

(Dr) Dr Chris Moudiotis, Dr Sue Hellewell, (PDSN) Julie Kitchen, Ruth Dalton, (PDN) Heather Tabram, Emm Mortimore, (Dietitian) Maria Leveridge, (Admin) Emma Tootell (Secretary) 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

E-mail:

rde-tr.PaediatricDiabetes@nhs.net

Young people at the centre of diabetes care

## Families with Diabetes

The Families with Diabetes (FWD) National Network was formed in December 2012 to provide a national voice for Families with Diabetes.

The aims of the FWD National Network are

- ◇ To ensure that Parent, Patient and Carer views and experiences are considered equally important as those of health care providers.
- ◇ To represent a wide variety of families across all 10 networks
- ◇ To promote good practice
- ◇ To provide engagement opportunities to increase patient involvement using meetings and social media
- ◇ To share the experiences and views of Families with Diabetes with Clinicians across the UK through local Parent Representatives and by publishing articles in Paediatric Diabetes, and
- ◇ To engage with influential individuals and organisations within the Paediatric Diabetes community.

Families will be asked to give their experiences and opinions on the care their children receive (particularly health care professional communication, improving diagnosis, structured education and care within schools). Responses will be gathered together and presented to the various clinics and networks.

Summaries and minutes of the network meetings will also be published so that the families can see how their voice is being heard and how their involvement is helping to improve care for all families both locally and nationally. The next FWD National Network meeting is in Leeds on 7<sup>th</sup> September 2013.

The parents who represent families in the South West are Karen Harrison and Louise Arnold. They can be contacted by

email at [kd.ra.harrison@gmail.com](mailto:kd.ra.harrison@gmail.com) and [louise@larnold.co.uk](mailto:louise@larnold.co.uk) or by post at 52 Hill Road, Wotton under Edge GL12 7LW.

A Facebook Group has been developed for families in the South West – the South West Paediatric Diabetes Network. <https://www.facebook.com/>



Please like us and share your opinions and experiences of your diabetes care with us

## Are you getting 10 out of 10?

This campaign was designed by Diabetes UK to raise awareness of the importance of regular checks and good diabetes care for your child.

1. Care from a specialist team
2. Regular checks
3. The right treatments
4. Support so you can do it yourself
5. Help with feelings or worries
6. The right care when you are in hospital
7. A smooth transition to adult diabetes services
8. A say in the care you get
9. Support at school
10. Equal opportunities

Get more information from the link:-

<http://www.diabetes.org.uk/Documents/campaigning/type-1-essentials/type-1-essentials-0313.pdf>

**Type 1 essentials for children and young people** outline the 10 things any parent should expect from their child's diabetes care. It includes the care, checks and help that the child or family need to make sure their condition is managed well – in hospital, school and wider society.



# BITESIZE

## Dr Chris says.....

It gives me great pleasure to introduce our first newsletter on behalf of The Exeter Children & Young People's Diabetes Service. Since I took up the post of lead clinician in May 2011 I hope you have seen the Paediatric Diabetes Service evolve while still maintaining our core values of compassion & support to children with diabetes & their families.

I do believe the public are becoming more aware of how challenging managing diabetes is. Compared to our European contemporaries, there has been recognition that the UK has not funded Paediatric Diabetes Services to the same level & therefore nationally our outcomes are not as good compared to countries like Germany. I was very keen that early on we secured extra funding in the form of the Best Practice Tariff for Exeter & I hope you are now starting to see the rewards of this.

Our multi-disciplinary diabetes team has changed & expanded. Julie Kitchen has become our Lead Nurse following the retirement of Kirsten Jones & Ruth Dalton was promoted to Specialist Diabetes Nurse. Two new nurses are currently undergoing their specialist diabetes training (Heather Tabram &

Emm Mortimore) & we have also appointed a full time Paediatric Diabetes Dietitian, Maria Leveridge. Dr Sue Hellewell continues to help me run the service & we will be welcoming Sophie Bishop, our new Psychologist who starts in September.

The net effect of this is that we can offer more intensive insulin regimens from diagnosis, focus more on good nutrition & in particular carbohydrate counting and offer more opportunities for starting insulin pumps. We now offer HbA1c testing in clinic, both in the paediatric & transition clinics & replicate our paediatric clinic model in the MacLeod Adult Centre for our young people aged above 16. Finally we are endeavouring to use more computer download data for our patients on insulin pumps.

I hope you have started to experience all the changes above & I hope we continue to serve you to the best of our ability. Patient feedback is incredibly important to us, either formally or informally. Please let us know if there is anything we can do to improve the care we offer & we will be asking if you would like to take part in the National Diabetes Experience survey again in October

## Starting a new school?

We are aware that many of you will be starting at a new school or in a new class in September. We will be happy to arrange to visit your school, to provide education to the staff caring for you or your child.

As we are sure you can appreciate, we get a large number of

requests for visits at the start of the new term.

If you could please give us plenty of notice we will arrange to visit your nursery / school or college as soon as possible.

Call the Paediatric Diabetes Nurses on 01392 403727



Paediatric Team photo River Dart (L to R) Heather, Chris, Julie, Emm, Maria and Dave (MacGregor)

(see also the FWD item on page 4). The team also participate in the National Peer Review programme that is looking at all Centres offering paediatric diabetes care in the UK. The results will be available to the public in 2014 – 15.

I feel particularly lucky to have such a dedicated team working in Exeter & to illustrate above is a particularly spectacular picture of us at the River Dart Country Park following our Snackpack annual trip this year with 25 children with diabetes (David McGregor is a paediatric trainee who wishes to become a Diabetologist in the future).

Have a lovely summer and we look forward to seeing you in clinic soon.



Carbohydrate Counting?

Let Maria know if you need help with the school catering. Many school caterers can provide the carbohydrate content of their meals or Maria can visit and estimate the carbohydrates with you.

Call her on 07827239019.

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### Websites for children and young people with diabetes

- <http://www.diabetes.org.uk/Guide-to-diabetes/My-life/Kids/>
- <http://www.tldstars.com/web/>
- <http://www.lifescan.co.uk/parentskids>
- <http://www.lenny-diabetes.com/>
- <https://kids.accu-chek.co.uk/kids/#>





Clip and Climb May 2013

## SnackPack

SnackPack is a support group for children with diabetes and their families. We offer support via telephone, personal meetings and the website. We organise group outings for all the family such as Clip and Climb and zoo trips, sometimes we even hire the cinema. The purpose of the outings is to allow the children with diabetes to meet other children with the illness and to be able to see others doing blood monitoring and injections and to realise they are not alone with diabetes.

The parents and families of the children get chance to talk to each other and discuss how

**Snackpack Committee**—we always need new members to join our committee. Can you spare some time to help? Contact Ellen on 01626 439569

they cope with having a child with diabetes in the family. Often the children and parents stay in touch after these events.

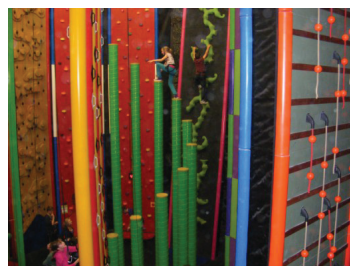
We also organise an annual residential weekend for 25 children from the group, they attend without their families but in the care of the Paediatric diabetes team from the RD&E. This gives the children chance to learn to control their diabetes through carb counting and dosage reduction when doing activity but mostly gives them self confidence and self esteem and a little independence. Many of the children have never seen

another child with diabetes and have never been away from their families since diagnosis.

If you would like to be added to our secure database please contact Ellen Bradburn on 01626 439569, there is no fee to join and we will not pass your details to any other person without your permission.

Forthcoming events include a beach party/BBQ in Exmouth on 8th September 4pm and another event in October half term. All the information will be on the Facebook page and our website

[www.snackpack.org.uk](http://www.snackpack.org.uk)



## Blackcurrant ice lollies

A great way to keep cool this summer



Super yummy blackcurrant lollies!

If you don't have any lolly moulds use a small plastic cup with a plastic spoon in it for a handle!

500g blackcurrants  
500mls water  
Sweetener to taste

Simmer the blackcurrants in water until the skins are soft.. Sieve out the pips. Allow to cool then sweeten to taste.

Freeze in ice lolly moulds until solid.

Makes about 10 lollies (3g carbohydrate per lolly)

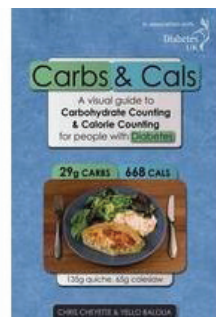
You can also make ice lollies with your favourite smoothies, fruit juice or make up strong sugar free squash

Please email me with your favourite recipes

☺  
[maria.leveridge@nhs.net](mailto:maria.leveridge@nhs.net)

### Q & A

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



**Snackpack** have kindly donated 20 Carbs and Cals books to the Diabetes Team so that all children with newly diagnosed diabetes can start carbohydrate counting from diagnosis



## Bye, Bye Ruth for a while

We all wish her well Ruth Dalton, Paediatric Diabetes Specialist Nurse leaves us in October to have her baby.

We wish her well during her maternity leave. Ruth will be back with us next Summer (2014)

## Feeling poorly? Read on for some top tips for managing your diabetes when you are ill

With all the lovely hot, sunny weather we have been having recently no-one wants to look ahead to the colder and wetter days of Autumn and Winter. Here are some important tips to help you if you become unwell with colds or viruses. It is also important to be able to keep yourself safe if you have any tummy upsets (sickness and / or diarrhoea).

1. Have the phone numbers at hand of the Paediatric Diabetes Team to be able to phone for advice if needed. Please do not hesitate to call if you are unwell and unsure how to best manage

your Diabetes.

2. Refer to any illness management guidelines you would have been given on the CHOICE or NOTES courses, if you have attended these.

3. Ensure you have a blood ketone meter (Optium Xceed) and enough blood ketone test strips at home to be able to test for ketones.

4. If any ketones are present (over 0.6mmol) phone the Paediatric Diabetes Specialist Nurse on-call for advice.

5. Regularly test your blood sugar levels (minimum 4 times a day).

6. Drink plenty of fluids to keep hydrated, these may need to be sugary fluids if blood sugar is low (call the Paediatric Diabetes Specialist Nurses for advice).

7. NEVER OMIT INSULIN—phone for advice if you are unsure how much insulin to give.

**Please always page the on-call Paediatric Diabetes Specialist Nurse 8am-6pm, or the Paediatric Registrar 6pm-8am, if you are unwell on:**

01392 411611



What would you like to see in the next issue of BITESIZE? Send any items to [maria.leveridge@nhs.net](mailto:maria.leveridge@nhs.net) by 17th November 2013.

## STOP PRESS!

The Snackpack Beach Party & BBQ will be on **Sept 8th Sunday at 4pm** on Exmouth beach near Occombe point end.

Bring your own instant BBQ and food/picnic and any beach games we can all share

## Snackpack Clip and Climb May 2013

Daniel Smith is one of the members of the Youth Committee on Snackpack.

Here Dan tells us what he has been up to recently with Snackpack

*Recently I went to Clip and Climb with Snack-Pack and really enjoyed being able to face the challenges of the different types of climbs they had along with meeting friends that I had made through SnackPack that I had not spoken to in a while.*

*What I enjoyed most was talking to other members of the group about their diabetes and how they coped with it and managed it.*



## Maria Leveridge, Paediatric Dietitian

Maria joined the Exeter Children and Young People's Diabetes Service in February 2013.

In the last couple of years a lot of work has gone into developing a set standards of care for paediatric diabetes called the 'Best Practise Tariff (BPT)'. The BPT criteria are to ensure high

quality paediatric diabetes services are provided to every child and young person with diabetes throughout the whole of England.

One of the standards is that every child or young person with diabetes should be offered an appointment with the dietitian at least once a year to talk through

your diabetes and answer all your questions about food.

Don't worry if you cannot make your appointment, ring through to the secretarial team on 01392 403695 to rearrange it on another Thursday afternoon or ask for Maria to visit you at home instead.



Maria Leveridge  
Paediatric Diabetes Specialist  
Dietitian  
07827239019  
[maria.leveridge@nhs.net](mailto:maria.leveridge@nhs.net)