

*Nail Patella Syndrome (UK) is a charity that provides information and support to those whose lives are affected by this condition and also for the use of the medical profession.*



Issue 9  
September 2005

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

On the 12th / 13th August 2005, the second NPS(UK) conference took place in the Moat House in Chester. It was the chosen venue for many reasons, and I am sure that most of you would agree, it was a wonderful occasion.

Our two cars arrived at approximately 2pm on the Friday, and it was all stations go!

We started setting up the conference desk, checked out the various rooms and basically made ourselves comfortable for the next couple of days. Before long, our delegates arrived and many friendships were formed almost immediately. It always amazes me how quickly we all seem to bond with one another and this conference was no exception.

On the Friday, our "Meet and Greet" began at 7pm. I am proud to say that on more than one occasion, I needed to request more chairs!

The buffet was delicious and there was plenty to choose from. We also had a huge array of wonderful raffle prizes that were donated from various shops in Devon where Lee Markham scoured the streets on behalf of NPS(UK)! As a result of all these efforts, we made £370 from the Friday evening raffles alone! Thank you so very much Lee.

During the evening, we were honoured to have Susan Guzman, who generously donated much of her time to hosting a couple of group sessions. Susan is a clinical psychologist who lives and works in San Diego, California. She was happy to attend our conference and help tackle some of the psychological issues that can manifest themselves in the daily lives of people who are affected by NPS. Susan was the perfect choice as, not only is she an interesting speaker, but she also shares NPS with many of us.

The group sessions began at 8pm with the first meeting directed towards people who do not have NPS, but who have loved ones who do. I understand that this was a huge success and very interesting, positive feedback was relayed to me.

The second group session began at 9pm and the attendance was vast! I know that neither Susan nor myself thought that we would see such a huge amount of people in one small room. It was wonderful to see that so many people had lots to say, but I would split this group into a further two or three sessions in the future as it was difficult to hear from everyone.

On Saturday morning the talks began at 9am. We began the day with no major hitches and the attendance was brilliant. We had 70 adults in the room, and it was a joy to see so many new faces. There were people arriving from all over, including Norway, Denmark and The Netherlands!

The talks began at 9am with an introduction from myself and an explanation as to why we feel the necessity to have our NPS(UK) Charity. We were highly informed about NPS from Elizabeth Sweeney next. We then had a short break with some tea/coffee and returned to the Suite to hear from Christine Slavin, Jeffrey Towers and Adele Towers. They educated us on the effects of ADHD in NPS, imaging in NPS and also how to care for someone who is NPS affected. Lunch followed and the food was delicious as usual!

Afternoon session began at 1.30 and we heard from Caroline Jones, Iain McIntosh and Mark Neugebauer who informed us on the renal effects, genetics and the ophthalmologic findings. I have to say a huge thank you to Mark for bringing along some young colleagues of his to assist him in examining the eyes with the use of the slit lamps. It was extremely beneficial for many who attended and who already have glaucoma. It was also very encouraging to hear that the young men were very interested in learning more about NPS! I hope that we may see them again in the future conferences! Susan Guzman talked next about the psychological impacts of living with NPS. It can often be difficult to listen to as the emotions, very often, lie beneath the surface and listening to Susan means that we hear things that we may not have faced for some time. For me, it was highly emotional, once again, and following on from her was extremely difficult. We next heard from Shirley Raynor who told us all about the important financial issues that are involved in running a charity. She educated us on the costs of organising the conferences and also the costs that are sometimes incurred when planning and hosting fundraisers.

The day ended with a little presentation to our speakers who, once again, gave up so much of their own valuable time to educate us on what they do. They are wonderful people and I thank them on behalf of us all. We called out the raffle prize winners and one lucky person left with a brand new digital camera that was donated by one of our members! We then all gathered together for a photo session that has become an important part of these conferences.

Thank you to all of you who helped with the conference. There are so many people who donated gifts and their time and I want you to know that I am eternally grateful to you all! All that remains to be said is that I hope to see you all again in 2007!



*Special thanks to all of our speakers:-*

*Elizabeth Sweeney*

*Christine Slavin*

*Jeffrey Towers*

*Adele Towers*

*Caroline Jones*

*Mark Neugebauer*

*Iain McIntosh*

*Susan Guzman*

*Shirley Raynor*



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## Fundraising/Publicity updates



Our fundraising calendar has been pretty much full over the past few months. On the 16th May this year, I was invited to a lovely ceremony held in a local school here in East Kilbride. The invite came from the lieutenant in charge of the junior section of the 6th East Kilbride Boys brigade. It was a beautiful occasion as I was informed that the young boys had taken home little boxes and saved all their pennies on behalf of our charity. I was deeply touched by the kindness shown by the whole team and I was honoured to present the boys with their medals for achievements throughout their year at the Boys Brigade. I was presented with a cheque for £123.00 from them and I will never forget their kindness shown to me on that memorable evening.

On behalf of NPS(UK), thank you so much to these young men!

In June, the Cycle marathon began. Mick Smith and Lee Markham had been training hard and planning their routes for the past few months to undertake this huge commitment on behalf of NPS affected people everywhere. On the 5th June, the men began their arduous trek from Land's end and planned to arrive at John O'Groats just over two weeks later. The Cycle was a huge success and so far we have raised an incredible £1075! I have been promised more and I am overwhelmed at the generosity of some people. I feel that the men and their families have shown such incredible kindness to our needs and I wish to thank them publicly for the sacrifices they made on our behalf this year. I would also like to add that the kindness shown by Bill and Anne Sneddon, and Bill and Sheila Libberton was deeply touching as they showed their support in various ways as you will read. Thank you so much to all of you!

### Submitted by Sheila Libberton

#### *Lands End to John O'Groats*

#### *Sponsored Cycle ride*

*With the last newsletter came a form asking people to sponsor 2 men—Mick Smith and Lee Markham— who were going to cycle from one end of the country to the other to raise funds for NPS(UK)*

*The men were using Youth Hostels and B&B's en route. Unfortunately, Lee was injured early on and had to retire. Gallant Mick carried on by himself. In one of the Youth Hostels he was to use, Wanlockhead—(Scotland's highest village) - Mick was to cater for himself. Our admiration for these two men was such that we decided we would feed them at Wanlockhead. By this stage however, there was just Mick. On the 16th June, a very, wet, cold miserable day, we set off complete with soup, shepherd's pie, macaroni and cheese, apple crumble, coffee, tea, wine, fruit etc, etc... We also took cereal, bacon, eggs etc.. for the following day's breakfast. When we arrived, it was still wet and cold, to think that Mick was still cycling in such weather for the benefit of us NPSers!! We had great admiration for him before meeting him. On our arrival at the Youth Hostel, Mick met us looking very fit indeed for a man of his years. We thoroughly enjoyed our evening with this great guy who greatly appreciated his meal. I do hope his cycling clothes were dry by morning as they were dripping wet when I hung them in the drying room. We found it difficult to leave this wonderful man to cycle the rest of the way through Scotland to John O'Groats where he was met by his daughter and partner.*

*We arrived home at 11 pm, glad that we had been able to help this admirable man. I don't know how much money was raised, but this deed was certainly worthy of every one of us asking friends and family for their support.*



*When Mick arrived home after the train journey, he was met by family and friends who had a banner out for him. The neighbours' children were shaking his hand and saying "Well Done!"*

*True stars indeed!*

*Thank you Lee and Mick*

*Bill, Anne, Bill and Sheila*





On Sunday 21st August, a local football team in the East Kilbride area decided that they would like to raise funds for our charity. They decided to host a 11 a side football tournament in the Showpark. They advertised the event by contacting the East Kilbride News and also by putting posters up all over the place. They handed out programmes on the day to all who attended this event and inside there was a huge explanation as to what Nail Patella Syndrome is. It also highlighted our website, so hopefully we have educated a few more people.

The day itself was brilliant, especially for a mad football supporter like myself! I stayed for the entire duration and enjoyed every minute of it! The 4 teams involved were Ballerup AFC, who organised the

event, Duncanrig AFC, E.K. Rolls Royce, and EKYM. The football began at 12.45 and continued until 5pm. The final was between Ballerup and Duncanrig and with the final kick of the ball, Duncanrig emerged the winners.

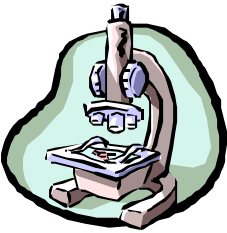
I was then asked to present the winning team with their medals and the trophy...what a difficult job this can be sometimes!! I had the job of kissing 17 sweaty men and presenting them with their winning medals! After the match, I was invited to Legend's Wine Bar where they had prepared a buffet for the players and supporters.

It was a memorable day and the publicity we made was great. The East Kilbride News covered the story for three weeks running and the total collected is over £300! I am waiting for the call to come and collect the cheque!



## Close contacts with other organisations

As many of you know, GIG (Genetic Interest Group) and CAF, (Contact a family) are very important organisations that help support our charity in many ways. GIG have helped to promote NPS by contacting me on various projects that come their way to publicise rare genetic conditions. Needless to say, I accept all projects and have recently become involved in a project called "Telling Stories" that is taking place at the University of Glamorgan. It is aiming to provide an understanding of real life genetics by creating a web based education resource for the nursing professions We know that health care professionals such as nurses, midwives and health visitors should be educated in genetics. It can be difficult for them to make the link between what they are taught and how this relates to the people they may be looking after. We know that hearing real stories about people's experiences can make a difference in helping them to understand genetics. This project will gather real life stories from the public and professionals to show the impact those genetic conditions have on real life. We hope it will help health care professionals to gain a better understanding of genetics in practice.



I have completed all the forms and submitted our story and hopefully I will hear from them in the near future. I will keep you all informed.

I was asked to write an article in the Summer edition of the GIG Newsletter to discuss my experience in talking to BBC Radio 4 earlier this year. This will hopefully allow people an insight and prevent them from doing something similar to promote a genetic condition that may affect their lives. If you would like to read the article, it is now available online at [http://www.gig.org.uk/docs/gignewsletter\\_summer05.pdf](http://www.gig.org.uk/docs/gignewsletter_summer05.pdf)

GIG also very kindly accepted to promote our conference this year in their Newsletter which is distributed throughout the UK. I am sure that we have highlighted Nail Patella Syndrome in a very positive way.

## Other media sources

In June, I received a phone call from a newspaper journalist who I had spoken to in the past. She was interested in writing a personal story for the "Take it easy" magazine, which comes free with the Sunday People Newspaper. I gladly accepted and gave the interview. I will keep you informed of the outcome.

As many of you know, I had a major computer crash on the evening before the conference and on my return, I knew I had my work cut out for me. Thankfully, I have retrieved most of the data, but I was unable to read any mails that were arriving in my mailbox until two weeks later. I was alarmed to read another lead from GIG who had been contacted by the producers of "This morning" which is presented by Fern Britten and Philip Scholfield. They plan to do 10 case studies on rare genetic conditions and will be shown from early September. I contacted the producers by email immediately, but I have not heard any response as yet. I have a feeling that we may have missed the boat on this occasion, but they will have our details. I also have a new media source for this programme which may come in useful in the future.



## More fundraising!

At this moment in time, I am working on our next fundraiser. This one has become a yearly event and this will be our third year! It is always an event in our fundraising calendar that I look forward to as it is a day full of fun!

Our Five a side tournament began in 2003 with 8 teams. We entered our own team, NPS United, consisting of my husband, Keith and some of our friends and neighbours. The event was a resounding success and the winners received a shield which I got engraved with the winning teams' name on it. They also received a bottle of champagne and £50.00 in cash. Each year the shield is returned and the winner passes the shield to the new winning team. I also provide them with a buffet afterwards as they are all exhausted as a result of the football. Throughout the year, I get many calls asking if we are going to host this event and wanting to know if they could enter a team. Needless to say, the event is growing as the entry forms are increasing! Last year we had 12 teams and this year, we are expecting 14/16 teams!!



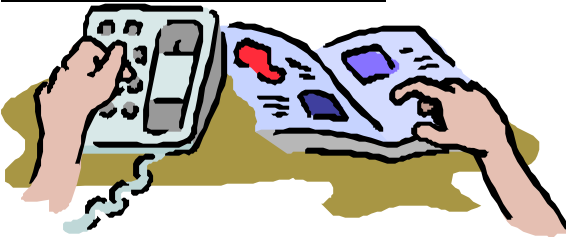
I have contacted the local newspaper to publicise the event once again and hopefully we will receive more interest.

Each year, a great friend Jim Alexander plays in the NPS United team and as a result, his company BOC Gases match everything that we earn on the day. Last year was such a success as we raised £1,410 in total! We are hoping to raise a similar amount this year, so I will keep you all posted in the next newsletter.

This year, I have decided to do a double fundraiser on the same day! I have hired the bar area in the "Fives" where the tournament will take place for the evening also. I have hired in a DJ for the evening and I will supply a buffet and some raffle prizes. Thankfully, I have received many offers of help for the buffet as I will have to organise two buffets for the one day!! I have printed out tickets for the evening and will sell them at £5.00 a head. It should be a lot of fun and I am sure that we will raise a

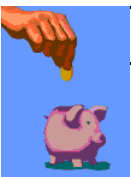
lot more interest in our charity!

### Webb Ivory Catalogues



I would like to remind everyone that we can supply you with the Webb Ivory catalogues, which is such a simple way of raising money for our charity. The catalogues are beautiful and the prices are very reasonable. Everything you purchase, a percentage of the cost goes directly into our NPS(UK) bank account. It is quick and simple to use, you can even place your order over the phone. Please make sure that you quote the fundraiser source code though as you place your order. This can be found highlighted at the top of the order form.

Debby Humphries has set this all up on our behalf and either Debby or I would be happy to send you a catalogue if you wish. I have four of them sitting on my desk as I type this newsletter, so please be quick!



### Collecting tin donations

I would like to thank every one of you who have taken collecting tins and placed them in your local shops/clubs in your area. The response has been great and the money raised is extremely helpful. We raise funds and a great deal of awareness for the charity in this simple way.

**If you or your family members are willing to give the "gift of life" then you will need to register your intention, and carry the donor card at all times.**

**Phone the Organ Donation Literature line on 0845 60 60 400**

**Or write to The NHS Organ Donor Register**

**PO Box 14**

**FREEPOST**

**Patchway**

**Bristol BS 34 8ZZ**

## NPS(UK) finance report

Submitted by Shirley Raynor

NPS UK Finance Report – September 2005

First of all, I want to say how much I enjoyed meeting everyone at the conference last month. It was wonderful meeting old friends again, and seeing some new faces there. A big thank you to Carol who gives up so much of her time to organise this event!



On to the finance, then.....

Last time I wrote to you we were looking forward to the conference, and raising more funds towards the cost. Money coming in included:

Donations & collecting tins	£302
Bike ride sponsorship	£1075

Obviously our greatest expense has been the conference itself. The total cost of running the event this year was just over £6450 – this includes buying the t shirts, mugs and so on we had for sale.. I think the Moat House did us proud once again, the service was quick and painless– we needed more chairs and, woosh! there they were! – the catering on Friday evening and Saturday lunchtime was excellent.

We raised quite a lot of money at the conference itself, about £800, from selling mugs, t shirts, key rings and, of course, raffle tickets. We had some very able sales ladies, it was VERY difficult to say “no” to them! Thank you also to the generous donors of all the wonderful raffle prizes; there were so many we were able to run 2 huge raffles!!

The only other expense this time is the purchase of an external hard-drive for Carol’s computer, to be used as backup. Some of you know that Carol’s computer crashed the day before the conference, and lost some of her NPS project work. Whilst a lot of her work has now been recovered, we have decided that a backup hard-drive is the best solution. This has cost us £110, and I hope it is being delivered to Carol as I write this!

So once again, many thanks to all of you who raise funds for us. If you are planning any fundraising events in the near future, and think that you might be able to sell any t shirts, mugs or key rings, please let Carol know – we did have a good supply left over at the end of the conference and she will be able to tell you what we have.



If anyone has any ideas, comments, suggestions on fundraising or publicity, please feel free to contact me at any time on the details at the back of the newsletter.

You may want to attempt something similar to what has been going on lately and would like ideas of where to start or need assistance with prizes, tickets, posters etc....

You may have a novel idea and want to get as many people involved as possible. You may have contacts in the media industry or wish to work on promoting ways of improving our publicity efforts of the past.

Whatever your ideas or comments, they are greatly appreciated and I would love to hear from you!

## Roy's maps

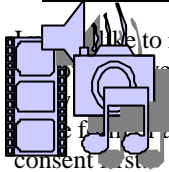
One of our American NPS friends has spent a few years gathering all the names and numbers and locations of NPS affected people in the world. The resources have been from various places and Roy Pirtle thought that it would be a great idea to get a map and some pins. He started off by putting the pins on the places where each of these people lived and now the maps have grown!

Roy, very kindly, shipped over the maps for our benefit at the conference in August and I think that many people were truly amazed at the amount of people listed. It is also wonderful to see at a glance where in the world people are located. There were lots of comments on how much work this must have been and I am sure that it took many days, weeks and months to put together.

I am sure that Roy will be happy to hear that there are a few new names to be added to the ever increasing list and I will add them to his list before I ship the maps back to him. Thank you so much Roy for all this work. I am proud to call you my friend!



## Photos



I would like to make up a little disc for future conferences of people who have become part of our "NPS families" over the years. It would be nice to show this at the start of the conference. I would like to include as many photos as possible and if you would like to be included in this, please send me some either by email or by post. I will put them on a disc to the address below. I have some lovely photos of many of you, but I would need your consent to use them.

## Financial assistance

Many of you have asked about help with benefits that you may be entitled to. It is always something that causes a great deal of confusion and I also have first hand experience of this in my own life.

Thanks to one of our members, she has found a website that is very useful in providing some guidelines in where to go.

<http://www.bhas.org.uk/dla/index.shtml>

<http://www.youareable.com/forums/forum.jspa?forumID=1>

The sites are particularly useful for people who are looking for information on DLA.

Another useful site is <http://www.dwp.gov.uk/medical/med-prac.pdf>

## Website update

We are now able to update our website regularly and we will be shortly adding a few more details/pictures/information etc.... If there is anything that you would like to see included in the site that you feel may be useful, please feel free to send me your comments at any time!



## Contact details and useful sites

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

Alternatively email me on [dobbinsek@btinternet.com](mailto:dobbinsek@btinternet.com)  
Phone me on 01355 241277

For more information on Nail Patella Syndrome, please check out the following websites.

[www.npsuk.org](http://www.npsuk.org)

[www.nailpatella.org](http://www.nailpatella.org)

Look out for our next edition of the Newsletter which will be issued in January 2006!

