

Hilltops activity weekend

MAY 09

On 9th and 10th May the Youth Group ran a trip to Hilltops Activity Centre for 13 -16 year olds.

Teenagers had the opportunity to partake in a number of activities, such as mountain biking, a high ropes course, zip-wiring, an assault course and the Super Swing where you are dropped from a great height. The weekend was very successful, with everyone trying new things and meeting other young adults like themselves.

Thank you to the Youth Group for organising and supervising the event, we can't wait for the next one!



upcoming events 2009/10

Christmas Party

Saturday 12th December 2009
Gas Social Club, Roundtree Way, off
Mousehold Lane Norwich NR7 8SQ

A fun family afternoon, with food, Raffle, meet Santa and his helper, disco / games.
Contact Steve 01603 464688
vicechair@norwichdiabetesyouth.co.uk

Snowtubing

15th November 2009

Norwich Dry Ski Centre
10.30-11.30 (4-10yrs) 12-1pm (11-Adult)
Contact Gail/Paul 01603 427595
treasurer@norwichdiabetesyouth.co.uk

Go Karting & Barbeque

18th April 2010 - Cromer

Age 8+ and at least 1.37 meters tall.
11.30-1.30pm £10 per person. Please book early to avoid disappointment (only 48 places available). Contact Daren 01603 439236

Hilltops Activity Weekend

7-9th May 2010 for 8-16 yrs

Contact Gail/Paul 01603 427595
treasurer@norwichdiabetesyouth.co.uk

Summer Charity Ball 2010

Saturday 5th June 2010

Marriott Sprowston Manor Hotel
7pm till late

Ticket cost £50 (individual tickets)
10% DISCOUNT for group
bookings of 8 or more tickets

Welcome drink, 3 course meal, Live band, DJ, Auction, Raffle and more.
For ticket sales, auction prize donations, raffle prize donations or general enquiries contact Amanda Dodds 01603 300925 or email: amanda.dodds@uwclub.net

Have you got any ideas for activities you would like to do or see happening in the group, or do you have any time to help? Let us know we would be pleased to hear from you!

Bewilderwood family fun day

JUN 09



It was a bright sunny day as we headed to Bewilderwood The Curious Tree house Adventure. Having pre bought the tickets meant no queuing which was great as by 9.30am there was already people waiting for the twiggles to open the doors.

The day was full of adventure and fun. With boat rides along the the lazy river, (watch out for Mildred the Crocklebog), wobble wires, a muddle maze, tree house climbs and slippery slopes, building dens and swings, there was plenty to enjoy.

We had a great picnic spot, leafy lawn, which was tucked away in a quiet part of the wood. It was an ideal place to come and meet

others from the group if you chose to or if you wanted to do your own thing there were plenty of places to chill out and eat.

Just under 100 people attended the day from the group, ages ranging from babies and toddlers to grandparents. Everyone seemed to have a great time, even my nephew who is thirteen and was talked into helping out for the day, I couldn't keep him off the slides and zip wires. There were lots of parents getting in some sneaky slides down the slopes too, you know who you are, and I think we all fancied ourselves as den building masters. Thanks to every one who came and hope to see you again next time.

See the latest info about our group - visit our website:
www.norwichdiabetesyouth.co.uk

Committee news

It has been another amazing and hugely rewarding year for the youth group.

Yet again we have managed to do more events than ever before! We have managed to get more donations, more support and provide more educational items for our friends at the hospital. The support we have received from the Jenny Lind is fabulous and we really are grateful for the time and effort everyone puts into supporting us and helping us to do some of the events that really would not be possible without them. We must also mention the people on the committee – parents of children with Type 1 diabetes, who give their spare time to help keep the youth group alive, continually spending their time to support, run activities and help come up with ideas to raise funds that make the group tick, also who support in creating the newsletters and website and other printed and posted material. We also must thank our group of supporters, who help the committee in running events, even if it's only for a few hours - sincerely thank you. And to the kids and parents who attend activities and events we host.

However, a huge plea, for any parent or friend of the group who has some time to commit once a month to join the committee. The feedback we get from the kids, their parents and also the hospital are testament as to why we are so important and offer such a fantastic service to the Norwich and District area.

Our activities are not just about getting children with Diabetes together so they can see they are not alone, but to give their parents an opportunity to share ideas as how best to live with this condition. I personally have got so much out of this group, not just the rewards from seeing the kids (and my own daughter) taking part in events that perhaps they would not otherwise get the opportunity to do but also from the things that some of the events teach them. I have seen children going to our activity weekend who have never been away from Mum or Dad since they were diagnosed; children who learn to do blood tests and even inject themselves for the first time - a step to independence and a fantastic and rewarding thing to witness.

We are not only helping our own children, but in some small way improve, help and support those of the 350 children in the area. So my quest for 2010 is to find some new support to help grow the committee, and keep it alive for the coming years. Anyone who is prepared to join the committee or put their name forward to support really is welcome and please, please get in touch as soon as possible.

Thanks again and I look forward to meeting you at our future events.

Rob Scott - Chairman

Our pump journey

SEP 09

My daughter Honey was diagnosed with Type 1 Diabetes at 15mths old in March 2007, that was over 2yrs ago, she is now 3.

We used mixed insulins initially but soon found that in a baby so young the best way forward was basal bolus (MDI) to suit her little and often eating/drinking habits. Basal Bolus gave Honey much more freedom to eat and was better at first but again we soon found that Honey needed smaller amounts of insulin than even a junior pen could deliver. We then started getting an interest in insulin pumps and wanted to find out more about them.

A big reason for wanting a pump was because we had real problems during the night. Honey would rise every night at 3am but we could not solve this as 0.5 unit of Levemir would have a big effect on Honeys levels. An extra 0.5 would make her bg levels drop by 10mmols, not giving the extra she would then rise by 10mmols.

Honeys levels during the day were also unsettled. We could never give the insulin pre meal but had to wait until after and weigh leftovers so we could work out the carbs, this would cause a big rise. This all amounted to a high Hba1c of 9.6 before pumping. This in its self was a motivation to get a pump for her.

Honey was having up to 10 injections a day on basal bolus regime, Honey still enjoys eating little and often and I felt that this was far too much on such a small person in order to let her lead a fulfilled life.

So I decided to meet with other parents that had children with pumps, and although I knew it would be hard work especially to begin with I went ahead with starting Honey on a pump when we were offered one.

I can wholeheartedly say that its been the best decision for Honey and for us as a family. The reason this has been so good is that we were given a tool to work with and we made it work. Honey can now have those smaller amounts of insulin that her body needs, we can make 0.05 increments with her pump. Honey has got 19 different basal rates over a 24hr period suited to her needs.

The biggest change is the difference in Honey herself, her personality changed in the space of a week. Before pumping she would get tearful, lethargic and tended not to join in with my other children. As Honey was diagnosed so young we just thought this was her. Honey is now a happy, very active relaxed child who loves to play along. Several people commented on the change in her and this is because her sugars are not swinging high to low everyday. They are much more in range than ever before. Honey feels better in herself and it shows!

We change Honeys infusion set every 2

days and this is so much better than injecting 10 times a day. Our family have been able to become more involved with giving a bolus'. Also we can be more discreet when giving a bolus, rather than having to keep injecting her in public in her bottom and legs. When Honey eats I can give a bolus for half of the carbs up front and then the rest after if she eats all of her meal. If Honey decides she would like something else 20 mins after eating I can do this easily pressing buttons rather than her enduring yet another injection.

The pump allows you to give temporary increase/decrease to the basal rate. This has been a huge advantage with illness, just recently Honey had a temperature/cold and her sugars soared so I put on a 30% increase and she came back into range. I used this for 4days then took it back down when she was well again. With sickness you can put on a decrease in the same way when the sugars are dropping fast. Exercise is another important factor and we can decrease the basal for activity out of her normal routine such as swimming and indoor play areas etc. This helps to cut down on any hypos post exercise. You can have a weekday and weekend basal rate for when you are at school and one for when you are either more active or less active at weekends.

Honey wears her pump in a pump belt around her waist, she has never tried to remove the pump or pull on her set. Honey hardly seems to notice it is there and although it is almost always attached to her it does not slow her down or stop her from doing what all other 3 yr olds are doing. Angel Bear.com have a really good range of belts etc. It is part of her now and the best news of all is that her first hba1c since pumping has come down to 7.0%.

I am very pro pump especially for Honeys age group but it is very hard work to begin with especially. You have tremendous support from your pump trainer but you are sleep deprived to start with. This is because you really do have to test every hr/2hrs 24hrs a day to help set up your basal patterns. I was already putting in alot of work with tests and I always have night tested, I had prepared myself for the sleep deprivation. The pump is not a fix alone, you have to put in the work and learn all that you can in order to use the tool to its fullest. Carb counting really does have to be spot on and you need to be confident in your calculations. Invest in some good scales, the Nutri - Weigh ones are highly recommended by myself and other parents.

Anyone who is offered a pump has an amazing opportunity and I would do it again every time. If anyone who reads this would like to meet us and to look at Honeys pump I am happy to do so.

Thanks for reading and Good Luck - Jenna

News from the Jenny Lind

Dr Nandu Thalange
Consultant Paediatrician, Jenny Lind
Children's Dept, NNUH NHS Trust

Questions and Answers

Many thanks to those of you who filled in the questionnaires you got with the last newsletter. There was a lot of support for an alternative clinic somewhere else in Norwich – so long as parking was satisfactory! Lots of people still want to come to the Jenny Lind, though – especially now it has been made over! There was also some support for clinics in Dereham and Diss, provided that you got the same service, as in Norwich. Our Cromer clinic has proved popular, and we certainly want to give you a good service, wherever it is. Your replies are really helpful to us, when it comes to taking on NHS Bureaucracy – the views of the customers are very important to the powers that be!

We will shortly be starting a patient survey in the 14+ clinic in the Elsie Bertram Diabetes Centre, like the one we did in the Jenny Lind, last year. Please take part, if you are given a questionnaire in clinic – it genuinely does help us improve our services to you. We recently adjusted appointment times in the 14+ clinic to try and reduce waiting times, which has been a big problem in the past.

Jenny Lind Clinics

As some of you will already know, clinics in the Jenny Lind Department have changed. In order to make Clinics less crowded and hectic, we have added an extra clinic on Thursday evenings between 4 and 7pm. We have also changed the nurse-led intensive treatment clinics (ITCs), so that they now run at the same time as the consultant clinics, on a Wednesday morning and a Thursday evening. The ITCs are for anyone who needs a bit more support or help, between your regular appointments. Hopefully, thanks to the changes, you will find outpatients less crowded when you come in future!

Rapid Action

You will recall from the last newsletter that NHS Norfolk had set up a rapid action team to improve diabetes care for children in Central and West Norfolk. The Rapid Action Team has now completed its report, but we are still waiting for the action! There was some publicity in the Eastern Daily Press about improvements to

children's diabetes services, but this was old news being (inaccurately) recycled.

Mothers and Babies

We are now up to full strength with our diabetes specialist nurses – Gill Ward, Jane Clarke, Jo Gibbons and Faye Stubbs. We will shortly be interviewing for a research nurse to replace Jo, now that she has joined the ranks of specialist nurses. Sadly, Debbie Upton has moved on to greater things – she is now responsible for all nurse training in the Jenny Lind children's department. Thanks to funding from NHS Norfolk, we have appointed a consultant psychologist – Jo Derrisley – to support children and families with diabetes. At the moment, Jo is on maternity leave, but she will start work with us in the spring. Speaking of maternity, our specialist dietitian, Lucy Findlay, has given birth to a healthy baby boy – many congratulations to Lucy, Simon and big sister, Maya! Lucy will be on maternity leave till next summer, and so we are delighted to have Julia Eldridge back, to cover Lucy's leave.

Information

The big news is Podcasts! Thanks to the generosity of Takeda, a big pharmaceutical company, we developed podcasts for teenagers with diabetes. They have been nationally acclaimed, and Dr Datta, who led this project, spoke about the podcasts at a national meeting, last month. Following on from the success of the podcasts for teenagers, we will be developing a new set of podcasts covering more general topics, which are important for everyone living with diabetes. Not forgetting the written word, we have been revising our range of leaflets, and hopefully, they will soon be ready. When they are finished, you will be able to see them on the Diabetes Youth Group website, as well as picking up copies in clinic.

Top gear

You may have noticed that we are using a new system, called Diasend, to analyse blood glucose results in clinic. The good news about this system is that we can upload a bigger range of blood glucose meters, meaning that you can have more choice about which meters you use. Diasend also works with our continuous blood glucose

monitor, the Freestyle Navigator. Unfortunately, one of our Navigators has broken, and cannot be repaired. If you are waiting for a continuous blood glucose monitor, it will mean extra delays – we're really sorry about that. We are hoping that, with the support of the Youth Group, and Abbott who make the Navigator, that we will soon be getting at least a couple more.

As you will remember, the main company we were using for Insulin pumps, Smiths Medical, who made the Deltec Cosmo, have stopped making the Cosmo – if you are a Cosmo user, don't worry, as Smiths are still in business – they are just pulling out of the diabetes market. They have pledged to provide full support to all existing users, until the end of your pump's warranty. If anyone is concerned about the situation with the Cosmo, have a word with the diabetes team. Animas are offering a free switch-over to the Animas 2020, for anyone who wants to change. Our UK pump supplier, Advanced Therapeutics, (AT), is now providing a superb pump from Korea, the Dana Sooil, which some patients have now started on. It is very nifty, as it has a remote control unit, which is also a blood glucose meter, and it comes in a range of vibrant colours!

Research

Our research activities have quietened down a bit, as we are still waiting for two big studies to start up, and one big study has just ended – but we hope we will be getting going with more studies the near future. One is a long-term study to reduce risks of diabetes complications using drug treatment, and the other is a study of insulin glargine or insulin detemir in teenage girls. A number of you have been kindly helping researchers in Cambridge, with the "artificial pancreas" study – a sort of automatic insulin pump, which controls how much insulin is released, according to your blood glucose level – it could mean the end of fasting tests, and temporary basal rates for illness! The researchers are hoping to have a device for home-testing next year, and will be looking for more volunteers, if you're interested. We aim to produce a diabetes research newsletter this autumn – you'll be able to pick it up in clinic. It will tell you about all the studies we are involved with.



Quasar Elite SEP 09 great fun for all!

This was such a fantastic event and was enjoyed by the 28 kids and several adults who attended.

2 hours and 3 exciting games of quasar with cold drinks and pizzas in between to refresh and re-invigorate everyone. Thanks so much to Gail Howes for organising this event again.

Don't forget to visit our website!

New pages arriving any time now - including a forum and blog site, latest diabetes news and fun stuff - videos, pictures from events and diabetes information.

www.norwichdiabetesyouth.co.uk

Young People with Diabetes

Diabetes podcasts

Dr. Vipan Datta Consultant Paediatrician from the Jenny Lind Children's Department has gained funding and launched their first series of eight podcasts for young people with diabetes.

These podcasts are intended for young people aged 14 or over. They deal with the issues they can face with their condition in a realistic way.

If you want to listen to the podcasts either go to our website and follow the link or go to www.nnuh.nhs.uk/podcasts/diabetes/



Super waitrose



Waitrose Supermarket in Eaton kindly donated £330 to the Norwich and District Youth Group through their 'Community Matters' initiative, where each month £1000 is distributed amongst three local charities.

Shoppers can help vote on how the sum is divided between the three chosen organisations. Gail Howes accepted the cheque on behalf of the Youth Group from Sally West-Lindell at Waitrose. Many thanks to all concerned.

Fishing magic

For the last few years the James Farrow Memorial Fishing Event has raised money for the Youth Group.

This year they did yet another amazing job of raising £2,000 which we have received over the last few weeks. Once again thanks to all involved and for the wonderful donation and especially to Richard and Di Farrow for their support with our group. Check out the Fishing event at www.fishingmagic.com/news



world diabetes day
14 November

Find out what's happening by visiting www.worlddiabetesday.org

Fund raising support and donations

Have you got any ideas for activities you would like to do or see happening in the group, or can you help? Let us know 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: Paul Howes - Treasurer, Norwich & District Diabetes Youth Group, 5 Parkside Drive, Old Catton, Norwich, Norfolk NR6 7DP

Online donations: Acc. No: 0606644, Sort Code: 30-98-58



We need your email address, so we can contact you via email to reduce our costs.

Please email chair@norwichdiabetesyouth.co.uk

Parents and friends

Can you join our committee or help with activities and fund raising!

t: 07776 125156 e: chair@norwichdiabetesyouth.co.uk

our thanks

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

Rod Thorne, Laura Aitken, Mrs Rischmiller, Waitrose, Richard and Di Farrow.



Arnolds Chartered Surveyors' Charity of the Year 2009 is Norwich and District Diabetes Youth Group

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Don't forget to visit our website!

New pages arriving any time now - including a forum and blog site, latest diabetes news and fun stuff - videos, pictures from events and diabetes information.
www.norwichdiabetesyouth.co.uk

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