



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.

An update from the Chair

Submitted by Carol Dobbins

Chester 2003– Our First NPS(UK) conference



Pictured above is a photo of many who attended the conference.

What an incredible weekend.

My version of events started on the Friday morning as we set off for Chester with 2 cars. I was driving one with my daughter, Nicola and Julie-anne Pickett, my dear friend from Illinois, who I have worked with over the years to promote awareness and raise funds in our sister organisation NPSW. Our car was jammed with literature, prizes for the raffles, toys and games and much more.

Keith, my hubby, was driving the other car with his mum Sheila and Aunt Marion who were our kids room carers for the day of the conference, and also my son Stephen. His car was equally full as we all set off for the beautiful city of Chester.

We arrived just after lunchtime and were greeted by a very friendly staff at the Chester Moat House who directed us around the building and all the places we had booked for the day. I must confess, I was absolutely astonished at the layout of the rooms and the support from the staff was just wonderful. The Chester Suite was laid out for the Friday evening “Meet and Greet”, the Malpas Suite was given to the children,

*Many thanks to so many who helped make this an incredible success:
Elizabeth Sweeney
Iain McIntosh
Adele Towers
Jeff Towers
Mark Neugebauer
Jennifer Dunston
Ketki Desai
Shirley Raynor
Julie-anne Pickett
And many more!*

The Edwards 1st Suite was given to the children where they could eat at lunchtime and the Charles 1st Suite was where the conference was to take place. We were also escorted to our own little conference check-in desk where I quickly stuck as many posters up for all to see that we meant business!! As the hours passed, more and more faces appeared and the excitement really began. Over the past weeks, months and even years in some cases, I have just spoke to these people via email or on the phone. It is an incredible moment finally getting to see the faces.

For me, meeting the children was incredibly touching. I know that in many cases I have hoped and prayed for so many of them to get through some of their problems they have unfortunately had to face in their young lives, and finally getting those long awaited hugs was heaven.

Thank you kids!

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The "Meet and Greet" began at 7 pm on Friday August 15th. There were a lot of people, far more than I had anticipated and I made a few calls to the Hotel staff requesting "More chairs please!" The finger buffet was wonderful and the bar was well used! The children and adults had a great time chatting with their new found friends and comparing body parts. In some occasions, there were even some wonderful party tricks to see. You will need to ask Amani Haskins and Susan Hopkins about these!!

On the morning of the 16th August, I got up at 6.30 am to get ready, steady the nerves and go and see what was needing to be done in the preparations for the day itself. The Audio-visual guys arrived very early which was a great bonus as I am not an expert on these matters at all! These guys were brilliant and I owe a great deal of thanks to them for being so patient with a complete novice in this area.

Many people filled in their registration forms on the Friday evening so it meant that we could start on time. The children's room filled up with lots of excited kids and Sheila and Marion entertained each and every one of them very well indeed They all had little party bags and balloons to take home with them at the end of the day They had games galore and I knew that they were in great hands so the parents and family members could go ahead and enjoy the conference.

The room filled and the talks began. It was incredible to see such a huge turnout – 110, to our first NPS(UK) conference, some people discovered their relatives for the first time in years, or in another case for the first time ever! It was very touching

The panel shared their wealth of knowledge and answered many questions for so many and everyone was given the opportunity to ask questions in the afternoon if they felt they wanted to ask more. Many people took part in the medical research purposes by giving blood and filling out questionnaires etc... which is so vital for us all to help with the research.

The food was incredible at lunchtime as the adults retired to the Silks Restaurant and the kids sat in the Edwards 1st Suite.

At the end of the day, the children made a presentation to the speakers and also to Julie-anne for all their hard work and unbelievable work that they do for us all. I could never thank you enough. I was very shocked at the most beautiful presentation that I also received and I was touched beyond belief.

We finished with the raffle prizes, football coupon winner and also some great photos. It was a great finish to the most amazing day.

For me, I found some great new friends, both adults and children and many of them are in my heart forever. I will never forget those hugs from the little kids– NPSers are definitely the best huggers in the world!



NPS(UK) Fundraising updates

Since our last newsletter, our campaign to raise awareness and increase our funds have improved dramatically. It was a very busy time, but equally so much fun.

On the 29th March 2003, we organised a disco fundraiser in our local pub, the Stewartfield Farm. It was a huge success and we raised a great deal of cash and also gained much publicity in the local newspapers, once again.

On the 18th May 2003, two wonderful ladies ran the Ladies 10K In Bellahouston Park in Glasgow for us and raised a great sum of money. Thank you to Angela and Rosemary for all you have done for us!

On the 24th May 2003, my husband, Keith and nine other willing participants decided to take on an incredible challenge for NPS(UK). They thought that they should try and raise awareness and funds by climbing 5 munros in one day! I am so very proud to say that they very successfully completed this without

injury or any major aches and pains. Between them all, they raised a whopping £2,000. This was a great accomplishment and also a great boost to our funds as we planned the first NPS(UK) conference.

Thank you so much to each and every one of you guys for all that you have done and continue to do for us.



21st September 2003, The Great North Run

Thanks to Jacquie Gilbank, once again, she has found a willing volunteer who would like to take on this challenge for our cause. The gentleman has his NPS(UK) t-shirt to wear on the day also, so hopefully will generate a little more interest in what we are doing.

On behalf of us all, good luck!

We also have some support from a school headmaster who has said that he will remember us at their next event in the school, in Mid Glamorgan, which may be very soon. I will update you on this in the next Newsletter. Very exciting stuff! Thank you so much to Kath Lovatt for looking into this for us.

We have had various suggestions and many people have asked for collecting tins to be sent to them. In Mid Glamorgan I just ask people to remind me who would be keen on doing this?

I have a neighbour who spoke with his boss about organising a fundraiser football match and asked if they would support this idea. He was told that they would match all the money that is raised in an event like this, so this sounds like a great boost for us.

Another kind neighbour tried the same tactic and was told that they will match up to £500 per employee from the company if they provide proof that they have taken part in a fundraiser...so I better get my thinking cap on

Regarding publicity, we have moved on since the conference in Chester. I have been working with a lady who produces a magazine called "I can do that!" She is going to print a story about NPS and all it entails. This will go out to hospitals, GP surgeries and pharmacies throughout Scotland.

I have also given an interview to our local newspaper, the EK News about the conference and they will keep the story running in the paper to promote awareness.

We have had more people who have approached their local media and one has even managed to appear on local Radio. This man also managed to get "The Sunday Independent" interested in writing a report too. It is the biggest selling Sunday broadsheet in the Republic of Ireland!

We have had a lovely lady come forward who works within the voluntary sector and would like to assist with producing thousands of leaflets throughout England as this would benefit our awareness campaign tremendously. Thank you so much with this offer!

I was also alerted to an article that is running in the Daily Express, called "Charity champion" and it describes many different charities and their functions. I wrote to that immediately and am awaiting a reply. Thank you so much, Thea, for contacting me about this.

If anyone has any other ideas they would like to raise, please do not hesitate to contact me anytime.

Fundraising/ Public awareness ideas?

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.

Do you know of anyone who may be in a position to help us?

Do you have any contacts with companies who may have a Charity Fund and who may support charities here in the UK?

Do you know of any local shops, pubs, clubs who would be willing to place one of our collecting cans on their premises?

Do you have access or know anyone who may have access to unwanted office supplies? i.e. paper, envelopes, pens, ink jets, unwanted equipment such as copiers, printers etc...

Can you help increase awareness into this rare genetic condition? i.e. newspaper sources, media contact, medical journals etc...

I spoke to some of you who offered lots of support in Chester. Please contact me again and we can discuss the details.

If you 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

With many thanks!



Shirley, Julie-anne and Lisa in Chester.

Thank you so much to Shirley Raynor, our NPS(UK) treasurer, and also to Dr. Elizabeth Sweeney, our NPS(UK) secretary. Your work has been just incredible and it would never have all come together without you.

Elizabeth (centre) chills out after the conference with Ketki to her right.



You must all realise by now that the success of the conference was down to all of you. People have helped in so many ways by raising money, and awareness and I just can't thank you enough for what you do, but it is so important to realise that the simplest little things are also so very important.

Thank you so much for all the beautiful letters of support, I will treasure them all forever.

We are, most certainly, going to plan another conference in the UK in 2005. It will likely be in Scotland so I will look into this further and allow plenty of time for saving the cash and getting time off work etc...

More on that in the next Newsletter!



Finance Report September 2003

Submitted by Shirley Raynor

NPS UK Finance Report – September 2003

It doesn't seem very long since I was preparing my last report to you all, when we were looking forward to the conference and we had so many people working very hard to raise the money to hold it. At that time – April - I was very pleased to report that we had £3200 in the bank, but between then and the conference our bank balance more than doubled. What an incredible achievement! So many people contributed to this increase; Carol Dobbins ran a disco and raised almost £600, we had an individual donation of £1000, and some very brave Scottish souls climbed 5 munros in one day to raise about £1600. On top of that we had so many other generous donations and events raising funds. By the time the conference date arrived, our total income was over £7000!!! I have now updated this, and the new total is shown on my summary below.

Our expenses over the last few months have mainly involved the conference, not surprisingly. Until that date they were very modest, only just over £300 – these are included in the summary underneath. The conference itself cost just over £4200, but to offset that we received conference registration fees from those attending, plus we had income from the raffle and sale of NPS mugs and keyrings. After taking all of the conference takings into account, the conference actually cost us about £2900; or about £26 per attendee. I personally think we got brilliant value for money, and I have to thank all of those people who either helped to organise the event, or spoke at it, or gave a gift for the raffle, or helped in any way so that we could provide this wonderful conference at such a modest price. Anyway, enough waffle from me, now for some numbers...

These figures cover all of 2003 to date

Income		
Fundraising		4415
Donations		2615
Conference Income		1339
		<u>8369</u>
Expenses		
P O Box	52	
Postage	21	
Printing	95	
T-shirts for runners	90	
Collection Boxes	104	
Mugs/keyrings	90	
Conference equipment hire	242	
Gifts for speakers	120	
Conference Hotel bill	3835	4649
Balance		3720

The funds remaining will be a huge asset to us for our plans to target doctors and specialists, to try and make them more aware of NPS and the various effects the condition can cause, as well as continuing to provide everyday support over the telephone, and by post to all of the NPSers around the country.

Once again, I will sign off by saying THANK YOU to everyone who has given time, effort, advice or money to make our organisation achieve so much in such a short space of time.

Rosie's account of The Conference

Submitted by Rosie Sharratt- aged 14

Despite the long journey from Bath to Chester (but not as long as some people's, I know!) the conference weekend for NPS was a great success, from the hotel to the speeches to the staff ... When we arrived we went to the conference desk to meet Julie-Anne (in her St Louis T-Shirt!) who gave us our name badges. Then we went up to our rooms (which were lovely) to freshen up a bit, and later in the evening we went down to the conference reception, where we met loads of people with knees and nails just like ours! It was nice but weird being able to compare nails instead of hide them or have to continuously explain that you definitely don't bite them.

Me and Nicola Dobbins went round selling raffle tickets for Saturday, the main prize being a DVD player. I'm not sure what the total amount raised was, but we got through at least three raffle books! On Saturday, the conference began shortly after breakfast at 9 O'clock, which I went to. Because I'm fourteen, I managed to get the best of both worlds, the talks and the kids' room and pool! At the break I went to the kid's room, and I, Kyle, Jim and my brother Ben went for a swim, and Nicola and Megan soon joined us. The ladies who looked after us in the kids room were really nice and friendly, and the talks I went to were very interesting although I got a little bit lost on some of the genetics! After the talks, the winning raffle tickets were drawn, and the conference was finished. Lots of people started to go home, which was quite sad because the weekend had gone too fast! I can't wait for the next NPS conference in the UK, it was a great experience!

Fresh ideas from some young minds!

In the next edition of our Newsletter, I would like to add a "kids Page".

In my opinion, we have some pretty smart young ladies and men out there who have NPS or who are living in a family where other members deal with NPS issues. I saw many of these little faces in Chester this year and I was really impressed. I reckon there are some little artists, authors or comedians out there who would like to share their pictures, stories or jokes with us all in the next Newsletter in January 2004. Prove me right on this and I promise to add your work to the next edition. Just get your mum or dad to post it to me or email it to me, easy as that!

For this to work, I think we need a kids logo design, with possibly a slogan. Which one of you can come up with a great logo?

I would like to add a letters area to our page where you can ask questions, share emotions, talk about issues that may concern you. You can even use it to just say "Hi" to a fellow NPSer and become pen pals.

Let me know when your birthday is too and I will add your name to the next issue reminding people that you are a year older!

So, come on then, prove to me that kids with NPS or who live with family members who have NPS are pretty cool!

Contact details and useful sites

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

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

Nail patella Syndrome website with useful information can be found on

www.nailpatella.org

A new site is being constructed at www.npsuk.org

Look out for our next edition of the Newsletter which will be issued in January 2004.

NPS(UK)

