

*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 8  
May 2005*

## An introduction from the Chair Submitted by Carol Dobbins

My Goodness! It has been a whirlwind four months! Loads and loads of wonderful fundraisers have made this a busy time. I am also very excited to say that things are very exciting with regards to raising the profile within the media. More on that later!

### MORE FUNDRAISING IN WALES!

On Saturday 5th March, I travelled down to Wales from Scotland with Keith to watch a dance show put on by the talented Lovatt children's dance school which they attend. The journey was okay until we hit major road works and I reckon we were lucky to arrive within seven and a half hours! Any more fundraisers in Wales, I will fly!!

We arrived at Kath and Wayne Lovatt's house and they were all busy preparing for the dance show. The children, Alice and Rosie, were excitedly gathering all they needed and rushing out the door.

Wayne was extremely kind in ensuring we had a lovely meal before attending the Dance Show in aid of NPS(UK). We left soon after and arrived in time for the show to start. Kath was running around making sure that everything was going to plan and that everyone was buying a raffle ticket!! I could see that there was a great turn out on the night and the raffles were selling fast. There were loads of great prizes available. The show was just brilliant. All the boys and girls put such a lot of hard work into making this such a wonderful show. Some of the kids even had the tremendous courage to stand up in front of a packed audience and perform a solo song and dance. Alice Lovatt was one of these girls and I have to say I was so very proud to watch this performance. She is a young star in the making.



Alice performing her solo!

The compere on the night done a great job in reading out a small piece I had sent to explain what NPS actually is. I guess that most people wouldn't have known so he educated the crowd and let them know that Keith and I were in attendance on behalf of the charity. It was also nice to see that all the little programmes and tickets had "in aid of NPS(UK)" for people to see.



Rosie Lovatt displaying her talent!

Young Rosie Lovatt's performances on the night were just brilliant. I could see in her little face how much she enjoys what she does

She is a lovely wee dancer and so full of confidence. I know for a fact that NPS will not hold this young lady back in what she decides to do in her life.

Overall, the night was a huge success and the sum raised reached £900! A lot of hard work went into the organisation of this event and I would like to thank Kath Lovatt and all at the dance school for all their support, once again.

## So what's inside?

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## Fundraising/Publicity updates



On February 12th, Jacquie Gilbank organised her Valentine's Disco event. As usual, this was a great success and I am pleased to say that the sum raised was £320. I hear that it was a lot of fun and I am extremely proud of Jacquie for going ahead with this once more for the benefit of our NPS community. Each time these events happen, we are allowing the subject of NPS to be talked about in a community. I feel proud when people come up to me and say "Oh, you are that lady who has NPS!" It shows they are reading the newspaper articles and it also shows that NPS ignorance is becoming a thing of the past. Thanks to the efforts of Jacquie and many more people, we are certainly making a difference!

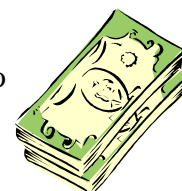


Jacquie also received an incredibly kind donation from a friend who wanted to donate a mountain bike to help increase our funds. The man who decided to help was touched by what he had heard from the publicity that Jacquie and her family have been able to spread in her local community. As far as I know Jacquie has been selling raffle tickets for this and I will let you know the outcome in the next edition.

In the last edition of our Newsletter, I mentioned that Lisa Threadwell asked her husband for support in their local school where he works as a music teacher. A school concert was organised and a lump sum of £100 was raised from George Green's Secondary School in London. Thank you so much for your wonderful support!

As I previously mentioned, on the 5th of March, the Wales Dance School where our budding young stars Alice and Rosie attend raised a brilliant total of £900 on the night. A great deal of work and incredible commitment went into this and I would love to thank Kath Lovatt and all who helped.

As usual, our collecting tin donations have been providing us with the necessary funds that help with the running daily costs for the charity and I would like to thank all those who continue to help in this valuable way. Both Bill and Anne Sneddon have raised a great deal of money this way so far and recently provided us with another £20 cheque! Thank you so much for this support. If anyone would like to contact me with regards assisting in this way, please feel free to contact me on the details at the end of the Newsletter.



Many of you will be aware of the Webb Ivory fundraising this year and I am very pleased to say that as a result of your support on this, we raised £165.26! This was organised by Debby Markham and she done a wonderful job in making sure that everyone received their catalogue when requested. It is such a simple way to raise funds over the Christmas period as the products are lovely and each item paid for means that our charity receives a percentage of the purchase price. If you would like to support the charity in this way this year, I would advise you to request catalogues early to avoid the Christmas rush!

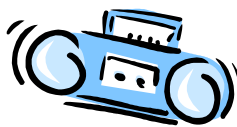
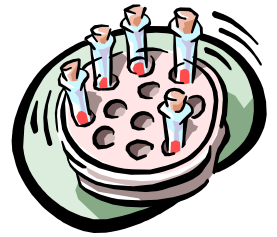
Debby would like you all to know that there are also catalogues available throughout the year, so if anyone would like a copy, please let me know and we will issue you with one immediately.

We have also received some very kind donations over the past few months as a gesture of support and I would like to say a huge thanks for this.

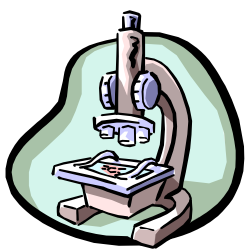
A special thanks has to go to Thea who made a very generous donation in memory of her father who sadly passed away last year. It is not very often in my life when I am lost for words, but this time I am. These acts of love and kindness just overwhelm me with emotion. On behalf on NPS(UK) thank you from the bottom of my heart.

Nail Patella Syndrome UK works closely with two organisations on a daily basis. Both of these networks provide our charity with many interesting projects and seminars that may be available to our community. Very often an opportunity will arise where we have the chance to publicise many aspects of the fact we live with a rare genetic condition. As you know, this is such an essential part of our work as we are able to help others who may read an article, listen to the radio or watch the TV and realise that this may be the reason why they have problems with their nails, knees etc.... We can then provide them with the contact details they need to receive all the necessary information. There are still many people who do not know that their kidneys and eyes can be affected and do not realise the importance of getting them checked regularly.

CAF (Contact a family) contacted me in January to let me know that the Sky News journalist Derek Tedder wanted to speak to me regarding a possible documentary regarding some research that is presently being conducted in Manchester University regarding bone growth that may help people with problems in this area. I spoke to him on the phone a few times and the date was set. Unfortunately, on this occasion there was a trial in Scotland that took all his staff and he was unable to cover the story, however, I have since stayed in contact and he has said he will remember us in the future...fingers crossed!



GIG (Genetic Interest Group) also contacted me on two separate occasions in the last four months, regarding a radio discussion show called "It's my story" and also a Channel 4 documentary discussing the effects people may have relating to the advances in genetics. The hope to film interviews with people who are affected by the advances in genetics, who face decisions about whether to use the technologies available to test themselves, their families or their foetuses



On 27th April, the BBC reporters arrived at my home and we spent a lovely afternoon together talking about the fact we live with a rare genetic condition. The reporter, herself, also has a condition that is extremely rare and she faces many difficulties in her daily life. She has two beautiful children and discusses whether she should have had more or would that have been fair? The programme discusses many aspects of the often painful decisions that have to be made when faced with having a child with a genetic disorder. It will be aired on June 2nd on BBC Radio 4 at 8 pm. I hope that I don't sound like I am rambling as it is a wee bit daunting talking to a large microphone in my face!

I have also received an email from the production manager at Bivouac Productions who are discussing the documentary on genetic testing and eugenics. It is still being considered by Channel Four, who are interested but, are taking longer than hoped to make a final decision about whether to commission the film in full. She has promised to keep in touch and hopes to have an outcome in the next few weeks.

An exciting new website is being introduced which will help nurses, health visitors and midwives learn about genetics and promote understanding about the effects the conditions have on our lives. The project "telling Stories" plans on collecting 80 affected individuals. The website will promote the care and understanding of various conditions and at this moment, I am writing to them on our behalf. I would love to have NPS listed so I reckon I will post an invite to our conference in August too! The team will be travelling across the country looking for a range of different people who are willing to tell their own stories. The project will be run by a team from the University of Glamorgan, University of Plymouth and the Genetic Interest Group. The project is expected to take approximately 18 months. I will keep you all informed on the outcome of this!

## NPS(UK) cycle marathon 2005



I would like to take this opportunity to remind everyone about the charity bicycle ride from Lands End to John O' Groats. Don't Forget, if Mick and Lee are going to be passing close to your home, they would love the support, also if anyone wants to join them at all along the way, for any length of time they would love to see you. Please do your very best and support this incredibly brave attempt for your NPS community.

The Cycle Ride will last anything between 15 and 18 days. This will obviously depend on weather conditions and/or any other hiccups along the way. Hopefully for Mick and Lee, it will go smoothly and I will be able to report a great success in our next issue of the Newsletter in September.

### Approximate schedule

Sunday June 5th—Day 1 From Lands End, the A30 to Penzance and then minor roads to King Harry Ferry around St. Austell and then onto Golant Youth Hostel near Fowey.

Monday June 6th—Day 2 through Looe to the Torpoint Ferry, through Plymouth and across Dartmoor to Steps Bridge Youth Hostel.

Tuesday June 7th—Day 3 through Exeter, Honiton and the middle of Somerset to Street Youth Hostel.

Wednesday June 8th—Day 4 head up towards the Bristol Suspension Bridge and then across the Severn Bridge, through the Wye Valley to Welsh Bicknor Youth Hostel.

Thursday June 9th—Day 5 go via Leominster to Clun Youth Hostel

Friday June 10th—Day 6 head up to the West of Shrewsbury through Ellesmere to Chester Youth Hostel

Saturday June 11th—Day 7 cycle North East through Chorley to the West of Blackburn to Slaidburn Youth Hostel, which is North of Clitheroe.

Sunday June 12th—Day 8 head up and skirt the west side of the Yorkshire Dales National Park through Appleby-in-Westmorland to Dufton Youth Hostel.

Monday June 13th—Day 9 head up and through Carlisle and into Scotland, through the Dumfries to the highest village in Scotland - Wanlockhead Youth Hostel.

Tuesday June 14th—Day 10 may be a rest day as they go in search of food!!!!!! Then they will go again along the B7078 alongside the M74 up towards Glasgow to Loch Lomond Youth Hospital

Wednesday June 15th—Day 11 is the A82 through Luss, Ardlui, Crianlarich, Tyndrum, Bridge of Orchy, Rannoch Moor to Glencoe Youth Hostel

Thursday June 16th—Day 12 is the A82 through Fort William, Spean Bridge and then onto Invermoriston Youth Hostel. Self Catering here again.

Friday June 17th—Day 13 goes up to Duigwall, Alness, Ardgay, to Culrain for Carbisdale Youth Hostel.

Saturday June 18th—Day 14 up to Tongue Youth Hostel.

Sunday June 19th—Day 15 the A836 North and East through Betty Hill, Thurso and finally JOHN O GROATS.



Debby is planning to keep a diary of events as they happen so I am sure that the next newsletter will be filled with lots of interesting facts about this fundraiser!

Please, please support this as best you can as these guys are absolutely sacrificing a lot of their time and effort for our benefit. I have enclosed a sponsor form if you would like to make a donation or ask your friends and neighbours to help.

Please just send your donations to the address at the end of this newsletter. If you would like to pay by cheque, please make it payable to NPS(UK).

Finally, I would like to say to Mick and Lee on behalf of NPS(UK), good luck and bot-

toms up!!



## NPS(UK) finance report

Submitted by Shirley Raynor



Time to put my finance report together again – and we've had so many generous donations in the past 4 months.

Our collecting tins have brought in £54, fundraising efforts £1375 and direct donations of £645. I would like to thank everyone who has made a contribution, either of money or of their time in organising an event. It really is very much appreciated.

We've already started incurring some costs on our forthcoming conference, about £1000 so far. On top of that we have had the usual costs of postage to pay for to send out our regular newsletters.

Taking into account our income and costs over the past 4 months, we now have £10,969 in the bank. As I said in my last report to you, this means that our 2005 conference will be a very special event. I hope I will have the chance to meet some of you there this year!

Once again I would like to ask for your suggestions about other ways that NPS UK can use the funds so generously raised. If you have any thoughts on this, please contact Carol (her details are elsewhere in this newsletter) or me. My address is:

Shirley Raynor  
84 Winsley Hill  
Limpley Stoke  
Bath  
BA2 7FA

[shirley.raynor@gmail.com](mailto:shirley.raynor@gmail.com)

### **Fundraising suggestions**

If anyone has any ideas, comments, suggestions, 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 right now.

## Important conference updates

I am pleased to report that all the conference plans are going extremely well and we will have a great host of speakers who are willing to attend.

Elizabeth Sweeney, giving an overview of NPS, Christine Slavin, talking about the ADHD research that is underway at present, Jeffrey Towers discussing NPS and radiology, Adele Towers, discussing primary care for NPS, Iain Mc Intosh, discussing the genetics and also we are hoping to have Caroline Jones who will discuss the kidney function. At present, we are trying to get Mark Neugebauer who spoke about the eyes at the last conference also.

This year we are pleased to say that we also have Susan Guzman who will speak about all the psychological aspects of living with NPS. The benefits of communicating with others on something that tends to be kept private are immense, in my opinion and I think this will be a great asset to our conference this year.

We will have two separate important group sessions planned for the event also which will allow people with NPS to talk: and those who do not have NPS to also vent their feelings. 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 menus before you arrive to same time when you get there. The children's menu was varied and I hope to have a similar choice this time.

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. If it lives up to the standards of last one, we are all in for a treat!

After the conference, we are likely to have a little presentation and draw some raffle prizes. We have loads of lovely donated prizes this year also so I think many of you could be going home with a little prize!

I am also hoping to sell some t-shirts and/ or mugs/ keyrings etc... If anyone knows of any good contacts in these areas, please give me a call!

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

All that remains to be said is that I hope you take this opportunity to come to the conference this year. I promise you that it is a wonderful occasion! See you in Chester!

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

Look out for our next edition of the Newsletter which will be issued in September 2005

