



An introduction from the Chair
Submitted by Carol Dobbins

As every bit of publicity is vital to us. Clare has family members who share NPS with many of us and she decided that she would like to take this opportunity to run for our charity and raise awareness and add some money to our funds too. Clare tallied up a total of £540 for our charity and I would like to thank those of you who used our Paypal account to donate online. It is very simple and easy to use. If anyone has any questions on how to use this, just contact us and we will let you know. She was extremely successful and I have to say that the weather this year at the event was very difficult. I personally think she is just amazing and how anyone can run so far in such gruelling conditions just beats me!

Thank you Clare,
Clare has kindly written a piece for us all to read. See below.

As most of you will know, Clare Brady bravely ran the London Marathon for us this year. We are all extremely grateful to her for doing this

Submitted by Clare Brady

Thank you to all who supported me. It was great to know you were out there watching me and a big incentive not to give up! I became addicted

to the weather forecast before I went and by Sunday my worst fears were realised, it was to be hot, humid and sunny. However, I ran the Edinburgh Marathon in temperatures of 26C and got round, it was just the time of 4 hours 30 was probably not to be (again!).

Anyway nothing to be done except put on a hat and sunscreen. It has to be said the weather gave us fantastic spectator support. The atmosphere at the start was wonderful, everyone talked to everyone else as for one day we all had the same goal in common. I even had the hair bobble out of one of the marshall's hair as mine broke just before the start, thanks to whoever you were, I would have been driven mad without it.

The first half went well, only five minutes behind time and busy looking for cameras to wave at. After this came the "why do I do this?" phase, it was way too hot in the midday sun and I was rapidly losing time. I had a "pull

yourself together woman" talk and a look at the watch and decided under 5 hours was still possible. I managed to pull off a good last 6 miles, the sun clouding over helped. The best bit was to turn the final corner and only

have 200m to go, I even found the energy to sprint across the line. Cutting it fine, but delighted to have made it in 4 hours 57 minutes.

I think the finishers t-shirt summed it up perfectly. "You saw impossible, I saw the finish line". I decided to run the marathon when I was 10 and didn't do anything about it for years now I've completed something that was only a dream and it was great to be able to help NPS along the way.

Can't wait for 2008. If anyone would like to join me please contact me.

Remember the marathons other little phrase "impossible is nothing".

More marathon news!

Race Day 1st September
2007 10am



New for 2007, the freshnlo Junior Great Scottish Run will take place the day before the senior race.

I am very proud to say that we have four brave young men who want to run this race for us. They will attempt this 3k run on behalf of NPS(UK) and we will provide them with their t-shirts and be there to cheer them on at this incredible event.

One of the young men is my son, Stephen Dobbins, who has NPS and has wanted to do something like this for years to help promote our charity and raise some money for our funds. Three of his friends would like to share the enjoyment of this event with him and run for NPS(UK). They are Paul Mullen, Rhys Jephcott and Darren Lloyd. They are all 10 years of age! I hope to have some exciting news on the results of this event in the next edition of the Newsletter. If you would like to sponsor the boys, you can do easily, by using our Paypal account online.

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On the 19th / 20th May, 2007, Kevin Whincup and friends have organised another incredible event. NPS(UK) would like to wish them all the luck in the world and thank them for taking on this challenge to aid and benefit our charity. More on this in the next Newsletter!



Submitted by Kevin Whincup

Well there is more news on the cycle ride that is happening on the 19th and 20th May on the IOW (Isle of Wight) on the Saturday 19th May both Robert Kesterton and myself will be setting off from Lymington and going clockwise around the route so we will do the UK mainland first. Then once we arrive on the IOW we will be heading to the campsite at Thorness Bay and stopping the night there. We will be joined at the campsite later on Saturday by Catherine Walker who is also doing the event. Catherine is an instructor at the gym that i go to and is in training for the Iron Man competition and also there is another eleven people from the gym that will be joining us later on the Saturday after there have done the cycling marathon at the gym which Catherine is the instructor. Also Catherine informs me that there is a few of her friends that are also interested in doing the event as well. All cyclists are ready for the challenge. On Sunday 20th May we will all be setting off on the IOW part with a change to it ! The change is that we will be cycling the whole way around the IOW which is about 80 Miles. So now the total mileage for the cycle event is around 130 - 150 Miles and that is still to be completed in the two days. I have been training hard and am really looking forward to this event now. I have already decided on my next challenge that i will attempt next year and that is to do a mountain climb for NPSUK which will be Scafell Pike in the Lakes and I'm also hoping to get a place in the 2008 London Marathon.

On the sponsor side for the cycle event

Southwest Trains have now offered 6 free train tickets for the riders to get from London to Lymington.

Wightlink Ferrys have offered 3 free return tickets for the riders to travel from the mainland across to the IOW.



Western Printers have offered 5 free T-Shirts for the riders to wear whilst doing the event which have now been delivered.

The Wimbledon Guardian have provided press coverage for the event and ran a news story all about the event and also gave information to people about NPS and NPSUK

Cycling Plus have also provided press coverage for the event and have put it both on the website and also in there magazine.

Isle of Wight county press have also provided press coverage for the event as well and have told me to contacted them before the event and also after the event to let them know how it went.

Red Funnel have also provided free tickets for riders that are going to be traveling from Southampton to Cowes.

Park Resorts have provided us a free pitch on there campsite for the night for the riders that are doing the event.

Hamble-Warash Ferry Company have said there will give the riders discounted travel for the event.

There are 15 cyclists that are taken part in this event now and there are ...**Catherine Walker** -Gym Instructor
Robert Kesterton -Security Officer **Kevin Whincup** -Security Officer **Nina P** -Esporta gym member **Jules** -
Esporta gym member **Michael** -Esporta gym member **Dianne** -Esporta gym member **Julia** -Esporta gym member
Nina F Esporta gym member **Ian** -Esporta gym member **Steve McGown** -Esporta gym member **Cath McGown** -
Esporta gym member **Jill** -Esporta gym member **Isabella** -Esporta gym member

NPS(UK) would like to wish each and every one of you all the luck in the world with this exciting challenge!

We have received many donations over the past few months from many sources and I would like to thank you all for your kindness.

I was given a cheque of £100 from a friend who organised with their family that over Christmas, they would make a donation to NPS(UK) instead of buying each other little gifts.

What a beautiful gesture! Thank you so very much to this wonderful family!

Thank you to Jacquie Gilbank, who donated another cheque of £142.91!

Thank you for the collecting tin money and Paypal donations. You are all wonderful!!!



Final plans for 3rd NPS(UK) conference!

I am so pleased to say that all the plans are going well. The date is the 10th, 11th and 12th August 2007.

The place is the Crowne Plaza (formerly the Moat House) in Trinity Street, Chester.

We expect approximately 120 delegates from all over the UK to attend.

Our speakers will be coming from various parts of the world.



I am pleased to report that all the conference plans are going extremely well and we are very excited about the speakers who are willing to attend on this occasion. Elizabeth Sweeney, giving an overview of NPS, Christine Slavin, talking about the ADHD research that is underway at present, Steven Zaretsky, discussing orthopaedic issues relating to NPS, Adele Towers, discussing primary care for NPS, Iain Mc Intosh, discussing the genetics, Kevin Lemley, discussing the kidney function, Mark Neugebauer, who will educate us on the eye issues and also we are happy to say that Anna Allford from GIG (Genetic Interest Group) will come along and discuss the Family Route Map project with us all to try and get a clearer picture of what we need.

As soon as the Agenda for the day is finalised, I will send it to you. I hope to also provide you with the details of the children's menus before you arrive to save time when you get there. However, it is likely to be similar to previous years and provide a great range of food.

NPS(UK) will also provide food for the Friday evening "Meet and Greet" as a finger buffet. **If there are any special dietary requirements, please let me know as soon as possible and I will let the catering staff know.**

We will also provide two coffee breaks on the Saturday and a full lunch. For those of you who have attended in the past, I am sure you will agree the food was beautiful! After the conference, we will have a little presentation and draw some raffle prizes. We have loads of lovely donated prizes this year, but we are always looking for more. If you have any ideas or unwanted gifts, please get in touch. It would be good to have a couple of nice star prizes.

This is also a nice time for a photo opportunity. Please feel free to bring your cameras. We are also hoping to try and film some of the conference this year, which may give some of the people who would have liked to have come, but for unforeseen reasons were unable to, the opportunity to view it at a later date.

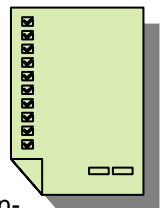
We will also sell some t-shirts and/ or mugs/ other merchandise etc...

Once we have purchased these goods, we are likely to sell them online at www.npsuk.org where you could have the t-shirt before the conference if you would like to wear it on the day!

If you would like to take advantage of our Travel Fund, please apply before the 31st May and this has to be our deadline for working out how much we can help you with your costs. NPS(UK) cannot cover all the costs, but will do their best to assist as much as possible with Travel arrangements.

PLEASE APPLY BEFORE THE 31ST MAY TO ALLOW TIME TO ALLOCATE HELP WITH TRAVEL FUND COSTS, IF YOU WISH TO APPLY. All forms can be downloaded online at www.npsuk.org or alternatively, contact us on our freephone number.

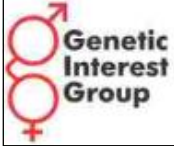
I ask also that you **PLEASE RETURN YOUR DELEGATE FORMS AS SOON AS POSSIBLE** as this gives us an idea of the final head count to cater for. We only charge a very small fee for the conference of £10 each with no cost to anyone under the age of 16. The reason we do this is that we all feel this has to be such a vital occasion for so many people and it is our best interests to make it financially feasible for all. I have attached the Delegate forms with this newsletter.



All children at the conference will be happy to hear that we still have our play room with our helpers who will all be CRB checked. Our helpers are Marion Ballantyne and Sheila Dobbins, once again, who are willing to hear any of your ideas regarding the games you would like to play. Please get in touch if you would like to suggest a few ideas. As usual, we will have Playstation, ? DVD, lots of colouring books, paper, pens etc... We would like to organise a Christmas card collection designed by our own NPS members and this might be a great opportunity to do this. We would also like to plan an NPS calendar and this could be discussed, planned and designed here too! Don't forget to bring your swimwear if you would like to go into the pool!

I have also attached the list of alternative accommodation with this newsletter once again, as the telephone number and address to send the forms to has changed.

PLEASE BOOK YOUR ROOMS NOW, TO AVOID DISAPPOINTMENT WHEREVER YOU ARE GOING TO STAY AS AUGUST IS EXCEPTIONALLY BUSY!!



You may remember from previous newsletters that last year, I was asked by GIG, if we would be interested in participating in a new project. The project would be funded by the Jeans for Genes Campaign and an educational grant from Genzyme for two years. The project is entitled "Family Route Map Project". GIG selected NPS(UK) as one of the groups to participate in this study. The aim of the Project is to help families and individuals access services and information that is currently available in the UK. GIG will work with us to assess the current situation, through focus groups and questionnaires. They will also speak to medical professionals to find out what they feel patients are getting and what they should and could receive.

NPS(UK) will have our own route map created, helping families affected to access current services and information available.

Some of us attended a focus group meeting in December of last year where we met Anna Allford, who is the project officer, and Melissa Winter, the communications manager at GIG. It was a highly productive meeting and Anna would like to use the opportunity of our meeting in conference to provide her with more feedback on this very important project. I would ask that as many people take part in this at the conference where Anna will ask a few questions about our experiences with NPS, and how it may have affected us within our health care system.

I am delighted to say that the first report for this project is now available to be downloaded online at www.gig.org.uk If anyone would like a copy of this to be sent to their home address, please get in touch with us on the usual details.

I am sure that there are many ladies out there with NPS who may have thought that they would love to have a chance to see what it looks like to have attractive nails. I know in my experience, I wanted to have presentable nails for a wedding once and it all ended in severe pain! This year, I am honoured to have Lisa— anne Donohoe come along to the conference and take a look at our nails to see how she can make us all feel a little more glam! She is a fully trained beautician and is happy to donate her time to our charity during this conference. If you would like her to look at your nails, just let us know when you arrive and we will certainly do our best to make sure you are seen.



It has been brought to my attention that many of you would like to have an evening to relax and unwind after the conference, so this year, NPS(UK) will also provide a D.J. and possibly a karaoke for the Saturday night where those of you who may have travelled a distance can relax and unwind, grab a few drinks at the bar and dance the night away! We also aim to have some more raffle prizes drawn on that night.



On this conference, we aim to have small, private discussion groups that will take place on the Sunday morning. At the moment, we plan to have these discussions between the hours of 10am and noon, however, it will entirely depend on how many people are willing and/or able to attend. We plan on having four main groups sessions, all chaired by someone, who is there to open and close the meeting. It is your chance to talk about your feelings and share them with people who are likely to have felt similar emotions in their lives. The idea is to feel that you will realise that you are no longer alone and that there is great comfort in sharing with others who relate.

The four sessions are NPS—Adults, NPS—Children, Non-NPS—Adults, Non NPS—Children.

Everyone deserves a chance to speak.



Our conference, overall, will take place over the course of three days. It will begin at 7pm on the Friday night, with our "Meet and Greet" where we will provide a finger buffet to all who attend. This is a lovely occasion to meet the speakers informally and chat with some new NPS friends and their families. We will have raffle prizes on this night.

On the Saturday, the talks begin at 9am, so please try to get there early as we expect large numbers this year and if anyone has mobility problems, please get in touch with us beforehand to ensure your comfort and safety on the day. The talks will break for an interval in the morning where we will provide some tea/coffee. Talks will resume and then break for lunch which is provided by NPS(UK) for families and their children. There will be a break in the afternoon and then we will conclude at approximately 5.30, however, they have been known to run over our time slot a bit!!!

We will then all have time for a bite to eat or a well earned rest before providing all those left with an evening to let your hair down. I can't wait to see all those dancers out there!!

On the Sunday morning, we will have the group sessions and the plan is that the conference concludes on the Sunday at noon.

I am very excited to see you all there! I have spoken to many of you on the phone who are willing to come along for the first time, and I have to say that I am pretty sure you won't be disappointed. It is a wonderful occasion to meet others with this condition and to ask all those questions that you will undoubtedly have. Make the most of this opportunity to get what you came for.

All that needs to be said, is see you there!!!

Fundraising/Publicity/Project updates

Submitted by Kath Lovatt

I've filled my time

over the last few months with sorting out all the little niggly bits that the Lottery Grant form requires. One thing for sure is that we will be bang up to date on all policies for NPS UK, which is only a good thing. The only bad thing is that all this paperwork takes up such a lot of time and effort and I must say I appreciate anyone that has helped out with any of it along the way as there is such an unbelievable amount of brain ache involved!



Earlier in the year I sat for days sorting out a questionnaire that I mailed to everyone. This was sent out to you because part of the Lottery Grant requires research into why we should want to spend the money on such an event. Many thanks to those of you that returned them either by the stamped addressed envelope or by email, as I very much appreciate this. However, anyone that still has them lying around at home, I would be really grateful if you would fill in the required information, even if you don't like the idea of a Families Day or have no intention of attending. It's the response that I need. If you would like to complete the form and can't find it please feel free to ring me on **0800 121 82 98** or email me on npsuk_info@yahoo.co.uk and I can send one out to you.

Wim is doing a great job of updating the website. We are eternally grateful to him for this as it would just give me something else to bang my head against the wall about!! I would like to add that the website is there for you, not just for our benefit and if you feel there are things you would like to know more about or you think we should include, then please get in touch! I have said before if you think there should be something on the website that we may have missed or should include, then again, please get in touch as the website is for everyone!

We shall also be starting work on the children's web site before long. Anyone with idea's or children that want to have their say on this matter please – we want to hear you idea's as Wim, Carol, Shirley and myself do a good job of acting like children occasionally but are far from it!

The conference is taking up a lot of time and planning, but we are getting there and we all feel it will be the busiest yet. We have a great mix of speakers attending, who are valuable to anyone with Nail Patella Syndrome and I salute them for giving up their spare time to go to Chester for the weekend. We would be grateful if anyone has any raffle prize donations for the weekend – if you could let one of us know that would be great too. I have written to all of the Premiership football clubs and rugby clubs asking for signed shirt donations and unfortunately nearly all wrote back apologising but wishing us well! I have one more club to write back to (fingers crossed) a month before the event so there is a little hope! We have also decided that this time we should do a little more socialising! We are in the midst of arranging a disco and karaoke for the Saturday evening so make sure you have your best singing voices with you! We don't intend having the music up too loud, but if you're not too keen on that idea the bar outside will accommodate you. We are trying to do something for all!

I would also like to thank Claire Brady so much for running the 26 miles around the Flora London Marathon course. I spent that day glued to the TV looking out for her, but didn't spot her. Anyone that would like to view Claire's pictures on the internet can do so by going to www.marathonfoto.com you need to type in Brady and her marathon number – 16823 and pick the Flora London Marathon from the drop down menu. She really did us proud and raised £540 for NPS UK. Claire is fortunate enough not to have NPS but she has family members that do, which is a very touching gesture. Also coming up is the Cycle Ride which Kevin Whincup has organised. Kevin has NPS himself and he is a star for taking on this challenge! He will be cycling a crazy amount of miles on 19th & 20th May, along with other volunteers who are as mad as he is! If you would like to sponsor Kevin or make a donation towards this then we have Paypal set up on the website which can be found on the fundraising page that can accept any currency. Good luck Kevin and crew!

Please remember that we have the free phone number in place which is **0800 121 82 98**, and if you need to get in touch, or require any help or information, or just need to talk to someone with NPS, then please get in touch.

I look forward to seeing and meeting as many of you all at Chester – please do come and introduce yourselves to me as it's great to put a name to the face!

NPS(UK) finance report

Submitted by Shirley Raynor

Hello once again
– time really seems to be rushing by
& the conference will be here before



we know it. I am very pleased to report that we have already raised enough money to pay for it, thanks to all of our hard-working fundraisers and generous friends and donators. This year, for the first time, we will also be able to offer some limited financial assistance for those who want to attend the conference in Chester, but can't meet all of the costs themselves. If you would like to know more about this, please get in touch, or check the website.

We have just over £14,800 in our account at the moment. Since I last wrote to you in December, we have raised £2250 from donations. As well as our normal running costs – stationery and postage, we now also have our freephone telephone line. This costs us so far about £60 a quarter. We have also had to replace Carol's computer, which died a sudden death – this is a vital piece of equipment for our charity, and the new one has cost about £730 altogether. You may recall that we had to replace her printer last year, so hopefully we now have a good system for her to produce the newsletter for you quickly and easily.

Kath Lovatt has recently spent hours and hours putting together an application to the Lottery Fund for financial help towards the family fun day she is planning for 2008 – let's all keep our fingers crossed for that!

I'm looking forward to seeing lots of old friends in Chester in August, and hoping to make some new ones too – I do hope you can make it.

I would like to take this moment to ask you to keep the Douglas family in your thoughts and/or prayers. Ruth Douglas lost her battle with life on the 7th May, 2007.



All our love and support is extended to the entire family during this very difficult time.

Lynn, Steve and Chris Douglas has asked that all funeral proceeds are given to two important charities in their lives; the Saint George's Crypt

in Leeds, that works with homelessness, and also to Nail Patella Syndrome UK.

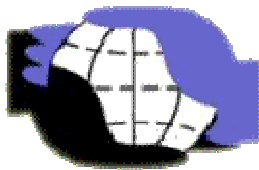
The funeral takes place on Friday 18th May, 2007.

Bless you all xxxxx



Any correspondence, donations, letters can be sent to:-
NPS(UK) / Nail Patella Syndrome UK,
PO Box 26415,
East Kilbride,
Glasgow G74 1QX
Scotland

Look out for our next edition of the Newsletter in September. If you have any photos or stories from the conference that you would like me to add, please feel free to send them to me.
You can also use our free phone number of 0800 121 8298 to call us at any time.



NPS UK
Registered Charity 1000621

For more information on Nail Patella Syndrome, visit:-
www.npsuk.org

Alternatively, email me Carol Dobbins on dobbinsek@btinternet.com
Phone me on 01355 241277