



**An introduction from the Chair
Submitted by Carol Dobbins**



What a busy few months! A lot of very exciting moments and memories that will remain with me forever!



On the 3rd Of September , the day of the Junior Marathon arrived. We were all really anxious and disappointed with the weather! It was just horrible. Heavy drizzle and the ground was soaking wet! Nicola got up nice and early, got a healthy breakfast and started sipping water! All these rules had been hammered into her brain for this day!!! We left to pick up her friend, Caroline and her dad and drive into the Glasgow Green for the event. We met Laura and her family there and it was so touching to see the girls all ready with their NPS t-shirts on! They looked brilliant! Just as we got out the car, the rain eased off. The girls found their starting point where I stood with

them, clicking the camera as usual!! They were all so nervous as the countdown drew near. Finally the horn blew for the first bunch to start. They were the wheelchair users and off they went to the pipes and drums being played! Finally, the horn blew and Nicola, Caroline and Laura started moving amongst the massive crowd of entrants this year. It was over 1,900 children between the ages of 9 and 17! I find the whole thing incredibly moving as lots of these young people are running for a cause. They seem to have learned so early in their lives that great pleasure can be had from giving rather than receiving! Some of the little ones were wearing t-shirts of loved ones who are no longer with them and they worked so hard to raise funds and awareness for this.

Nicola had trained very hard for the event, so her pace was surprising to her. She and Caroline stayed with each other and Laura found her own pace too. They wore their t-shirts with so much pride and as I stood there watching them running along towards the finishing line, purple faces, panting for breath, I felt the flood gates open. They were absolutely amazing and I actually find it hard to say thank you because it doesn't seem enough.

Their race times were much quicker than they expected! The times are printed on the official website of

www.runglasgow.org. Nicola, Caroline and Laura were 13 years of age and you can see their race times there.

We raised approximately £350 for this event and I am so grateful for their wonderful commitment and energy!!

If anyone knows of any others who are willing to take part in a run like this or any of the other marathons that take place through the UK, please get in touch with me and we can hopefully, raise more awareness and funds for our condition! We have had an incredible marathon running year in 2006 and I would love to find the same level of support in 2007!

NPS(UK) Official website news

You may have noticed lately that our website is looking a lot brighter and has a few nice little touches. We have many plans to expand it further and I am in the process of writing up some content for the media section as we have received some fantastic press attention of late. We have ideas of writing up some personal stories that will be of great help to those who are newly diagnosed and who are looking for an honest account of life with NPS. If you feel you would like to add your story to this, please get in touch with me and we can work on this together.



We owe much of this incredible work to one man who, very modestly, works tirelessly in the background doing such a wonderful job for us all. The website is such an important part of what we do to promote Nail Patella Syndrome, find others, share our information with fellow NPSers and also with the medical profession. It is vital to keep it updated and look interesting to the reader. It also needs to be navigated easily for all to use and I think that the work Wim has done lately deserves a great deal of praise! I know he will be a little embarrassed by this mention in this Newsletter, but I reckon he deserves it! So, Wim, from us all at NPS(UK), THANK YOU SO MUCH!

**So what's
inside?**

<i>Glasgow Junior Marathon runners. Website news!</i>	1
<i>Fundraising updates from Kath Many thanks for supporting J4G</i>	2
<i>Focus group meeting in London with GIG An account of the day from Kevin Whincup</i>	3
<i>Evening Times Awards Wellchild</i>	4
<i>Finance—Shirley Raynor NPS(UK) Cycle</i>	5
<i>NPS(UK) Conference 2007 Contact details London marathon</i>	6

Fundraising/Publicity updates

Submitted by Kath Lovatt



I have been kept busy that's for sure!

Firstly, after completing the grant application for the Halifax Bank of Scotland (HBOS), for cash that we need to use to organise the "Family Event for 2008", we were left hanging in the balance for quite a while as we received no acknowledgement of the application at all. The application was stressful enough especially when deciding how much to ask for as we didn't want to seem greedy or the complete opposite. After weeks of thinking NPS UK didn't stand a chance finally to my great surprise a letter and a cheque arrived for £1000, which was a great achievement for us. After that one the world's my oyster and have recently started an application with the 'Awards for All' through the Lottery Commission. This

application is far more complex and had a heap of work involved and will take a number of weeks to complete. As the money will be used for the Family Event a Child Protection Policy has to be put into place, so if anyone has any experience of this, then any advice would be gratefully received.

The 0800 telephone number has been a huge success, especially since the website has been revamped. The amount of enquiries that has come through has proved that the decision to do this was a very worthwhile cause. Hopefully now we can organise a separate telephone line as the calls come in on my private phone line and I believe that the phone should be answered in a professional manner. Please do not hesitate to use the number **0800 121 82 98** for anything NPS related whether you think big or small. I am more than happy to help or point you in the right direction.

The website has been updated by Wim Van Schaik in The Netherlands. Wim has worked tirelessly on the site and we think he has done an outstanding job! It's much more appealing to the eye and it will be kept up to date as much as possible. I work with Wim very closely on this project and it is very time consuming to say the least. We would appreciate any comments on the website or anything else that you would like to see on there. When reviewing the site, please try and take the view of someone that knows nothing about Nail Patella Syndrome and what you would like to know – we would love to hear your views. Also "our" website (and I say OUR website because its for Everyone's benefit) needs updating on a regular basis. If you have a story or details that you think should be on one of our pages then please do not hesitate to send the information through, preferably with a good quality picture that you are happy to have used on there.

Regarding large events we have welcomed the support of Nicky Piper MBE. Nicky is a former Commonwealth Light Heavyweight Champion Boxer, (Google him!) and would be able to help us out with auctions and presentations etc. I am delighted that he agreed to do this for us as he is a very busy man, but he will spare NPS UK some time. We are continuing our search for more celebrity faces to help NPS UK and have written several hundred letters in the past few months. I have had some signed photographs sent through from cast members of The Bill, and I will continue to pester people as much as possible!

I had an offer that I could not possibly refuse from one of my family members who runs a printing business. She has so much scrap paper that I was offered it to turn into note pads, so I went over for the day and guillotined loads of paper and glued together lots of pads. I have also got a stamp with NPS UK on it along with the important website address and telephone number which I am still stamping onto each page of each pad! These are ideal to keep by the phone and we hope to sell these at Chester, along with lots of goodies that will help put a little bit back in the pot! I also made some A5 pads with all the relevant details which should come in handy. So, kudos to my big sister Linda, as she is also generous on her offers of discounts for NPS UK.

I have been in touch with Tesco with the aim of being allocated a date to have collection buckets outside of their Tesco Extra stores as "every little helps!" I am waiting to hear back from them and would love to hear from anyone that would be willing to help out with this and wear an NPS UK t-shirt for the day! It's a great way to raise a few pounds and awareness along the way.

May I say a huge thank you to all of you who supported the Jeans for Genes campaign this year. It was a huge success and I know that many of you raised money in various ways. It is always difficult to talk to large numbers of people and I know that some of you visited your local schools to discuss what life is like living with a rare genetic condition. Many of you contacted local newspapers and worked alongside the media to raise awareness...and it worked!

A young man in a local school here in East Kilbride stood in front of his entire school at assembly and shared everything he knows about my son, Stephen, raising awareness for NPS and helping with the J4G Campaign.



Thank you to all of you for your support with this very special campaign. You can read about Stephen's story on www.jeansforgenes.com and click on personal stories.



genzyme



You may remember in the last issue that at the beginning of June, 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. I accepted immediately and have been working with them over the past few weeks. 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.

FOCUS GROUP MEETING IN LONDON

The meeting in London on the **2nd of December** at **The offices of GIG**, was amazing! Everyone had the chance to discuss the topic with ease. It was a recorded discussion about being a patient or family member affected by Nail Patella Syndrome. Everyone was encouraged to have their say and the meeting lasted approximately 2 hours. We had a lovely bunch of people come along and were so brave in sharing their honest accounts of what it was like to try and get some support for their various problems with NPS. Many thanks to Laura Cook and her mum, Bill and Anne Sneddon, Kevin and Teresa Whincup and Claire Sugden for all their valuable input. Many thanks to Anna Lane, the Project manager and Melissa Winter at GIG for their wonderful hospitality on the day. They provided us with a lunch that Marks and Spencer's would be very proud of!!! Friday night was lovely too as we met some new faces and caught up with those we haven't seen for some time. Candida Harris, the BBC journalist, came along for a wee while too and it was lovely chilling out informally and having a few giggles. I caught sight of the waiter looking slightly puzzled by us all comparing limbs!!!



The Family Route map should be a great thing to have for so many of us as it so often the case that we have no idea who can help us and where to go for that help. I can't thank all of you for coming along to this. I had a blast meeting you and sharing our stories together.

MEETING OTHERS WITH NPS FOR THE FIRST TIME

Submitted by Kevin Whincup



Packing my suitcase on the 30th of November 2006 ready for my wife and myself to travel too Kings Cross for a meeting on the 2nd December 2006 with NPSUK and GIG to help create a route map for people with NPS. On the morning of Friday 1st December 2006 my wife and myself set off to the station to get the tube to Kings Cross. As we arrived at the Travel Lodge in Kings Cross, I was feeling a bit apprehensive on meeting other people with NPS as I had always thought it just affected my family before I found the NPSUK charity and had only been around my family and nobody else with NPS. When we all met for a drink at the bar on the Friday night it was so amazing just meeting other people with NPS and sharing our stories on our own experience. I learnt a lot from just sitting down and chatting while having a drink, even things that I didn't know that was connected to NPS and I now know is. On the morning of the 2nd December we all met for breakfast in the reception and well what a queue there was for that. And when we did get to be seated for breakfast we all had to get separated as there wasn't enough space for us all. After we all had breakfast we waited for the taxi to take us to the GIG

building for the meeting. We arrived at the meeting and went into the room and all sat down and had some water. When we where all there we started the meeting which was recorded so nothing was missed. Everyone was asked to speak about there own experience and what help there had been offered and what help there had had from there doctor or hospital. After we had closed the meeting we all had some lunch which had been provided by the girls from GIG. Then we all said good-bye and got in separate Taxi's to head to the station for our journey home. I think the route map will be really good and will help the next generation of NPS suffers will get the help that is needed more easier as the route map will be able to tell them who is best to contact in there area. I know I got a lot out of the meeting myself and I am looking forward to the conference in Chester and meeting other NPS suffers.



Many thanks to Kevin who has asked for support in many ways from his colleagues at his previous job at Thames TV where he asked for signed photos or gifts to be donated to our charity that we can use to auction or raffle at our future events. We received a lovely bag of "Rainbow" soft toys from Fremantle media and have received some signed pictures from members of "The Bill". Nice work, Kevin!

You may remember in the last edition of the Newsletter that I had been contacted by the Glasgow Evening Times as they were launching their search for Scotswoman of

the Year. I was very honoured to hear that someone had nominated me and it was very touching and a huge honour to receive this news. To me, my life is very ordinary and I just work away at the things that are important to me. I know that we need to reach out for more support and I know that we need to find others with this rare condition and support them in every way we can. I also know that I am lucky to have so many of you right beside me all the way and it makes it all so very worthwhile!!

One thing is for sure... I will never forget the evening of the 23rd October 2006 for the rest of my life! Before I start, can I just say a huge thank you to all the texts I got on the way to the City Chambers!! Your words will stay with me forever.

I was so nervous about the big screen. I am not the most comfortable person in the world about looking at myself in pictures or on screen. This was a two minute clip that included my daily stuff with the charity, my reasons for the work we do, what NPS is, and finally, the most beautiful little piece from Stephen.



My friend Lisa and I heading out!

When the STV cameras came to film us, they asked if Stephen would like to say something and he said that he would. I told him that I would leave them all to it as he might feel more comfortable saying what he really wanted to say without me listening in. I thought that my heart would burst as I watched our little soldier talk about how "fine" life is, and how he knows what he has, but it "doesn't stop me. I have loads of medals and things and I am really happy." Then the clip went onto me doing all the boring stuff and then talking about what NPS is and how it affects us all and why we need to raise awareness throughout the world for what we have and finally, the clip ended with Stephen. He sat in the back garden, swinging his little legs on the garden wall, very

composed and matter of fact, when he was asked, "What do you feel about your mum?" He smiled and said in his boyish manner, "Oh, I just love her, and all she does for me....." After that, I didn't hear much. I can't say how much those words touched so many people in that room. His acceptance for what he has and his loving words at the end let people see that despite all the difficult times we share, we can still be happy and do something to try and make it better for the future generations. I know that we are doing that and I know that the next generation will have it easier as there are people beginning to listen.

The winner was the Professor Anna Dominiciczak who was recognised last year with an OBE for her outstanding contribution to medicine. She is a wonderful woman who has done some incredible work.



Linda Robertson, Evening Times Journalist, and I on the evening of the Awards

To me, as you all know, it isn't about winning, it is about spreading awareness and I can't tell you how brilliant that was. I spoke to many people and have received a beautiful email today from Linda at the Evening Times who wants to do anything in her power to help us. I think we will become good friends as we "clicked" the first time we spoke and we sat together sharing tissues watching Stephen.

I will never forget the night. I feel my job to raise awareness on the night went really well and I hope that many more people will talk about NPS. I hope that I have not disappointed anyone for not winning this title, but I think by now, most of you know that these awards bring great platforms to raise awareness and that is far more important than any award.



Entertainment on the night!

Every 30 minutes, a baby is born with a genetic disorder. There are over 5,000 known rare disorders. They affect children and adults and many are long-term, progressive and disabling. WellChild is dedicated to supporting sick children, whatever their illness. We work to find ways to prevent and cure childhood disease and illness and to improve the treatment and care of sick children.

My 9 year old son, Stephen was recently nominated in an awards ceremony for Brave Child that took place in London on the 25th October. One of the teachers at his school felt that he should be nominated for his bravery and courage despite all the problems he has faced living with NPS. He is one happy little chappy!! He received a beautiful certificate in the post for this and I am now going to be working with the Wellchild team on promoting our condition.

For more information on this wonderful organisation, please visit www.wellchild.org.uk



NPS(UK) finance report

Submitted by Shirley Raynor

It doesn't seem like two minutes since I was drafting our last finance report, but here we are again!!

Happy New Year to all of you!

We have had quite a big increase in our funds since the last report – we now have about £13,500. Since September we have received about £450 from Everyclick, the internet search engine that gives a donation every time someone uses our link on there; we have also had £125 sponsorship money from Nicola Dobbins and her friends from their Fun Run, the ongoing donations from our collection boxes, generous donations from our members and a single company donation of £1000! Many thanks to Kath Lovatt for mailing round lots of companies – it was worth it.

We are so grateful to everyone who makes this wonderful effort to raise funds for our charity – a big thank you from all of us!!!

This quarter we have also had to replace some of Carol's computer equipment – running off these newsletters had finally killed off her old printer and we have replaced it now with something that hopefully will get the job done more efficiently. We have also set up an NPS phonenumber – this is a freephone number that we can use in newspaper and magazine articles, so that individuals don't have to give out their home phone numbers in the press, and people can phone in without charge.



NPS UK Charity Cycle Ride



Saturday 19th May 2007

We have had a great offer of a sponsored event on behalf of NPSUK. Kevin Whincup, who has NPS, is going to cycle 66 miles in 48 hours following the Solent Coastal Route.

We are currently looking for volunteers and sponsors to assist with this event! If you think you are up for the challenge, please get in touch! You may know someone who would love a challenge like this, please get them to contact us too.



Itinerary

- Start at Lymington then head across to Yarmouth by ferry.
- Cycle from Yarmouth to Freshwater, through Brightstone to West Cowes.
- Ferry from West Cowes to East Cowes.
- Back on the bikes at East Cowes and cycle to Fishbourne
- Catch the ferry over to Portsmouth then another ferry to Gosport and ride towards Warsash.
- Get a ferry from Warsash across to Hamble and then cycle onto Southampton
- Get the last ferry and head across to Hythe. Once at Hythe it's the final bit of cycling back to Lymington passing by Beaulieu

Please email us on npsuk_info@yahoo.co.uk if you can take part or would like to sponsor a cyclist!

We would appreciate any ideas on sponsorship!

NPS(UK) Conference 2007

The NPS(UK) Conference 2007 will take place on Friday 10th, Saturday 11th, Sunday 12th August 2007.

The location will be the Crowne Plaza, (formerly known as the Moat House) Chester.



The plans are well underway!

This year we have a Travel Fund in place to help pay for any travel expenses you feel you may need some assistance with. If you want to know more about this, please send me an email and I will explain it further. I have Travel Fund application forms ready to use and I will be happy to post them out to you at any time.

I also believe that announcing these details at this stage enables people to make some plans and save some money too. I am working with the Chester and Cheshire conference desk, once again and they sent me a list of alternative accommodation in the surrounding areas too. I will distribute this with this Newsletter. They are a wonderful service to us and if you call them, I am sure they will assist you with your accommodation needs too.

Our conferences are so valuable to so many people and it is always a wonderful opportunity to get the chance to share stories with others who share this condition and also to get the chance to meet the wonderful medical team who play such a vital part in all that we do. Every year, I am very proud to say that the feedback is wonderful as people very often as a result of meeting others, and gaining more information from our speakers, learn to deal with it all on a better level.

We plan on having a wide range of talks this year once again and have invited many professionals who hopefully will accept our offer and tell us their particular views on their subject in relation to Nail Patella Syndrome. I am pleased to say, we have three wonderful speakers who have accepted already and I am sure we will have many more.

This year, we also have a nail technician who will come along and talk to any of our ladies who may wish to have their nails attended to on the day. Many of us have difficulty in keeping our nails freshly manicured for long, but Lisa will wave her magic wand on anyone willing to give it a try!!

As usual we plan on having our Meet and Greet evening on the Friday where many of us get together, often for the first time, and share our stories with one another. It is a lovely opportunity to get to learn more about one another on an informal basis. We are likely to organise a raffle for this night as we often have some lovely prizes to donate. NPS(UK) also lay on a finger buffet for all those who wish to attend.

The Saturday is usually filled with talks and I am sure that you will be amazed at the information you will receive from these wonderful speakers. All the snacks, and lunches are provided by NPS(UK) on the day also. I will send out the usual menu lists for children in advance and if anyone has any special dietary requirements, just let me know and I will liaise with the catering team.

Plans are still being discussed at the moment regarding a possibility of some smaller group discussions being held on the Sunday morning, but we still need to get some feedback to see if this is a viable option.

All that remains to be said for now is that I hope to see lots of you there! I am very sure it will be something you will never forget!

LATEST NEWS

I have just received a phone call from a Mrs. Clare Brady, who would love to run the London marathon for us. What an incredible gesture. It takes place on the 22nd April 2007 and is 26 miles long! Please could you do what you can to help support her in this tremendous effort.

Contact details and useful sites

Any correspondence, donations, letters can be sent to:-

NPS(UK) / Nail Patella Syndrome UK,
PO Box 26415,
East Kilbride,

For more information on Nail Patella Syndrome, visit:

www.npsuk.org

www.nailpatella.org



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

Phone me on 01355 241277