

# R.H.S.C. DIABETES NEWSLETTER

For those attending Paediatric and Adolescent Clinics in Lothian

August 2016

## New Staff Introductions

We are pleased to announce the arrival of two additional staff members to our team since our last Newsletter:

- Dr. Daniela Elleri: Daniela has joined the diabetes and endocrinology team as a new consultant. She did her training in Cambridge and has a special interest in diabetes and technology.
- Ms. Louise Reynolds: Louise has much experience in diabetes management, having worked on both Ward 1 and PICU (paediatric intensive care unit) here at RHSC. She has joined us to cover the diabetes nurse specialist post vacated by Elaine Hogg during her maternity leave period.

## Blood glucose targets and the new NICE guidance for children with diabetes

NICE (National Institute of Clinical Excellence) have recently published an updated guideline on the management of children with diabetes. We discussed the new targets set in the guideline at a National Diabetes Meeting in Scotland and have agreed we will bring these changes into our local diabetes management plans.

The key changes are:

1. Optimal HbA1c is 48mmol/mol without significant hypoglycaemia. Our clinic target HbA1c is unchanged at less than 58mmol/mol, and the aim is that the majority of patients have an HbA1c of less than 58mmol/mol.
2. BG targets are 4-7 mmol/l pre meal and 4-9 mmol/l at 2 hour post meal check.
3. Corrections will now be calculated to correct back to 6mmol/l.
4. Inject pre meal 5-20 mins [adjust according to 2 hour post meal BG].
5. BG average target for 7 or 14 days is less than 8mmol/l.

We will discuss the new targets at your clinic visit.

- You will be sent a copy of the clinic letter, and this will state the new targets.
- You will be given a copy of the revised correction factor tables at your clinic visit, which have been adjusted to the new target.

- If you are/your child is on a pump, we will advise you to reset the target to 5-6mmol/l.
- If you are/your child is using a Smart meter, the settings will need to be adjusted to 5-7mmol/l.

## Diabetes website:

[www.edinburghdiabetes.com](http://www.edinburghdiabetes.com)

We now have a paediatric and adolescent section on the Edinburgh Centre for Endocrinology & Diabetes (eced) website. Please use the link above and at the top of the home page, click on RHSC Diabetes.

As you will see the page is under development and further updates will be added shortly.

Meantime you can access the

- RHSC Diabetes Handbook: use each chapter icon as required
- Newsletters: 2015 & 2016
- Worksheets for insulin pump users

We do hope that you visit the RHSC Diabetes web page. We aim to update information on a regular basis to keep you informed of any developments, and to support you in your/your child's diabetes management.

## Diabetes Clinic: Improving information sharing at clinic

At the adolescent and adult clinics in Lothian, people attending the clinic are asked to complete a diabetes clinic form at each review. This has improved the clinic process and allows the person to think about specific issues they wish to talk about before they see the doctor. We wish to start using a similar form at the paediatric clinic. This form will allow you/your child to write down some of the key bits of information we require, before you come into the clinic room. There will then be more time in the consultation to discuss issues you have identified. The aim is to improve how we support you with your diabetes.

## Libre Meter

Some of you will have heard about the Libre meter. This is a special meter connected to a small sensor which automatically measures and continuously stores glucose readings day and

night. You can get more information about it at the website: <http://www.freestylelibre.co.uk> Currently the Libre meter is NOT available on prescription, but it is hoped that this will become the case. The cost of one sensor is £45 (each of them will last for 14 days), and the starter pack that includes the hand held meter + 2 sensors is around £140. If you decide to purchase it, please be aware that you should do all the usual blood glucose testing for the first 48 hours and then, if you are happy with the correlation of readings between both systems, you can reduce the finger prick testing. Also, please remember to check a finger prick test if the Libre meter suggests a hypo or the trend arrows show the BG is going up and down quickly.

## **JDRF Type 1 Catalyst Event at the House of Commons:**

### **A Parent's Report**

On Monday 25<sup>th</sup> April 2016, JDRF (Juvenile Diabetes Research Foundation) held a Type 1 Catalyst event at the House of Commons. I was thrilled to receive an invitation to this parliamentary reception along with two of my children who both live with type 1 diabetes. The idea of the event was to celebrate progress in type 1 research, involving 100 JDRF supporters, researchers, healthcare professionals, politicians and research funders.

On the day of the reception we arrived at the House of Commons proudly wearing our JDRF t-shirts. After passing through security we were directed to a meeting point where we mingled with other JDRF supporters and heard some of their stories and experiences of living with type 1. We were then shown into a beautiful reception area with an amazing view of the Thames and the London Eye. We were welcomed by the JDRF staff and had more time to meet other guests, including Tommy Sheppard, MP for Edinburgh East, and the Marketing Director of Abbott, Ollie Mitchell. Mr. Mitchell was delighted to hear that my children were wearing the new Libre sensor. He asked the children how they were finding it and was pleased to hear that they both thought the sensor was 'awesome'!

We were lucky enough to be able to buy the starter kit for the Libre sensor in time for our London trip. The children were apprehensive before attaching the sensors onto their arms but once they were on we were all thrilled at how fantastic they were. My daughter scanned her arm 26 times on the first day of wearing the sensor 'just because she could'! We found that

having the ability to check the children's blood glucose at any time gave us a much better idea of how their blood glucose was trending. On our trip to London we did a lot of walking and it was very cold, but having the sensor meant that we could check bloods more often and were able to avoid hypos by catching blood readings that were going low. We also worked out that between the two children, since they have been diagnosed with type 1, they have pricked their fingers over 35,000 times, so to give their fingers a rest was just brilliant!

We listened to some inspiring speeches and heard about the ongoing research into finding new ways to manage type 1 diabetes more effectively. After photo opportunities with Karen Addington, JDRF's Chief Executive, and Jamie Reed, the MP who organized the event (and also lives with type 1), our visit to the House of Commons was at an end. That evening, back at our hotel, we chatted about our day and agreed that we felt such gratitude to all the amazing people out there who help families like ours who live with type 1 every day of the year. We also felt hope that if research continues to progress, one day our children may be part of the lucky generation who can say ....I used to have type 1 diabetes.

## **High HbA1c policy: reminder about the importance of weekly contact with the diabetes team**

This is a supportive and structured approach to help families and young people work with the diabetes team to improve their diabetes care, when their HbA1c is significantly above target. Please also see the reference to the NICE optimal HbA1c target: 48mmol/l without significant hypoglycaemia.

We detailed an update to our high HbA1c policy in our February 2015 Newsletter, and as yet we are to update this for the on-line version of our Handbook: see Clinic chapter page 11.

Here is a reminder of our current HbA1c levels for the high HbA1c policy:

- **"80 – too high"** for all young people who have been diagnosed with type 1 diabetes for a year or more.
- **"70 too high"** for those who have been diagnosed for less than 1 year. This will be discussed fully with you at your diabetes clinic and please remember that the whole team are here to support you!

**Maintaining weekly contact with the diabetes nurse specialists is essential.**

## **Psychology Support Update:**

Hello, we are Sarah Ross and Andy Gentil and we are Clinical Psychologists working with the diabetes teams for children and young people 0-18 years within NHS Lothian. We wanted to say "Hello" to everyone and explain what we can offer nowadays.

Having diabetes (whether it is you personally or your child) can be hard work and keeping up diabetes control through the years can be a challenge. Everyone, with diabetes or not, can come across mental health issues, family problems and struggle with life stresses in school, work and home sometimes. Therefore, as Clinical Psychologists with backgrounds in both mental health and paediatric psychology, we can sometimes help with aspects of life with diabetes that other clinic appointments cannot quite reach. While we focus our input on problems around diabetes and its management, life is rarely as clear as that, so we can also discuss, advise or assess a range of wider mental health issues. Therefore, if you or someone in your family is distressed, has concerns about mood, problems with behaviour, family conflicts around diabetes, beginning to struggle to manage in education or wider life, or have a specific difficulty managing diabetes, then consider talking to us. If the problems are not diabetes focused, we might not be able to intervene directly, but we can still be helpful in directing you to people or services that can. We are now more accessible, as you can talk with us at your diabetes review clinics, we can be linked-in by any member of the diabetes team, we can offer appointments at Rillbank Terrace at RHSC, as well as seeing people with admitted to RHSC. Andy supports the adolescent clinics (14-18yrs at RIE, St. John's, Western General and Roodlands, and Sarah supports the paediatric clinic (0-14yrs at RHSC and outreach St. John's).

As with most psychology input, coming along is voluntary. Confidentiality and information sharing can be decided upon on individually and before discussing things, in case you are worried about that.

We look forward to meeting you, and we will do our best to help.

## **Books to help you support your child:**

[www.edinburgh.gov.uk/healthyreading](http://www.edinburgh.gov.uk/healthyreading)

Supporting any child as they grow and develop can be challenging at times, not least when you are also living with type 1 diabetes. Experts at NHS Lothian's Mental Health Service have come up with a list of books to help you address

certain specific issues or anxieties you/your child may have. Please click on the following heading on the above website:

### **Healthy reading for children, young people and families**

This is a list of recommended books and resources for children, young people and families. These are the titles Lothian's Child and Adolescent Mental Health Service recommend and offer self-help support to children, young people and parents. They cover a wide range of mental health difficulties, including anxiety, depression, bullying and eating disorders. It also includes resources for parents to help tackle problems, which can arise in childhood, such as challenging behaviour and sleep problems. Many of the books contain self-help exercises based on a cognitive-behaviour therapy approach.

Please do feel free to discuss any questions you may have on accessing this website, and we would love to hear of particular books which you have found helpful.

This website comes highly recommended – please do give it a look!

### **Parenting courses to help you manage your child's/teenager's behaviour**

Please Google:

Incredible Years Groups Edinburgh

Triple P Groups Edinburgh

### **Making Connections**

Making Connections is a programme to support young people diagnosed with type 1 diabetes.

To improve the overall clinic experience for young people with type 1 diabetes and address issues with disengagement and poor glycaemic control in this group, Diabetes Scotland invited people aged 16-25 years old living with the condition to participate in developing a "Youth Engagement Toolkit". The aim was to develop and deliver innovative youth engagement training and supportive materials for healthcare professionals working in diabetes clinics in Scotland to encourage a more supportive and accommodating environment for youngsters at clinics. In January and February 2016 our team attended workshops run by Making Connections staff to introduce us to the Youth Engagement Toolkit. We found these sessions very informative, particularly the sessions co-chaired by young people with diabetes. They promoted discussion within the team and we will be taking forward some of the ideas presented at the Workshops to help improve our young people's

experiences at adolescent diabetes clinics in Lothian.

### **Use of Pump Download Assessment Worksheets**

We would like to remind all insulin pump users of the importance of regular review of their/their child's insulin pump download. We recommend that you review it every one to two weeks, using the worksheet.

We would appreciate your completion of the worksheets prior to clinic. Please send us a copy of your completed sheet at the same time as sending the download in advance of clinic. The Veo worksheet and the 640G worksheet are now available on the website, as mentioned above, for you to download:

[www.edinburghdiabetes.com](http://www.edinburghdiabetes.com)

Please note that an explanation sheet is available at the end of the worksheet to help in the completion and interpretation of the download.

Do not hesitate to ask us if you have any questions about completing the worksheet.

### **Donations to RHSC Diabetes Fund**

We are very grateful for any donations to the RHSC Diabetes Fund, which we use to fund many additional activities to support diabetes care for our families with diabetes. The fund is used to support children to attend educational camps, provide materials for newly diagnosed children, and also help fund research activities and educational opportunities for team members.

We would like to mention particular thanks to the following contributors:

Erin's grandfather (Mr. John Collins) and his fellow team of cyclists from the Masonic Lodge. Primecare Health Limited and their sponsored cycle – thank you Natalie.

James and his family for their collection.

Bonnyrigg Primary School for their dress down day – thank you Scott.

### **Cinema Card**

If you receive DLA you are eligible for a Cinema Exhibitors Association Card. This entitles an adult to accompany a young person into the cinema free; paying only for the young person with diabetes. The card costs £6 per year. You can apply online at [www.ceacard.co.uk](http://www.ceacard.co.uk); pick up an application form from your local cinema, or call 02392248545 and request an application form is sent out to you.