



Issue 19
January 2009

An introduction from the Chair
Submitted by Carol Dobbins



What an eventful year 2008 was!! To be honest, a New Year suits me very well! This newsletter will be a little different to others that have been issued in the past as I would like to focus, predominantly, on the conference plans for this year. The Newsletter will be shorter in length too as I want to attach a few forms for you to look at if you are interested in coming along to our next conference. Unfortunately, I will be facing more surgery on the 14th January also where a fourth attempt will be made on my left elbow. A new prosthetic has arrived from America and the surgeon is willing to try again to see if I can regain some use of my left arm. I place all my trust in him and will hopefully be posting a good news update in the next newsletter!

In August 7th– 9th, we have secured a booking for our NPS Conference at the Crowne Plaza Hotel in Chester. This venue remains the first choice for our charity as it has consistently provided us with all that we need. We have built up a great relationship with the staff at the Hotel and they are looking forward to seeing us all again!

At this moment, we are awaiting response from our invited speakers and I will be able to confirm this with you all in the next Newsletter in May. We aim to provide a list of speakers who have knowledge and experience with NPS in a wide variety of areas, including genetics, renal, ophthalmology and orthopaedics to name a few. We plan to host our usual Question/Answer session where each guest has the opportunity to ask the speakers and NPS related question they may have. It is a great chance to get the answers to any issues that you may have regarding your health or the health of a family member or friend or even raise a question about the charity itself. We are all there to help in whatever way we can. You may feel that you would not like to talk in a room full of people, but that is ok too as you have the opportunity to write down your question which could be read aloud at the conference and you may remain anonymous.

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On this occasion, we would like to try and get a speaker to attend who will be able to answer questions relating to social services or filling out Disability Living Allowance forms etc... We have tried to achieve this in the past, but have been unsuccessful, however, hopefully this year we will be able to provide a slot for anyone who is interested in this.

On the day of the conference, we will supply a room for the children where they can play. This will be supervised by our helpers, hopefully, Sheila and Marion, once again, who have been happy to take this on for us for the last few years. We would also welcome any other volunteers who would be willing to help with this. All parents/guardians will just need to sign a simple form to give consent for their child/children to be cared for during the conference hours.

NPSUK will supply refreshments in the morning and afternoon during break sessions and also a beautiful lunch at the Crowne Plaza. For those of you who have attended in the past, I am sure that you will agree, the food is good!! All the children are given a choice of food from the children's menu which I should receive in advance of the conference. I plan on sending these out to everyone who is willing to attend with their children.

We are also very fortunate to have a kind offer from Heather, who attended our last conference and who also shares NPS with many of us. She would like to use her experience and talk to us about body posture in little group sessions of approximately a dozen people or so, which at this stage, we plan to host on the Friday evening, during the Meet and Greet. As this is still early planning stages, these plans may vary slightly, but, usually it is just a matter of reshuffling around a bit!

The Meet and Greet is always a very nice way of introducing yourself to others who share this condition with you or who have family or friends who live with this condition. It is very informal and our charity is happy to provide a finger buffet on that night. If anyone has any special dietary requirements, please let me know in advance and I can let the catering staff know. I have always enjoyed this occasion as it is often a time when people get the chance to really get to know one another more or even meet up for the first time. It is always lovely to meet new people and hear their stories. Many of our speakers attend this informal gathering also, so it is also a chance to get to chat to them. We usually have a little raffle during the evening also, so if anyone has any unwanted Christmas presents and does not know what to do with them, please save them for us. We need as many people as possible to donate what they can.



On the Saturday evening, we plan on having an after conference party, where we can all get together and chill out, have some fun and get the chance to know one another and share telephone numbers! For those of you who attended the last time, we had some very memorable moments of dancing and singing, that will stay in my mind forever! The children are also welcome at this event and last time the dance floor was graced by many little Fred Astaire's and Ginger Rogers! If you like Karaoke too, you may need to lubricate those chords...I wish Kath, Shirley and I had lubricated ours more at the last conference!! I think we screeched our way through "I am what I am" to the horror of those poor people sitting on the seats! This is your chance to entertain us!

Do we have any secret Elvis Presley's or Whitney Houston's out there? Do we have any talented children or adults who would like to sing, dance or play a musical instrument for us? What I realised at the last conference was that even though we live with some hurdles in our lives, we still know how to have a good time! It was so great to dance without feeling that people were staring at my bent elbows and I loved every minute of feeling that I was celebrating my friendship with some of the nicest people around and who had a greater understanding of what life is with NPS!



On the Sunday, we plan to host our little break-out sessions again, which I found to be very therapeutic for many. It is a chance to talk confidentially, for those who have NPS and for those family and friends who do not, but who care for someone who does. I often think that the needs of those who are family members of people who live with NPS are forgotten and on many occasions they have so much that they need to say too. We hope to host meetings for both adults and children separately and for those who have NPS and those who do not. I will never forget these sessions...they will live with me forever. For those who feel that they may like to attend, but are worried that they don't feel they would like to talk, don't worry. You can go along and listen, and I am sure that before long, you will be listening to people whose lives are incredibly similar to your own. You should then walk away feeling less alone and more aware that there is a huge network of people out there just willing to listen and be there for you.

Once again, we hope to invite the Everyclick mouse to our event, so look out for a large blue mouse wandering around! This highlights the work that they do for us! They have helped us raise a huge sum of money for our cause and at the last conference they came along and took some pictures of handing over a cheque for a large sum of money!



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





You may remember from our last Newsletter that Jerry Crook took part in the Just Walk fundraising event to raise a huge sum of money for our charity. Jerry is hoping to be able to do this again this year and my husband, Keith, would like to go along and support him by taking the challenge on too. Hopefully, he can drag another friend or two also and make this a much more social occasion for Jerry! If there are any other willing volunteers who would like to take on this challenge, please get in touch. There are various route lengths to choose from, so I

will let Jerry and the team of NPS walkers work out how long they plan on going! To be honest, the 10K route looks long enough to me, but I will support them whatever they decide to choose. The event this year is on Saturday May 9th and is located on the South Downs. The scenery is beautiful and the start location is Goodwood racecourse.

For more information, please visit www.just-walk.co.uk



In the last edition of the Newsletter, I was happy to let you know that Trevor Carmichael ran the Glasgow Half Marathon for NPSUK! He succeeded in a great time and was able to donate £580.00 to our charity! Thank you so much Trevor!

We also received £630.00 from Phil Lush who took on a challenging 55 mile walk along the coast of Kent. Thank you so much Phil!

James Kelly also donated all the printing of the Newsletters for us again. This is a great help for the charity as it uses up a lot of what we raise. James has also informed me that they sent around an email card instead of Christmas cards this year and therefore would like to donate the money saved to NPSUK! Thank you so much!

I would like to thank great friend, Gillian Docherty, who also did this and collected £30.00 for our charity!

Once again, my good friends, Julie and Paul Cumiskey, who own Fresh'n'less in Rutherglen donated more money to our charity. I tallied it all up over the year and in 2008, they donated £284.25 from 4 collecting tins in their shop!

Thank you also to Elders bar for their ongoing support from the collecting tins.

Now I need your help! 2009 is the year of our conference and we really need to get collecting as much as we can to make the conference a success. It has been very difficult for me to plan too much due to my upcoming surgery, but I really need to rely on those of you who feel you would like to take on a challenge.

If you feel you would like to try a marathon, a walk, organise an evening of fun, or come up with any other idea, please get in touch,. I can supply you with the sponsor forms and be there for you along the way.

If you have received any unwanted Christmas presents and are unsure what to do with them, we could use them for raffle prizes, so please bring them along with you or send them to me. If you think you could get some good raffle prizes for us, please get in touch. I have started collecting, but we don't have anything too exciting yet!

If anyone feels that they would like to help out as a volunteer in any way at the next conference, please get in touch too. I am sure that Kath, Shirley and I can assign a good job for you. There is so much to organise at an event of this size and I am a little bit obsessive about getting it all right!!!



I have entered NPSUK into the Everyclick Charities Challenge 2008/09 and registered NPSUK to take part in the 'Less than £1.5m' category. The competition is about getting as many of our supporters to use Everyclick to fundraise online for NPSUK as we can.

We need to ask friends, family, donors and corporate supporters to help us win this competition! This competition is not just judged on how much money we raise but also how innovative we are at promoting it.



If anyone has an novel ideas about how we can gain supporters for Everyclick, please get in touch! It is a wonderful competition.



For those of you who will be travelling to the conference in August this year, we are fortunate to be working with a great group of people at the Chester and Cheshire Conference Bureau who have provided us with a list of all the alternative accommodations in the area. They are usually all within easy reach and are there to help and advise you. If you would like to use their service, they have created a page especially for us on their website. Just click on the link



<https://www.conferencebookings.co.uk/delegate/CHSNPS> and you will be able to access the page and look for accommodation and reserve online!

For those of you without easy access to the internet, I have listed below a couple of Hotels that has been recommended.

If you would like to use their service, you can contact them on 01244 405636 and ask for Ashley Shacklady or fill out the booking form that I have enclosed with this newsletter.



Ideally located one mile from junction 12 off the M53, close to the M56 and one mile from Chester City Centre. The Comfort Hotel, refurbished in 1999 offers excellent bedroom accommodation in a quiet garden setting. All 31 en-suite bedrooms have extensive facilities designed with your comfort in mind.

Single B&B room is £55.00 Double is £75.00 Twin is £75.00



The Westminster hotel is the ideal venue for conferences and events. We are perfectly located near the train station and only 10 minutes walk into the beautiful historic city of Chester. There are fabulous executive rooms and affordable standard bedrooms all with free wireless, some with LCD televisions and ipod docking stations. We do the "best breakfast in Chester" well that's what our customers say! and we have a delicious and affordable restaurant and bar menu on offer all day from 12 noon. We have a great bar showing sky sports and playing tasteful music to relax too.

Single B&B room is £69.00 Double is £79.00 Twin is £79.00

These are only 2 examples from an extensive list that I have attached.

For those who feel that they would like to attend the conference, but feel that financially it may be difficult, then we may also be able to help you. NPSUK set up a Travel Fund which is designed to help those who feel that they would require some financial assistance. **Please note that NPS(UK) is limited in the number of individuals it can help and is also limited in the amount it can help each individual. Please understand that total expenses are not covered.**

All applications are strictly confidential and I have also enclosed the application form with this newsletter. We have a very limited pot of cash, so if you need to apply, please do so as soon as possible. We have a deadline of 31st May. This allows us time to look closely at each application and decide what contribution we may be able to make. I am sure that it helped a few people in the past to experience the conference and NPSUK ARE very proud to be able to provide this service.

Finally, I hope to see many familiar faces and many new faces at our conference this year. I can honestly say that it is an occasion that I would not miss for anything! (not even a snuggle with John Travolta!)

If you have ideas or suggestions, get in touch. The conference is for you!!

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 May 2009. If you have any photos or stories 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.

For more information on Nail Patella Syndrome, visit:-

**www.npsuk.org
www.npsw.org**



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