

However, having sent a second message stressing the importance of accurate carb values to people with Type 1diabetes, I have received another message today stating that my concerns have been forwarded to the relevant department for review – lets hope this is successful in getting a knowledgeable person to estimate carb values in the future!

Despite being in my 80s now I am still on the alert! Recently, I have been able to help a teacher friend with a Type 1 child in her class to access IDDT leaflets regarding schools. All the very best Jenny – your hard work and info supplied by IDDT are a boon to the diabetic community.

Putting it into action!

Hi Jenny

Many thanks for the booklets and tote bag that I requested. They arrived today. I have learned a lot and understand a lot more by reading all the information and I will certainly be putting a lot of what I read into action.

By email

IDDT News

Follow up on the good news about the neuropad®!

In the last issue we explained that neuropad® is a patented 10-minute screening test for the early detection of diabetic foot syndrome. The test is completely painless and is an early warning system for your feet because nerve damage is a common complication of diabetes but is often not noticed until it becomes quite advanced. For several years IDDT's website shop has sold neuropads but the good news we gave readers is that now neuropads are available free for people with diabetes on a GP prescription!

However, we found that many people were still contacting IDDT to purchase neuropads for £14.99 rather than going to their GP for free ones. Asking why, some people told us that the GP refused or had never heard of it but the majority told us that it was so much easier to pay for one than try to see their GP. Doesn't this say everything about our NHS! One man, let's call him Mr X, was determined to beat the system and when he was refused the neuropad by his GP, he argued and took a copy of our article to the surgery and guess what? He got it free on an NHS Prescription. Well done to MR X for his persistence, not just with getting the neuropad as he rightly pointed out, on the time taken to get a GP appointment!

Just to remind you: 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 to indicate a normal result. If the neuropad® test patch

stays blue, or turns patchy blue/pink, this indicates that you may have diabetic peripheral neuropathy and your sweat glands are not working properly because there is not enough moisture to complete the colour change.

Note: if you still prefer to buy one from IDDT: online at www.iddt.org/shop or phone IDDT on 01604 622837. We also supply a FREE booklet 'Looking After Your Feet' if you would like one, just ask.





IDDT Posters Picture of poster

For some time, IDDT has been receiving requests from healthcare professionals for posters for their waiting rooms to advertise our information booklets.

We now have these posters in stock available free of charge to healthcare professionals for their waiting rooms or for members to request them, to take to their surgeries to ask for them to be displayed.

If you can help by letting others with diabetes know they can receive free information from IDDT, please call IDDT on 01604 622837 or email enquiries@iddtinternational.org

It's still holiday time!

For those who are likely to take your holidays a bit later, don't forget you can have a free copy of our Holiday Tips booklet. This will help you with tips for travelling and staying safe while you are away.



IDDT membership

We are very grateful for the kind donations people make to IDDT because it all helps to enable us to carry on with our work. Having said this, sadly the cost of living crisis has affected some people and they feel they have to stop receiving the Newsletters and/or Type 2 & You because they cannot afford to donate. This worries us because one of our main aims has always been that people living with diabetes receive the information they need to manage their condition and hopefully having this information enables them to live a more stress free life. This is especially important with the NHS as it is now and people are not getting appointments and the information they need.

So, while we are certainly extremely grateful for donations, we do want to remind you that we don't want anyone to feel they have to stop getting the Newsletters or Type 2 & You

because they have been affected by the present economic climate.

Membership of IDDT is FREE and donations are entirely voluntary.

Just a final few words: if you receive a membership renewal letter regardless of whether or not you are donating, please do fill it in so that we have your up to date address and also what Type of diabetes you have. For example, you may have had your Type 2 diabetes treated with tablets and then moved on to insulin in which case, we send both Type 2 & You and the Newsletter, which has more appropriate information for people using insulin.



A new study carried out across European Economic Area and the UK by green group Transport & Environment (T&E) suggests that thousands of cases of high blood pressure, diabetes and dementia across Europe could be linked to the tiny particles emitted by planes. According to the study, 52 million people, more than 10% of Europe's total population, live within a 20km radius from the 32 busiest airports in Europe and are particularly exposed to ultrafine particles (UFPs) from aviation.

In Paris, 8 million people are affected by its two main airports and the exposure to ultrafine particles can be linked to the development of serious and long-term health conditions, including respiratory problems, cardiovascular effects and pregnancy issues.

- 280,000 cases of high blood pressure,
- 330,000 cases of diabetes and
- 18,000 cases of dementia in Europe, according to the new research.

Ultrafine particles, which are less than 100 nanometres in diameter (1,000 times smaller than a human hair) are particularly concerning because they penetrate deeply into the human body and have been found in the blood, brain and placenta. To date, there is no regulation on safe levels of UFPs in the air, even though the World Health organisation warned it was a pollutant of emerging concern over 15 years ago.

UFPs from planes are emitted at high altitude but also at take-off and landing meaning residents living near airports are particularly affected. People living in a 5km radius from an airport breathe in air that contains, on average, anything from 3,000 to 10,000 ultrafine particles per cm3 emitted by aircraft. In many cities, a correlation exists between peopleliving near an airport and lower incomes. This shows once again that the most vulnerable in society are most affected by air pollution.

The study finds that using 'better quality' jet fuel can reduce UFPs by up to 70%. The amount of UFPs emitted from planes depends largely on the composition of the fuel. The cleaner the aviation fuel, the less pollution it generates when burnt. Cleaning this fuel is done happens by hydrotreatment and has been used for decades to remove sulphur from fuels for cars and ships and could cost less than five cents per litre. However, jet fuel standards for planes have never been improved, even though it can significantly reduce air pollution around airports. Other measures to reduce UFPs and improve air quality include reducing air traffic and aviation's exponential growth, as well as using cleaner technologies like sustainable aviation fuels (SAFs) and zero-emission aircraft that release much fewer pollutants. Reducing UFP emissions through better quality jet fuel would not only be beneficial for the population living near airports, but also for the planet. (Press Release, 25 June 2024)

LOTTERY JACKPOT!

As a thank you to our members and Lottery players and as a celebration that 2025 is 30 years since IDDT formed, we are having JACKPOT Lottery draw.

THE PRIZES WILL BE:

First prize: £1,000 • Second Prize: £750 • Third prize: £500 • Fourth prize: £250

The Jackpot Draw will take place in early January 2024. If you are already a Lottery player, then you will automatically be entered into the JACKPOT. However, if you would like to join the Lottery to have a chance of winning the JACKPOT, you still have time to set it up, just contact IDDT.

Contact IDDT for a Lottery form by calling IDDT on 01604 622837, email karl@iddtinternational.org or write to IDDT, PO Box 294, Northampton NN1 4X5



IDDT Lottery Results WINNERS OF THE APRIL 2024 DRAW ARE:

1st prize of £479.52 goes to Anon from Chepstow 2nd prize of £359.64 goes to Trevor from Halifax 3rd prize of £239.76 goes to Raymond from Darlington 4th prize of £119.88 goes to Scott from Cardenden

WINNERS OF THE MAY 2024 DRAW ARE:

1st prize of £476.16 goes to Robert from Glasgow
2nd prize of £357.12 goes to Rosalyn from Middlesbrough
3rd prize of £238.08goes to Anon from Swansea
4th prize of £119.04 goes to Julie from Torfean

Note: The winners of the draws for June, July, August and September 2024 will be announced in our December 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 on01604 622837 or email karl@iddtinternational.org

If we can be of help in any way, please contact:

InDependent Diabetes Trust (IDDT), PO Box 294, Northampton NN1 4XS Tel: 01604 622837 email: enquiries@iddtinternational.org

Or visit our website: www.iddt.org

InDependent Diabetes Trust



SNIPPETS

High intensity theatre lists

In the run up to the general Election, it was announced that Labour plans to tackle the NHS waiting lists by establishing weekend and evening clinics through "Crack Teams" who will be deployed nationwide to implement this strategy with the aim to reduce the backlog. They aim to provide 40,000 more appointments a week by replicating successful high-intensity theatre lists seen at Guy's and St Thomas's NHS Foundation Trust. This is being written before we know the outcome of the General Election is known and whether it comes to pass remains to be seen but the reason for including it is to ask why only Guy's and St Thomas's Hospitals, both London based, are already using this system and not anywhere else in the country? Is it the north south divide again?

The health benefits of owning a dog

As we read frequently regular physical activity prevents the development of many conditions but is an effective treatment for various chronic conditions, including depression, hypertension, cognitive decline, osteoarthritis, and Type 2 diabetes. Physical inactivity is reported as the second most important cardiovascular risk factor, right after incorrect diet. This is why guidelines recommend at least 150 minutes of physical activity a week although it is estimated that only 20% of people achieve.

People who have a dog have a fourfold greater chance of meeting the physical activity guidelines than those who do not have a dog. In fact, dog owners are forced to walk to take care of their dogs, and this factor is strongly associated with a lower risk for CVD and death.

- Having a dog positively influences blood pressure (BP).
- Psychosocial benefits associated with owning a dog are stress reduction and improved mood and emotional state, reduction depression. It can also have positive effects on the well-being of certain subgroups, particularly single people, women, children and older adults experiencing the loss of a spouse or a divorce.

Longitudinal studies conducted on adults before and after owning a dog suggested that dog owners become more active and this finding has recently been confirmed in children. For all the benefits and pleasures that owning a dog can give, we have to remember that having a dog also means a commitment of 10 to 15 years!

CGM screening may lead to earlier gestational diabetes diagnosis

Research has shown that continuous glucose monitoring (CGM) identified signs of gestational diabetes earlier than oral glucose tolerance tests. CGM could potentially play a pivotal role in providing timely identification of distinct glycaemic patterns indicative of early dysglycaemia, blood sugars that are too high ot too low. (Diabetes Care, May 2024).

Message – don't believe what you read or see on the web!

Danielle Carr-Gomm, 71, died in October 2016 while taking part in a workshop in Wiltshire which promoted Paida Lajin therapy, which sees patients being slapped or slapping themselves repeatedly. Ms Carr-Gomm, from Lewes in East Sussex, had Type 1 diabetes and sought alternatives to her insulin because of her fear of needles.

30 people attending the workshop at Cleeve House in Seend were "keen disciples" of the leader of the workshop, Mr Hong Xiao from California.

In July 2024, Mr Hong Xiao was in court where he denied manslaughter by gross negligence. The court was told that Ms Carr-Gomm had been seen "vomiting, tired and weak" and had been "howling in pain". She had announced on the first day of the workshop that she had stopped taking her insulin. Mr Xiao did nothing to alert others to the risk but simply congratulated her and allowed a person with Type 1 diabetes to commence fasting without insulin.

There are three messages here:

- Don't fall for everything you read or see on social media.
- Learn the basics about Type 1 diabetes you can't stop taking insulin or you go into DKA and risk death.
- If you have needle phobia, seek medical help and to healthcare professionals, check for people who may have needle phobia, it hasn't disappeared because needles are now shorter and thinner – clearly people can be desperate!

A charity supporting and listening to people who live with diabetes

© IDDTSeptember 2024