

**NORWICH AND DISTRICT  
DIABETES YOUTH GROUP**

# NEWS

**SPRING/SUMMER 2014**



## HELLO AND WELCOME

**The new year has started off well as we have managed to publish our first newsletter of 2014 (Last one - Autumn 2012), which includes lots of information and forthcoming events.**

Since our last newsletter we have been using more of our donated funds to subsidise events to make it more affordable for the whole family to take part in; rather than spending on costly printing and postage. Hence we also dropped our traditional Hilltop weekend break due to high costs.

The alternative to advertise by post is to use our website: [www.nddyg.org](http://www.nddyg.org) and Facebook: **Diabetes UK Norwich & District Youth Group**, which we have done just recently, but we know there are lots of people that do not have access to the internet. If you do have a smart phone or access to internet please visit our sites and add yourself to our facebook page; I will gladly accept your request. Last month we filled a Snowtube event by solely advertising it on facebook.

Just recently we have received two large donations from The North Norfolk Diabetes Group and a group of business ladies from Aylsham to kick start our new year. So the Youth Group were able to purchase more W.H. Smith Vouchers for good HBAC1 level rewards and new 'Carbs & Cals' books that will be handed to newly diagnosed children in the clinic. A good idea from Karen Moye (committee member) was to add a small note about our group in each book and gift voucher, so we are hoping this will be a great success to recruit more families.

Whilst I'm mentioning the word 'recruit', we would be very grateful to hear from anyone that would be interested in joining our committee to help with new ideas and organise events for our younger children. You will have plenty of support from other committee members.

I hope you enjoy this latest newsletter and hope to see you at one of our upcoming events.

**STEPHEN PIZEY**  
NORWICH AND DISTRICT DIABETES YOUTH GROUP CHAIRMAN

# AGM YOU ARE INVITED! JENNY LIND 18 MARCH 7.30PM

We would like to invite you all to our Annual General Meeting to be held at the Jenny Lind, Norfolk and Norwich University Hospital, Colney Lane, Norwich NR4 7UY on 18 March 2014 commencing at 7.30pm. Light refreshments will be available from 7pm.

This is an opportunity to meet all the committee members, to see how and what we do as a group, to join our committee and get involved.

**ALL WELCOME!  
WE LOOK FORWARD  
TO SEEING YOU!**

## UPCOMING EVENTS SPRING/SUMMER 2014

**Family Bowling (2 games)  
with Stompers soft play area for u7's**  
Sunday 27th April 10.30am - 1.30pm

**Snow Tubing (2 sessions)**  
Sunday 4th May 10.30am and 12am

**Bewilderwood Family Day Out**  
Thursday 29th May 10am

**Eaton Vale Activity Day (4 events)**  
Saturday 12th July 9am - 5pm (BBQ from 5pm)

**FOR FULL DETAILS  
AND BOOKING  
SEE SEPARATE EVENTS  
LEAFLET WITH THIS  
NEWSLETTER**

**FOR THE LATEST NEWS AND UPDATES VISIT OUR WEBSITE [www.nddyg.org](http://www.nddyg.org)**

## BEWILDERWOOD DAY OUT '13



**In August 2013 we had another family day out at Bewilderwood organised by Stephen Pizey.**

This popular event was attended by 80 members of our group and was a great success, it was a great day out for all the family and also a good opportunity for families with children with Diabetes to meet, catch up and share ideas at the lunchtime picnic.

We hope to see you all at the next Bewilderwood Day Out on 29th May 2014. (See separate events leaflet for further details and to book).

## CHRISTMAS PARTY '13

DEC  
2013

On Saturday 7th December, the Youth Group held their ever popular Christmas Party with almost 100 guests on the day, all enjoying the festive tunes and being entertained with party songs from our regular DJ/Chairman: 'Steve's Disco'



The buffet this year was arranged, prepared and collected from the local Sainsbury's supermarket. Table top prizes were donated by local companies to accompany the main prizes that the group purchased with available funds.

Thanks goes out to all the committee members that helped out on this event, The Gas Social club for letting us take full control of the building and of course our own regular Santa for calling on the children and handing out all the presents.

A Christmas Party has already been mentioned for this year. Do you have any suggestions or new ideas? If so get in touch with us and tell us your thoughts!

## WORLD DIABETES DAY

NOV  
2013

**Norwich Castle and Norwich City Hall was illuminated in blue to mark World Diabetes Day on Monday 14 November 2013 and local schools across Norfolk also hosted a range of activities to help raise awareness of diabetes.**

Local headteacher Oliver Burwood, from Blifield Primary School, who has Type 1 diabetes, who had been organising the activities also hosted a special assembly in his school on to raise awareness of diabetes and its risk factors.

Children in schools supplied by Norse catering were also be asked to take part in a 'Doodle for Diabetes' competition by doodling and colouring in images of the iconic Norwich Castle. Norse then compiled these pictures to produce a book, which was donated to the Jenny Lind Children's Hospital, at Norfolk and Norwich Hospital, which treats children and young people with diabetes, to show them they do not have to manage their condition alone.

Andy Dodds (Vice Chairman) from the group went along to witness the turning on of the lights at Norwich Castle along with Keith Driver - Lord Mayor of Norwich.

**World Diabetes Day this year is again on 14th November 2014. So look out for our city landmarks turning blue.**

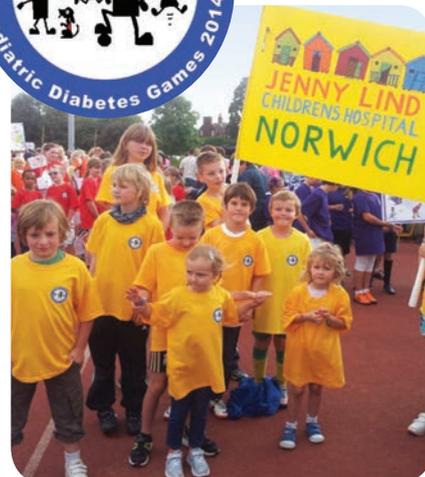
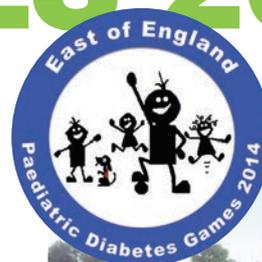
## EAST OF ENGLAND PAEDIATRIC GAMES 2014

**To be held at Bedford International Athletic Stadium on August 6th 2014. 10.30am - 3.30pm**

**For young people and their families with Type 1 Diabetes in the East of England region. It is an event where teams from each area join in different sporting activities.**

It's a fun day with a degree of competitive input but the events range from Running 400 meters to egg and spoon races so FUN FUN FUN! for all ages ranging from 3 to 16 plus years. Come along and support your Norfolk and Norwich Diabetes Team.

**Contact Jo Gibbons and/or the Specialist Nurse Team at NNHU on 01603 287504 for details and an application form or you can also get them from the clinics. Visit [www.paediatric-diabetes-games.com](http://www.paediatric-diabetes-games.com)**



*Above: Children from Norfolk at the last Paediatric Games held in 2012.*

# JENNY LIND NNUH NHS TRUST NEWS UPDATE

**NANDU THALANGE** CONSULTANT PAEDIATRICIAN  
JENNY LIND CHILDREN'S DIABETES TEAM

## A NEW START

Since May last year, we have been aiming to start children who have been newly diagnosed with diabetes, straight onto intensive insulin therapy with carb counting. Although it is more challenging to do, we think it will be better for children and families in the long run, as it means you go straight onto the best treatment. Hopefully this will mean we get children off to a better start, and - in the long run, we hope - a lower rate of complications. Research shows that children treated with intensive insulin therapy, particularly in the first four years after diagnosis, have a much lower chance of developing premature diabetes complications.

## BUMPER CROP

Fortunately, or unfortunately, we chose a bumper year to move to the new system; we had our highest ever number of new patients - 42 children with a new diagnosis, and 7 transfers from other parts of the country. We are hoping to start a focus group of newly diagnosed children and families. We need to know what we get right, and what we don't. What information and support do you need? It is always going to be difficult, but if we can do it better, we need to know. The adult diabetes service has patient advisors - people with diabetes who can provide moral support and practical (non-medical) advice - what do you think? Would this be a good idea for the children's service?

## BY APPOINTMENT

The diabetes service is under pressure, because of the increased appointments we are offering (every 3 months, as a routine) and the large number of new customers. Most of our clinics are full to bursting! To try and make things more efficient, and reduce the number of appointments cancelled by the hospital, we are moving to a new system. In future, your appointment will be sent out within 6 weeks of the date you need to come - we can't cancel clinics within 6 weeks of the date (except in a crisis) so it should mean the appointment you are sent won't change (unless you want it to, of course). At the moment, this just applies to appointments at the Jenny Lind and Roundwell Surgery, but we hope to extend it to Cromer, too. One way of solving the appointments shortage might be to have more clinics outside of Norwich. What do you think? Would it be a good idea?

## SHY AND RETIRING

Alas, Jane Clarke, one of our specialist nurses has decided to retire. She decided to go, before retirement age was increased to 87! We had a cheery send-off in the hospital Education Centre, including a wonderful cake created by Kris Howell's wife (also a dietitian!). We wish Jane all the best for the future, and hope to inveigle her back in future. We have advertised for a new specialist nurse and hope to have them in post by the summer.

## PUMPING UP

Last year we started a patient on a pump practically every week of the year! In some weeks, we had two patients starting. Pumps aren't for everyone, but they have moved on a lot in the last few years, so if it's a while since you last looked at pumps, why not come along to our next Pump Evening? It will be in the Education Centre on Wednesday 2nd July between 4-30pm and 6-30pm. The pump companies will be showing off their pumps - it's a great chance to come and see what's new and whether it's something you might be interested in. Even if you are really struggling with diabetes, a pump can sometimes be the best answer. Research shows that the biggest improvements are often seen in patients who are struggling the most, so don't be put off if your control isn't brilliant! The most modern pumps come with wireless remote controls and there is even a tubeless pump for those who want maximum invisibility. Our service is one of only two NHS England Pump Centres in East Anglia (the

other is in Cambridge). It is likely that in future new patients (under 19) will have to go to a pump centre to be started on a pump. We are not sure what this will mean for our service, as we are already really busy - but it's likely that we'll be getting a lot more patients from outside our area, than we do at the moment. We'll keep you posted.

## CONTINUOUS GLUCOSE MONITORING (CGM)

The Geoffrey Watling Trust and the Norfolk Diabetes Trust have combined forces to fund short-term continuous glucose monitoring (CGM) for our customers, for a 3 year period. A large part of the money raised came from an epic sponsored cycle ride by the father of one of our teenagers, Ed Masters-John O' Groats to Land's End, no less! Cheers, Ed! We use CGM to find out what's happening with glucose levels after meals, or at night. It's often really useful for pump patients, but all patients can benefit - particularly if you are having problems with bad hypos or your HbA1c isn't as good as your finger-prick glucose levels suggest it should be. Could it help you? Ask the diabetes team at your next appointment. The current CGM machines work for between 5 to 7 days, but Abbott Diabetes Care is bringing out a new improved CGM machine in the autumn (so we are told). It will be much smaller and will last for 14 days - we will tell you more, in the future. Abbott is promising that the cost will come down a lot, compared with the current CGM devices, but we don't have any details on price at the moment. This kind of CGM is for short-term use only - long-term CGM may become an easier option for some patients on pumps, but we are still waiting to hear more from NHS England.

## A BETTER FUTURE

All of you and us too, want better treatments for diabetes. Until now, the only treatment on offer has been insulin injections, but in the next few years, we are going to see new non-insulin treatments coming along. It will be exciting to have some other options for improving glucose control. As you know, we do a lot of diabetes research, so when those new treatments come along, we hope to take part in the studies (with your help, obviously!) that will make the future better and brighter. Right now, we have just started a new trial, SCIPI, comparing insulin injections or insulin pump therapy in newly diagnosed children. We will shortly start a study for teenagers with Type 2 Diabetes (most children have Type 1 diabetes), with an experimental treatment called Liraglutide. Liraglutide is an injection which improves glucose control but without causing hypos. Because Type 2 diabetes is rare in children, we are joining forces with the Queen Elizabeth Hospital in King's Lynn and the West Suffolk Hospital in Bury St Edmunds. The long term Adolescent Diabetes Intervention Trial (ADiIT) is designed to look at whether treatment of diabetes with blood pressure and/or cholesterol lowering therapy reduces risk of complications - particularly kidney disease. We are not recruiting new patients to the study now, and we hope to have the first results by the end of 2015. We are still looking for teenage girls for the Detemir-Glargine study of long-acting insulin - there are two, Detemir and Glargine - but which is better? Teenage girls need a lot of insulin to keep glucose levels under control, but that can lead to side effects like weight gain. If you are a girl between 12 and 20, on injections, you can help us to find out which is better! Speaking of long-acting insulin, we recently completed the BEGIN trial of a new long-acting insulin called Degludec - for the 8 children who took part, it was a really intensive study - we are really grateful to you! The results will be out in March - and if the results are good enough - we hope it will be a new treatment option. Unfortunately, it takes time to get new drugs approved, but, all being well, it may become an option in 2015. Fingers crossed!

## CENTRE OF THE WORLD

In the words of Martin Luther King, "I have a dream!" Dr T's dreams are like most people's nightmares, but for once, he's had a good one! Adults with diabetes (and our teenagers, too, of course) can go to the Elsie Bertram Diabetes Centre. Having everything - clinics, staff, admin people, etc - in one place makes it much easier to deliver the service you need. We would love to have a diabetes centre for children. We are doing some of the background work to see what we will need, and - given that the NHS is seriously short of money for new developments - we will also need to do some serious fund-raising to create it. We think our service could be so much better, if we had a Children's Diabetes Centre. We would still like to do more clinics out of Norwich for those living further afield, to reduce expense to families and loss of school time. If you think a Children's Diabetes Centre is a good idea, let us know!

# A BIG THANKYOU

On behalf of the committee, we would like to thank the following people and organisations for their recent kind donations and support:

Aviva	£250	North Norfolk Diabetes Group	£750
Mr Bacon	£140	Aylsham Calender Girls	
Drayton Junior School	£21	Organised by Helen Colebroke	£1297
R J Williamson	£200	Gas Club Collection	£24.30
Colby School Fund	£97	PCC of Shotesham	
Nick Johnson	£300	Organised by Ruby Woolacott	£336

## AYLSHAM CALENDAR GIRLS

On Sunday 16th February the Youth Group held its first Snowtubing event of 2014, This event was advertised on our facebook page and within 3 days we had a full take up of 40 places.

This has proved a very popular event, therefore it is being held again in May, Not only the children, but also the adults enjoyed this morning of fun. We were fortunate enough to be accompanied by the bright clear blue sky and sunshine to make the day even more enjoyable, after previous weeks of heavy rain

Between the two sessions we had snacks and refreshments with the added bonus of a cheque presentation from Mrs Helen Colebroke and her daughter Leah. They had donated the sum of £1,297.79 to our Diabetes Youth Group, which we are exceptionally grateful for to help towards our forthcoming family events.

The funds were raised by local business woman in the town of Aylsham in Norfolk, publishing their own calendar. The calendar features prominent Aylsham businesswoman and female residents



Above: Helen Colebroke presenting funds.

going about their daily work in the nude. Images include a hairdresser and a beautician doing the nails and hair of naked clients, the landlady of The Unicorn PH and the owner of a fabric shop posing discretely behind some of her products as well as images of Sara, Trudi, Helen and Su.

The project was an idea of Helen and her friends; Sara Westwood, Trudi Bradley and Su Cubitt. After seeing a Theatre Royal performance of the Calender Girls, they decided they wanted to give something back; especially after Trudi's diagnosis of breast cancer. Further more they also decided to give 50% of the money raised to our Diabetes charity due to her daughter, Leah, having Type 1 Diabetes

**HAVE YOU GOT ANY IDEAS FOR FUND RAISING  
OR ACTIVITIES OR CAN YOU HELP?  
WE WOULD BE PLEASED TO HEAR FROM YOU!**

If you would like to donate, please send cheques payable to:

Diabetes UK Norwich & District Youth Group, then send to: Daren Moye - Treasurer,  
Norwich & District Diabetes Youth Group, 31 Henby Way, Thorpe St Andrew, Norwich NR7 0LD

Online donations: Acc. No: 00606644, Sort Code: 30-98-58

Charity registered in England and Wales no. 215199 and in Scotland no. SC039136

## COME TO OUR COMMITTEE MEETINGS

AGM - 18th March 7.30pm  
Jenny Lind NNHU

First Tuesday of every month  
To confirm the venue please  
contact Steve Pizey  
on 07748 911288  
or email [chair@nddyg.org](mailto:chair@nddyg.org)

**OR BETTER STILL,  
JOIN THE COMMITTEE  
OFFER IDEAS AND  
SUPPORT OR JUST  
TO SEE WHAT WE DO?**

## COMMITTEE CONTACTS

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### SPECIALIST DIABETES NURSES

Jo Gibbons, Paul Hill, Suzanne Lee and  
Faye Stubbs 01603 287504

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