

# BITESIZE

Exeter Children and Young People's Diabetes Service

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December 2013

## Dr Chris says...

With the clocks going back and with the weather becoming colder. Autumn has arrived and the number of daylight hours has reduced. This can have a negative impact on diabetes control. Within this wonderful county, when the sun shines, there are many opportunities to pursue outdoor activities that promote healthy living and exercise. As it gets darker, we all become more sedentary and our use of "media time" increases. It is important that we think about exercise in the

context of diabetes control. It is well known that exercise makes one feel better and can improve one's self-esteem. The evidence for its effect on glycaemic control is a lot more difficult to tease out but I believe it is an essential component to realising good blood glucose levels. With this in mind, I have been collaborating with the Research Physiologists at the Children's Health and Exercise Research Centre (CHERC) at Exeter University to see if we can obtain some

funding for a pilot study looking at moderate and high intensity exercise in adolescents and to see how this affects one's glycaemic control, cardiovascular risk factors and body composition. My hope is that we will be able to recruit next year and will give you more information about this if we are successful in securing funding.

The team here wish you all a Happy Christmas, stay fit and don't eat too many chocolates off the tree!

# Have your say...

You will have been asked to complete a form in clinic this Autumn asking for your feedback on the care you receive in Exeter. One form for your parents to complete and one form for you to complete.

This is called a Patient and Parent Reported Experience Measure (or PREM) and it enables the experience of children and young people with diabetes and carers to be captured, analysed and acted upon resulting in a greater understanding of how they perceive the service and, most importantly, help identify necessary service improvements.

The completed forms are not seen by the team and your feedback is written into a report by The National Paediatric Diabetes Audit (NPDA). The NPDA is commissioned by the Healthcare Quality Improvement Partnership (HQIP), and has been managed by the Royal College of Paediatrics and Child Health (RCPCH) since April 2011.

In 2012 we completed a similar survey of your views and 60 people returned their forms in clinic. Your responses told us

#### Where we did well

You felt you had enough time to talk in clinic to the doctors and nurses

You felt you had access to 24 hour support and advice & we responded quickly to you when you called

You felt our written information was good

You would recommend our service to other people

Where we need to concentrate our efforts

You felt you had to wait too long in clinic before seeing a member of the team.

Not many of you had had a chance to see a psychologist or dietitian

You felt the dietitian could work more with you and your family about your diet

You would like more information on new technologies and treatments for diabetes

#### Some of your comments

Always friendly, approachable and always clear up any concerns we have'

'there could be more clinics so that it isn't so busy all of the time + we would like to have more info about new products to manage diabetes'

We now have

30 minute appointments for all young people, so you have time to talk. Some families need a little longer which is why you may need you to wait a little before your appointment.

Sophie Bishop our clinical Psychologist in post.

Our dietitian Maria Leveridge has been in post since February and is planning to meet every young person at least once a year. She is very keen for all young people to know about carbohydrate counting and how it can help you eat a wider range of foods and treats and keep your blood glucose levels even and within range.

Any of the member of the team are happy to talk about new and emerging technologies.



#### Inside this issue:

Barry and Ellen Brad- burn are leaving Snackpack	2
Snackpack AGM	2
Snack pack Longleat Trip	2
Bitesize Recipe Chocolate Brownies	3
Diabetes Research News	3
Nasal Flu vaccine advice	3
Meet Sophie Bishop Clinical Psychologist	3
National Peer Review Programme	4
Families with Diabetes (FWD) South West	4

#### Christmas food Websites

 BBC Good Food (carb counted) www.bbcgoodfood.com/ search/recipes? query=christmas&=Search

- Diabetes UK (carb counted) www.diabetes.org.uk/Guideto-diabetes/Recipes/ Recipes\_Listing/?page=1
- Gluten free recipes www.glutafin.co.uk/recipes/ gluten-free-christmas-recipes/
- www.juvela.co.uk/recipes/ seasonal-recipes/

#### BITESIZE



After many years of organising and fundraising Barry and Ellen Bradburn are leaving Snackpack. "Sail with Santa" on 8th December is their last trip. Come along and say goodbye at the Snackpack AGM being held at the Swan's Nest, Exminster on Monday 27<sup>th</sup> January 2014 at 7pm.

Snackpack Longleat trip in half term



My son, Jackson and I, boarded the luxury coach at 10am and enjoyed the lovely drive through the back roads to Longleat. Upon arrival, we drove through the Safari Park and had a bird's eye view of the wild animals in a natural habitat setting. It was very exciting when a female lion encroached upon the coach, we all giggled in excitement!

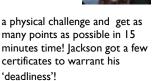
Afterwards, we were left to go and enjoy the park and to be honest with you, I had no idea

It was our first ever trip to Longleat and we had the most amazing day. We loaded up with lots of food and drinks and had our picnic on the coach whilst driving around the safari bit. I think the children were amazed at the deer going up to the cars and the lions following along next to them. They enjoyed then going into the park for the rides etc and the day ended with a spectacular firework display.

what to expect. But much to my surprise, there was a plethora of things to do and explore. My son was first drawn to the 'maze' which had a sign stating it would take 45 minutes to finish. I was not keen to embark. However, my son, the genius! finished it in FIVE minutes! We then found the "Deadly Challenge" which is where Jackson was totally in his element! Like the old TV show, "Crystal Maze", this entertainment area is set up to measure your ability to answer trivia questions on deadly animals, do

Thank you so much Ellen & Barrie for organising this we all had an amazing time. From Leah & family x





I am so thankful to Barrie and Ellen for providing us with this opportunity to go to Longleat. They continue to go out of their way to support our children and in allowing us to access special days out. It really was a day I will not soon forget!

Debbie Divell

After the safari, we walked round the rest of Longleat as families. There was lots of exciting things to do such as get up close to even more animals, go on rollercoaster simulators, have hot chocolate and cake in the coffee shop and look round the old house. There was also a Halloween exhibition going on which is why I ended up holding a tarantula!

We finished the day off with a spectacular fireworks display in time to music, with lots of really big fireworks. It was the perfect end to an amazing day out.

Chloe

below 10, which is amazing for her as she's been running rather high for quite some time.

The fireworks were the best we had seen in a very long time. So, well done Longleat for a fab day out, and well done Snackpack for organising a wonderful, very memorable trip.

Julia (Katies mum)

#### Snackpack Committee

We always need new members to join our committee. Can you spare some time to help? Contact Ellen on 01626 439569

www.snackpack.org.uk



" Katie, her sister and I had a brilliant day at Longleat with "SnackPack", the Exeter Children's diabetes Group. The coach up was good social time and the children chatting to each other, eating snacks along the way and testing their BS together! It was good to see some families that we had not had a chance to see in quite some time. Once we arrived, most of us went separate ways – it had been 9 or 10 years since we had been as a family. We did the Safari first which was brilliant as all the animals were out and about and lively.

We were quite hungry by the time we get back so hit the Pizza place straight away. Fantastic Pizza! Lots of activities keeping Katie amused all day and her blood sugars

## **Gluten Free Chocolate Brownies**

Adapted from http://www.diabetes-support.org.uk/forum and recommended by Kye's Nan Brenda

60g ground almonds, well sifted (take ages to sift!)  $\frac{1}{2}$  teaspoon baking powder

#### 15g cocoa powder 15g Sucralose 90g olive margarine (greater than 60g fat per 100g) 50g unsweetened dark cooking chocolate, chopped

Zest of 1 orange (optional)

1 teaspoon vanilla essence 3 medium eggs, beaten 50g chopped pecans (or 50g white chocolate chips if you prefer) Preheat oven to 180°C - (175° C fan oven)

Butter and line with baking paper a 7" × 7" (20cm-20cm) tin.

Stir together almonds, cocoa powder, baking powder, orange zest and sucralose; set aside.

In a microwave, melt the butter and the chocolate on a high heat, stirring frequently. Add the beaten eggs and vanilla; beat until well blended. Stir in the wet ingredients into the dry ingredients and mix well. Stir in the pecans (or chocolate chips if using). Pour into the prepared pan, spread evenly. Bake for about 15-20 minutes or until a toothpick inserted in the center comes out clean.

Check at 10 minutes. Do not over cook. Cool on wire rack, cut into 30 small squares.

CARBS—Pecan version -0.8g carbs per portion and chocolate chip version -1.7g carbs per portion

### Diabetes Research News

The NIHR Medicines for Children Research Network (MCRN) team members based at the Royal Devon and Exeter Hospital have been supporting recruitment to local children's studies since 2007.

Two of the diabetes studies that we are involved in are as follows: **TrialNet** is an international research study which is exploring ways to prevent and delay the onset of Type 1 diabetes. This study screens the relatives of people with Type 1 diabetes through a simple blood test. Further information about this study can be found on the following website.

http://www.diabetestrialnet.org/

**ADDRESS-2** is a study that will create a national resource of people aged 5-60 years with newly diagnosed Type 1 diabetes who can be contacted with details of future research studies. Further information about the study can be found on the following website.

http://www.address2.org/

For more information about what the local study team does or studies that we are involved in please contact the team on 01392 406437 or

rde-tr.MCRN@nhs.net

Jack & Lucy enjoying their blackcurrant lollies from the last issue!

## Nasal Flu vaccine

We have had a few calls recently from some parents for advice following their child's nasal flu vaccination.

Some young people have been experiencing mild flu like symptoms post vaccination. We would continue to encourage you to obtain the flu vaccination for your child, which is now available in a pain free nasal vaccine.

If your child does experience any side effects please feel free to phone us for advice.

It continues to be important to have access to blood ketone testing at home to blood ketone test during periods of illness.

#### Q & A

Got a query that you feel everyone will want the answer to? Send your questions to us by post, at clinic or at maria.leveridge@nhs.net and put BITESIZE in the subject line

## Sophie Bishop, Clinical Psychologist

Hello everyone! I'm a Clinical Psychologist and I've just joined the Paediatric Diabetes Team. A Clinical Psychologist is someone who is trained to understand how children and young people think, feel and behave. We know that young people living with diabetes and their families often feel worried, sad, angry or frightened about managing their condition. Talking to a Clinical Psychologist can help young people and their families to understand what is going on, and help them find new ways of coping.

If you are finding things difficult and would like to see me, you should tell one of the nurses, doctors or dietitian in the team. If it sounds like something I could help with, I will arrange a time to meet with you. This would be for us to get to know each other, talk about what is happening and think about what would be helpful to you as a family.

Sophie Bishop Clinical Psychologist



Page 3



#### **Exeter Children and Young People's Diabetes Service**

(Medical) Dr Chris Moudiotis, Dr Sue Hellewell; (PDSN) Julie Kitchen; Ruth Dalton, Heather Tabram, Emm Mortimore; (Dietitian) Maria Leveridge; (Clinical Psychologist) Dr Sophie Bishop (Admin) Emma Tootell

(Secretaries) Janet Churchward, Rennie Canhye

Royal Devon and Exeter **NHS** Foundation Trust



Royal Devon & Exeter Hospital (Wonford) Barrack Road, Exeter EX2 5DW

Phone: 01392 403727 Fax: 01392 402828/402715 E-mail: rde-tr.PaediatricDiabetes@nhs.net

Young people at the centre of diabetes care



#### National Paediatric Diabetes Peer Review

National Paediatric Diabetes Peer Review is a national quality assurance programme for NHS paediatric diabetes services.

The programme involves both self-assessment by paediatric diabetes service teams and external reviews of teams conducted by professional peers, against agreed quality measures.

The National Paediatric Diabetes Peer Review is part of the Clinical Network Assurance Programme.

The National Paediatric Diabetes Peer Review Programme aims to improve care for children with diabetes and their families by:

- ensuring services are as safe as possible;
- improving the quality and effectiveness of care;
- improving the patient and carer experience;
- undertaking independent, fair reviews of services;
- providing development and learning for all involved;
- encouraging the dissemination of good practice.

#### The outcomes of National Paediatric Diabetes Peer Review Programme are:

> confirmation of the quality of paediatric diabetes services; > speedy identification of major shortcomings in the quality of paediatric diabetes services where they occur so that rectification can take place; > published reports that provide accessible public information about the quality of paediatric diabetes services;

> timely information for local commissioning of paediatric diabetes services; validated information which is available to other stakeholders

We will be peer reviewed in March 2014 by a group of health professionals from other Trusts. They will look at the service we currently provide, see what we do well and help us identify any gaps and suggest improvements. Your feedback with PREM (see page 1) and your day to day feedback on our service continues to help us improve our service for you and your families.

## **Families with Diabetes**

The Families with Diabetes National Network (FWDNN)

The Families with Diabetes National Network has been established for almost a year & there are 10 networks across the country

#### Our priority issues are:

I. Improving the Management of Type I in schools

2. Reducing the Number of Children with Diabetic Ketoacidosis (DKA) on diagnosis

3. Structured education

4. Communication and patient engagement

The South West has been considering ways of reducing DKA at Diagnosis. Clinicians & Health Care Professionals are keen to use their contacts with schools, health visitors, GPs & Emergency Departments to raise awareness of the symptoms of Type I Diabetes & the essential need to do an immediate blood glucose test & same day referral to a Paediatric Diabetes Unit.

In other areas, East of England is about to launch their schools protocol on the 26th November & are organising an event for parents of teenagers. London & the South East Coast are planning another parents meeting for February & are working on Transition to Adult Services. North West has been clarifying how pumps are to be funded by commissioners & have been working on a document for schools.

The focus of the Parent Representatives in the FWD NN is to ensure that all the good work that is going on around the country is shared as widely as possible, adapted where necessary for local needs and implemented quickly to support clinicians and ensure that all Families with Diabetes receive the best possible care.

The parents who represent families in the South West are Karen Harrison and Louise Arnold. They can be contacted by email at <u>kd.ra.harrison@gmail.com</u> and louise@larnold.co.uk ,by post at 52 Hill Road, Wotton under Edge GL12 7LW or on Facebook - the South West Paediatric Diabetes Network Parents Group

https://www.facebook.com/groups/351695801609372/

STOP PRESS! Ruth had a girl, Molly Elizabeth

What would you like to see in the next issue of BITESIZE?

Send any items to maria.leveridge@nhs.net by 17th March 2013.