



# PAEDIATRIC DIABETES NEWS

February 2019



Dear Patients, Parents, Friends & Family,

Welcome to the 7th edition of the Paediatric Diabetes News. Hope you all had a good Christmas and are now all looking forward to the Spring. Examinations for some will be on the horizon and we all wish you lots of good luck and encourage you all to work hard.

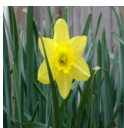
2019 is going to be a busy year for the team and we have included a run down of what is happening.

This edition includes an article from one of our active young patients who attends Westmorland General Clinic; and we are extremely privileged to have an article from one of our former patients who is now a Rapid Responder for the Paramedic Service.

We try to include articles which we think will be of interest and we are always on the lookout for new things to tell you about. If anybody has anything they want to share, please let me know for the next newsletter. I am always on the lookout for patients, parents or perhaps even a sibling or grandparent to contribute to the newsletter. Without your contributions, the Newsletter would be very boring.

If you would be happy to write an article for our Summer issue, please let me know on 01524 583827 or you can Email me:-

**glenys.mckay@mbht.nhs.uk**



Hi All

My name is Suzanne Jackson and I am one of the four Paediatric Diabetes Specialist Nurses in the diabetes team. I work primarily out of Westmorland General Hospital, covering the South Lakes and Kendal area. I can often be found attending clinics and on the Childrens ward at Royal Lancaster Infirmary. I have also been known to venture to Furness General Hospital, when the need arises, so I have met many of you already.



Prior to joining the diabetes team I worked on the Children's Ward, as a Staff Nurse, at the Royal Lancaster Infirmary for 11 years. During that time I was link nurse for diabetes, which meant I undertook extra training in diabetes so I could support other staff to provide the best possible care to young people with diabetes.

When an opportunity to work in the diabetes team for three months arose, I felt it would be a good opportunity to expand my knowledge. Nearly 5 years later, I am still here! During this time I have completed further training in diabetes at Birmingham University but the majority of what I have learnt has been from my colleagues and the families I work with.

Outside of work, I spend most of my time at soft play or the park, as I have a toddler who seems to be allergic to staying in the house. If I manage to get up before the toddler then I do enjoy running with friends and taking part in the park run in Williamsons Park in Lancaster. I also enjoy cooking, but I think is because I enjoy eating!

I really enjoy the close relationships we develop with children, young people and their families and hope that I help to make managing your diabetes a bit easier, particularly in the difficult periods.

## DIETITIAN COVER



We would like to introduce you to Marion Martin, who joined our team as a Dietitian in January.

Marion will be working part-time, covering all patients at Furness General Hospital and Westmorland General Hospital. You can contact Marion on 01229 87870 Ext 52012.

Paul Dunstan has now increased his hours for the Paediatric Diabetes Team and will now be able to attend all RLI clinics, including transition clinics.



Both Paul and Marion are now able to review patients in between clinics as part of our team approach to supporting patients and their carers. If you feel you would like a separate appointment please speak to your nurse, ring Paul or Marion direct, or contact Glenys on the office number to arrange a convenient appointment.

# UPCOMING EVENTS



# 2019



Happy New Year to you all

## 2019

looks set to be a busy year for the team with a few big projects planned. They are all about improving the service we provide and so we need your help **PLEASE**.

### Peer Review

TEAM

The most significant event of the year is likely to be our Peer Review visit. This is a visit by specially trained members of diabetes teams from other parts of the country, to look at how we are doing things in Lancaster, Barrow and Kendal. They want to hear about what we are doing well, so that they can share this with other units, and also to hear about where we can improve. This is a great opportunity to show what we are proud of, but also highlight the things that we would like to change.

After the visit they will produce a report with recommendations, which the hospital managers will receive. The report will be taken very seriously, therefore, if there are things which need to change, getting them into this report gives us the best chance of achieving that change.

The reviewing team will be coming to Lancaster on **Tuesday 30th April 2019** and will meet all the team on that day.

Speak  
Up!

They would really like to speak to families too. It is what **YOU** think that really matters. If you would be willing to come and speak with them, please let us know, either by ringing 01524 583827 or contacting your nurse. We would love to have families from Kendal and Barrow clinics too if you could spare us the time! Travel and car parking expenses will be available, the 30 minute slot for families is 12.00 pm and we would love you to join us for lunch at 12.30 pm.



### PREM survey

The National Paediatric Diabetes Audit is running the **Patient Reported Experience Measures (PREM)** this year. This is a national survey run in all units throughout the country, looking after children and young people with diabetes. It was last done in 2015 and gave us some really useful data to help us improve our service and see how we compare to other units.

It is going to be run again this year and we would really like everybody to complete it. I know it sometimes feels as if you have too many forms to fill in, but this is a really important one. Your data will be anonymous so please just tell us what you think!

The form can only be completed online but we do have hand held computers available in clinic for you to use.

If you want to complete this at home please go to <http://howarewedoin2018-19.co.uk> and you could

**WIN a £50 Amazon eGift voucher**



### Transition project

We are conducting a Transition Survey later on in the year as we want thoughts on how we can improve this service for our patients in the watch this space as we will definitely require your help.



**OUT** your  
16—19 age group. Please



## MANAGING DIABETES DURING EXAMS



Stress and anxiety can have a big impact on your blood glucose levels. Most people find that when they are feeling worried, their blood glucose levels rise.

Having high blood sugar levels can affect your concentration and you may find it hard to do school work. Research has shown that working with high blood glucose levels (above 15mmols/L) can make people work slower compared to when they have blood glucose levels within the normal range (between 4-7mmols/L).

Exams can be very stressful so here are some tips for how you and school can manage this. As diabetes is classed as a disability, and covered by the Disability Act, schools need to put in 'reasonable measures' so that you are not disadvantaged by your diabetes.

- ♦ The person invigilating the exam should be told you have diabetes
- ♦ You are allowed to have your diabetes kit (including hypo treatment and water) with you during exams. We suggest you put everything in a clear pencil case to have on your desk.
- ♦ You are allowed to have supervised toilet breaks, as often as you need.
- ♦ You are allowed to 'stop the clock' if you need to check your blood glucose levels, treat a hypo or have a toilet break.
- ♦ Most schools allow young people to choose whether they will sit their exams in the main hall or in a smaller room. Your nurse can write a letter of support for this if your school needs one.
- ♦ We suggest you check your blood glucose levels at the start of each examination and half way through the exam if possible, as you may not notice if you are hypo when you are concentrating on the exam.

Diabetes UK have developed a really good information pack about exams

<https://www.diabetes.org.uk/guide-to-diabetes/your-child-and-diabetes/schools/school-trip-and-exam-resources->

If you have any problems talking to school about the measures they need to put in place for your exams, please contact a member of the diabetes team for support.



## Will BREXIT affect our Diabetes Supplies?

We have had many enquiries from families, particularly those who are using pump supplies, regarding the continuation of stock following Brexit. Unfortunately, no one has any definite answers, as no-one knows what is going to happen.

We have contacted the Insulin and Pump Supply Companies that we use and they have all reassured us that there will not be a disruption in the supply of diabetes pumps and consumables. They are all stock piling consumables so they have at least a 6 week supply, just in case there is a problem in the beginning. We would advise that you make your order as soon as you open your last box of supplies and make sure you re-order any prescriptions from the GP in good time, just to avoid any delays in supplies.

If you are experiencing any problems ordering pump consumables please let Glenys know on 01524 583827 or contact your nurse. We NEED to know if you are struggling or having any problems ordering your consumables so we can work on your behalf to make sure ordering continues smoothly.



## FREE RECYCLE BOXES FOR ALL OMNIPOD USERS

We have recently been informed by Insulet that FREE and SIMPLE boxes to recycle used pods are available. Please ask for your box when making your next order. These also come with SELF ADDRESSED PRE PAID POSTAGE stickers, therefore no courier service slot is required.



# Airport Travel

Security is getting tighter and travel through an airport can be difficult for children and young people with Type 1 diabetes and their families.

We try as a team to make things as easy as possible. Please remember to order your travel letter from Glenys at the office, 01524 583827, allowing at least 5 working days before you travel.

Medtronic have provided us with an additional security letter explaining their products and the reasons why it can not be scanned.

We have a special travel leaflet available to all our patients that has been produced by our team.



**Manchester Airport** offers a lanyard service for hidden disabilities. You can arrange this prior to arrival or just simply report to the **Assistance Point** as you arrive, before checking in. You will need to report young persons name with Type 1, an Email address and a flight number. You will then be provided with a lanyard and you will be able to use the assistance lane for checking in your luggage and going through security. When in the departure lounge, you would need to let the gate staff know whether you want to get on the plane first or last. This lanyard is highly recommended by families who have already used this service.

For further details you can ring **0161 4892074** or see the website [Hidden.disabilities at.man@ocs.co.uk](mailto:Hidden.disabilities.at.man@ocs.co.uk)

**Liverpool Airport** offers a hidden disability service in the form of a Butterfly Flyer voucher as shown.

Please contact :-

[customerservices@liverpoolairport.com](mailto:customerservices@liverpoolairport.com)

with your flight number and date of departure. This is not a fast track ticket through security but is designed to assist you through the process as smoothly as possible.

## Butterfly Flyer

Please follow the Accessible route at Security. The route is identified by the 'wheelchair' symbol.

Name: \_\_\_\_\_  
Date: \_\_\_\_\_  
Flight Number: \_\_\_\_\_  
Travelling to: \_\_\_\_\_



## APPOINTMENTS

### Out-patients

We currently have 187 children and young people with diabetes across Lancaster, Barrow and Kendal and offer everybody at least 4 appointments per year (every 3 months). We often struggle to fit people in for appointments and really need your **HELP**. If you are unable to attend for an appointment please give at least 24 hours notice when cancelling your appointment, so we can try to fill the space.

### Retinal Screening

As a team, we are well above the average, for patients over 12 years attending for their retinal eye screening appointments, so **Well Done To You All!**

**PLEASE NOTE:** Eye screening appointments for **Cumbria** patients are now being offered early evening clinic slots, if required, at Atkinson Health Centre in Barrow and at Westmorland General Hospital. Saturday appointments are also available at Westmorland General Hospital.

**Retinal screening is very important, so please ring to arrange your annual review if you have not already done so.**





## Over to you .....

It is very important that we hear from you, **THE PERSON/FAMILY** living with diabetes. This edition includes an article from an former Furness General Hospital patient, Jay, who is a Paramedic. We also hear from Rachel about her scouting weekend, she attends Westmorland General Hospital.

*Please let me or your nurse know if you would like to contribute to the next newsletter.*

Hi everyone

My name is Jay Watson I was diagnosed with type 1 diabetes in my last year of secondary school about 11 years ago. I attended the clinic at Furness General Hospital and at the time this diagnosis was completely catastrophic for me. I must admit I spent some time in complete denial of my situation, I felt that my condition would hold me back with regards my career aspirations and in life generally; I think many young people feel this way when they are diagnosed; however, in many ways nothing could be further from the truth.



Following studying at university in 2013, I became employed by the North West Ambulance Service as a Paramedic and I am now, following a promotion, a Senior Paramedic Team Leader (SPTL). As a SPTL I am responsible for the management of a team of eleven clinicians, and I attend some of the highest priority medical/trauma emergencies throughout Cumbria; I am often acting solo on a rapid response car. I have been allowed to drive all emergency vehicles within the trust, including driving on lights and sirens; I owe this to: diligent control of my blood sugars, attending my consultant and eye screening appointments regularly and keeping fit and active.



Type 1 diabetes inevitably causes you to make big changes and some compromises following diagnosis; it does not however need to limit you and your aspirations. If you put the work in to manage your condition, plan ahead, keep fit and are responsive to your body's needs; then being Diabetic need not be a huge obstacle to overcome.



The best piece of advice I can give with regard coming to terms with your condition is try to change your perspective, instead of "FIGHTING" diabetes, "WORK" with your condition to be as well managed as you possibly can, and things get a lot easier.

Hi,  
My name is Rachel Phillips and I was diagnosed with Type 1 when I was 10 and in year 6 at primary school. I am now 12 and in year 8 at secondary school.

Last summer, I went on the Medtronic 640G pump and although it took a bit of getting used to, I really like it now and it has definitely helped me enjoy some scouting activities.

Since going on the pump, I have been on summer and winter camp with scouts and canoed down the river Kent from Burneside to Natland.



Winter Camp was at the beginning of January, we spent 2 nights sleeping in a tent in a forest in Northumberland. We did all sorts of activities, including a really long zip wire which went through the woods, and an anti-gravity ride. One of the highlights was the cave bus which was an old coach which had been converted into a series of tunnels, like a cave. We had lots of fun with a Bag Jump, we jumped from a platform tower on top of a van onto a huge inflated pillow, there was a free funfair (just like the one in Kendal) and an angry birds game where you catapulted balls to knock them down. I had a fantastic time. Our scout leader cooked all the meals and they were really good.

I wore the sensor that links to my pump and I am happy to say I didn't go low all weekend. I took some fold-up scales to weigh the pasta. All the other carby foods had the amount of carbs on the wrapping. Don't tell my mum but I did have buns, cakes, cookies and hot chocolate!



Freestyle Libre is now available in our area on the NHS, but only for people who meet strict criteria. This is the device that means you can scan a sensor in your arm to check your glucose level (the one Theresa May has) but it doesn't replace finger prick checks.

Only the diabetes team can prescribe it, not your GP. Anyone can try it for 2 weeks but to have free sensors for longer you must meet one of the following criteria:

- expect that using Libre will reduce the number of tests you need to do by at least 8 per day
- be unable to perform the recommended number of blood checks per day by other means
- have a HbA1c greater than 69mmol/L on pen injections but you or the diabetes team do not think an insulin pump is the best option.

Before starting on Libre you also have to complete an online training package, a questionnaire and attend a group training session.

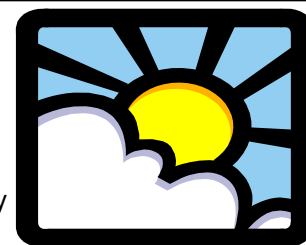
After 1 month, you must attend an extra appointment to check that you are using the device to scan at least every 8 hours. After 6 months, you must demonstrate that using Libre has made a difference. This is usually by showing an improvement in HbA1c or in quality of life. If you are not using it appropriately or it does not make a difference then funding will be stopped.

If you would like more information, then please contact your diabetes nurse or discuss it at your next clinic. If you do not meet the criteria above but would like to try it and consider funding it yourself then we would be happy to support you with this.

## YOUTH DIABETES WEEKEND

FRIDAY 21 JUNE 2019 - SUNDAY 23 JUNE 2019

NEWLANDS ADVENTURE CENTRE, KESWICK



Every year all our patients in **Years 9—12** are invited to join the Youth Diabetes Activity weekend.

Last year, 6 patients from our area took part and at least 3 of them are definitely keen to attend again this year. The cost of this weekend is £25 per person and includes all food, accommodation and activities.

### ACTIVITIES INCLUDE

High Ropes Course



Mountain Biking



Kayaking



Ghyll Scramble



Archery



If you want to attend this fun weekend, then discuss things further with your family first. If you want more details of this event, together with an application form, please contact Glenys McKay, 01524 583827.

The application form together with the £25 must be sent back to the Event Organiser as soon as possible. The Diabetes details section must be completed by your Diabetes Specialist Nurse. If you cannot see your nurse before you send off the form, the organisers will request the information on receipt of your application.

## HURRY AS PLACES ARE LIMITED

This is a fun weekend and a good way to meet other young people living with diabetes.

## THE RESEARCH CYCLE

### Diabetes Clinical Studies Group 7 (Diabetes CSG-7) Paediatrics



The Research Alliance was formed with James Lind Alliance, JDRF and Diabetes UK to Identify and Prioritise Topics to improve the lives of individuals living with Diabetes. In 2015, the Research Strategy concentrated on 3 areas: Care, Cure and Prevent. Regular face to face meetings and teleconferences are held throughout the year in London, facilitated by DiabetesUK. Young People have been recruited as well as Multi-disciplinary Health Care Professionals and Lay People.

**NOW** it's time to integrate these Research ideas to the Networks and to the patients in our teams. Look out for questionnaires in the Waiting Rooms and Social Media for your participation.

There are five priority areas:

Eating Disorders, Mental Health/ Wellbeing	C-peptide and Beta Cell Function Preservation
Technology and Outcome measures	Transitional Care
Prevention of complications with a focus on hormones eg: Puberty	

A former patient successfully completed a Psychology Degree. Her dissertation on looking at the Association between following a low carbohydrate diet with satisfactory blood glucose control and better well-being in adults with Type 1 Diabetes, is being considered for further development at the DiabetesCSG-7.

Do you have ideas for CSG7 to discuss and possibly for financial investment within the Priority areas?

Would you like to participate in current studies locally?



If you are newly diagnosed there is **ADDRESS 2**, which is a Register for further studies to approach in the future, if an individual meets the criteria.

**TRIAL NET** The Natural History Study is available for siblings and family members under the age of 40 years of individuals with Type 1 Diabetes. If a family member has markers indicating possible risk for Type 1 Diabetes there are further studies offered in beta-cell preservation, for example. The Study is based in Bristol but has local centres for recruitment at Blackburn and Alder Hey Children's Hospital.

For further information, please contact **Angela Waktare Tel 07773170471** or **Kathryn Allyson** in the Lancaster Research and Development Department Tel: **01524 512189**

## Local Support Groups

Our local support groups are always happy to welcome new families and you can contact them as shown below:

**Barrow Support Group** - The Barrow Group are always open to suggestions regarding future events.

**Please contact: Sarah Langhorn:- 07715266543**

Facebook: **Furness Paediatric Diabetes Family Support Group**



### Kendal Support Group

The Christmas party this year was held at Pizza Express in early December. This was well attended by approximately 15 families. All the children enjoyed free pizzas and drinks and everyone had a great time. Please watch out for details of the next event on the Facebook page

Everyone is always welcome.;

**Contact Sarah Metcalfe:- 07738377787**

**Lancaster Support Group** - This is a **NEW** edition since the last Newsletter. This group is growing in numbers and the main support is via the

Facebook page: **Type1diabetessupportgroupLancasterandsurrounding areas**

This group is meeting on an ad hoc basis and has recently meet for coffee with the children at Jump Rush and Salt Ayre.

**Contact is Demi Till:- 07392910862**

We hope you have enjoyed these few snippets of news and events and we will be producing another newsletter in the Summer time. We would really welcome your feedback, suggestions for further articles and please send any pictures or news to

**[Glenys.Mckay@mbht.nhs.uk](mailto:Glenys.Mckay@mbht.nhs.uk)**

