

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

It always inspires me to hear what others are willing to do for our charity! In this edition, I am very pleased to say that we have volunteers from all over the country who have dedicated some of their precious time to NPSUK. They have bravely taken on challenging walks and runs and raised the profile of our small charity yet again and they have also raised a great deal of money. This money is vital to keep our charity work ongoing. It is such an integral part of many of our lives now; simply to know that there are others out there who are just like us! Thanks to our volunteers, we have collected a great deal of money that helps to keep our dream alive. Many thanks to Jerry, Phil and Trevor for all their efforts!



**Jerry Crook (above)**

Jerry Crook, whose wife Tina shares NPS with many of us, decided that he would like to take on the challenge of the “Just Walk” event on the 10th of May this year. This 20 km walk took place on the edge of the South Downs in Sussex. Jerry managed to raise a huge sum of money. You can read more about this from Jerry on page two. If anyone would like to learn more about this challenge, you can visit [www.just-walk.co.uk](http://www.just-walk.co.uk). If anyone feels like they, or even a friend of theirs, would like to attempt this challenge, please get in touch. We are always looking for willing volunteers.

Phil Lush, who is the neighbour of Lisa Ward (nee Threadwell), who also lives with NPS, took on a challenge in June this year to walk from Hythe to Herne Bay, along the coast of Kent. This was a gruelling 55 mile walk and I am pleased to say that Phil successfully completed this, raising awareness and a significant sum of money for charity. .. **£630!!!**



**Phil Lush (above)**

Lisa planned to be there with him supporting him all the way, but unfortunately, NPS surgery got in the way! However, as I am sure that those of you who know Lisa will agree, she is a true fighter for the cause and decided that even though she would be facing very uncomfortable surgery in her neck, she would still do what she could to raise awareness. Lisa has given me permission to add this photo of her as she lies in her hospital bed, just after her surgery!! Now, that is a genuine supporter of



**Lisa Ward (above)**

NPSUK!!!! Lisa is recovering very well from her surgery and is gradually getting back to normal again. Thank you for your wonderful support!

Trevor Carmichael is a good friend and neighbour of mine and approached me recently to ask if he could run in the Glasgow Half Marathon for NPSUK. As you can imagine, I was very happy to accept and passed on the relevant sponsor forms to him. On the 7th September, Trevor successfully completed this challenge with a fantastic time of 2 hours and 15 minutes. He wore our t-shirt on the day and I am sure managed to raise some interest in the charity. He is collecting his sponsorship money at the moment, and feels that it is all going well. I will let you all know how much Trevor’s commitment to our charity raised in the next issue.

For more details on this marathon run, please visit [www.runglasgow.org](http://www.runglasgow.org)

If anyone feels like they would like to attempt this, or any of the other marathon events next year, please get in touch, using the details at the end of the newsletter.



**Trevor Carmichael (above)**

<b>So what’s inside?</b>	
<i>Our fundraising heroes!</i> <i>Jerry Crook</i> <i>Phil Lush</i> <i>Trevor Carmichael</i>	1
<i>Jerry’s story</i> <i>Other donations</i>	2
<i>Everyclick</i> <i>NHS 24</i> <i>Patient View</i> <i>Appeal for more stories and health related questions</i>	3
<i>Kath Lovatt</i> <i>Information on GAYE</i>	4
<i>Finance report from Shirley Raynor</i> <i>Everyclick information</i>	5
<i>Conference plans</i> <i>Contact details</i>	6

## SOUTH DOWNS WALK by Jerry Crook

Well, I was sitting at the computer one day wondering what I could do for our wonderful charity to raise funds to help raise awareness of NPS. Firstly, I thought of a run, then I thought I ain't built for running anymore, so that idea was sent to distant memory. Cycle ride, no bike. So I typed in "walk" and up came JUST WALK CHARITY, for a small fee you can walk what ever distance you want and all the money you raise goes to your chosen charity. So I signed up.

No turning back now, Carol did me some sponsorship forms and off I went gathering up sponsorship.

The weekend of the walk quickly approached. Tina and I traveled down to Chichester in Sussex on the Friday afternoon because we had decided to make a weekend of it. After 2hrs of driving we arrived in Chichester, quickly settled into our hotel. We had a lovely evening meal then an early night ready for the following day.

We were both up bright and early on Saturday. We left the hotel at 7.30am and arrived at Goodwood Racecourse; the venue for the start/finish of the walk about 20 minutes later. We signed in and were treated to bacon sandwich and a "cuppa" before the start of the walk. There were about 400 people taking part, some individuals, but most in TEAMS (hint hint). After a brief warm up, we all set off just after 9am. I had signed up for 20km (12 mile) walk. It was a really lovely day and the scenery was fantastic, believe me. The start was a bit slow because we had a lot of stiles to cross, but after a while we began to space out and get going. After about 5km we all stopped to pick up our packed lunches. Everyone chose their lunches put them in their rucksacks and headed off. We walked through lovely villages, then headed into the woods and took some shade as it was getting warm. Everyone was really friendly and plenty of people spoke and some asked what charity I was walking for, so they were politely informed and were very interested. I walked fairly steadily stopping at each check point to take on water and my packed lunch, at each check-point too there were even more refreshments on offer. After 4hrs and 30 minutes, I finished the walk and it was very satisfying to know that I raised just over one thousand pounds for NPS and to see Tina at the finishing line. After picking up my free t-shirt we set off back to our hotel.

The walk was a challenge and hard in places but overall a good stroll for confident walker and I knew all the army training many years ago would come in handy one day. So who is going to join me next year?

On Sunday, we checked out of our hotel and set off home after a lovely weekend. Nice hotel, great weather, money raised and my lovely wife Tina as company.

Yours Sincerely,

Jerry.



If anyone feels that they would like to join Jerry again next year, please get in touch! My husband, Keith, would love to join him, so we would like to have a team next year, as opposed to a single walker, which can become quite lonely. Next year, the event will take place on Saturday, May 9th. There will be various route lengths ; 60KM, 40KM, 20KM



Many thanks to those of you who continue to support our charity by using the collecting tins. This is a great way to generate funds. Every copper counts!

Special thanks go to Paul and Julie Cummiskey, for placing 4 tins in their shop, **Fresh n less** in Rutherglen, **Elders Bar** in Tollcross and Bill and Anne Sneddon, who continue to send what they can. This helps with the day to day running costs of the charity and also goes a long way to making a difference!



**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



In January 2008, we began our campaign to win the Everyclick.com Charity Challenge, by encouraging you, our supporters, to use Everyclick.com to help us to try to win the charity a national advertising campaign. Unfortunately, we did not win this time, but we wanted to thank you so much for helping us take part in the Charity Challenge.

Through your searches on Everyclick.com we have been able to raise a huge amount of money for NPSUK which will help benefit all those who live with NPS. This fantastic amount of money is also an unlimited resource, so the more Internet searches you perform on Everyclick.com, the more money we can continue to raise for NPSUK.

Everyclick.com has also just launched a free donation service for all UK charities. This means that you are able to donate money to us via their online donation service, at absolutely no administrative cost to us. So if you would like to donate directly to us, please visit [www.everyclick.com](http://www.everyclick.com) and follow the directions.

In the meantime please keep using [www.everyclick.com](http://www.everyclick.com). Thank you once again for your support, we really appreciate it.



The outstanding winner of the competition was Diabetes UK, whose supporters generated an 117,530 searches on Everyclick.com, thanks to the charity's innovative methods of gaining support for this campaign.

Diabetes UK has won an enormous Clear Channel Outdoor advertising campaign at 1,500 poster sites across the UK, which they will use to promote the awareness of Diabetes UK.

The first of the two runners up is The Arnold Foundation for Rugby School, who won the small charities category. Their entry was so impressive that the Foundation has also secured a local poster campaign with Clear Channel Outdoor, which will promote the awareness of bursary supported placements at Rugby School. The judges were hugely impressed that such a small charity with a specific, local remit was able to generate so much attention and support for its campaign.

The second runner up, and winner of the medium charity size category, is Cystic Fibrosis. The charity will receive free advertising space on Everyclick.com.

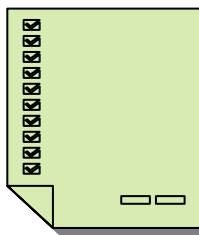
You can see all of the winning charity entries at: <http://charities.everyclick.com/charities/charity-challenge.htm>

Much of the work that we do, behind the scenes, so to speak, is to raise the profile of this rare genetic condition. By adding our details to databases throughout the length and breadth of our country, we increase awareness. We also take part in studies, fill out questionnaires etc...



Recently, I added our details to an incredibly valuable source of support to many here in the UK, NHS 24. Our details are now listed on the Scottish Support Group Directory, and I hope that we can expand on this for all other directories in the UK. The directory will be hosted on the NHS24 and Breathing Space websites and available to the public as well as their call handlers and counselors.

As the directory will be going live in the next few weeks, we completed the form and sent it back immediately.



Another organization I have been working with is Patient View. I took part in a survey with them a few months ago and recently they contacted me to say that thanks to our contribution they have been able to have an article on quality of life published in a peer reviewed journal on a new tool to measure the quality of life from the patients' perspective. A copy of the article is attached and the URL is [http://www.bjhcm.co.uk/public/275\\_279\\_BJHCMNazarko.pdf](http://www.bjhcm.co.uk/public/275_279_BJHCMNazarko.pdf)

They are now in the throws of the next stage of the project to put this tool on a more academic footing, their partners in this next stage are representatives from the University of Oxford (UK), Warwick University, University of Ireland and Macmillan Cancer Support.

*Patient Views  
for improving patient care*

#### [Question and answer medical section/ Personal stories](#)

You may have noticed that these sections are missing from our newsletter on this occasion. This is purely because no questions were put forward. I would love to hear from you.

**Please keep sending me all your questions for our medical section and stories for our "personal stories" section. I look forward to adding them to our next newsletter. You can send them by email or post.**





**Submitted by Kath Lovatt**

Here we are in September – where has the year gone? For me the last few months have been fairly quiet as I spent a majority of it recovery from major surgery and was unable to get on the pc upstairs and my lap top decided to die on me! However, that has been fixed and I am much more mobile now after a full knee replacement.

We have had some very positive comments regarding the Family Route Map that GIG produced. It would be fantastic if we could get it distributed to every genetic clinic and health practice across the whole of the UK, but we need more in the way of much needed funds to be able to do that.

I have taken many calls over the last few months on our 0800 number. Never be afraid or embarrassed to pick up the phone and talk to me. I myself as you are aware have NPS and also I have a 12 year old daughter that is affected. Everyone feels isolated with this condition as it's not something that is widely known about, so if it helps please do not hesitate to ring for a chat. I am still getting a large number of website enquiries and we also get many new visitors to our website on a daily basis which is tremendous because it clearly states that the information being provided on the NPS UK website is an asset. I know I say this every time, but if you have any ideas of what you would like to see on the site then please speak up. Carol, Shirley, Wim and I need the feedback and ideas!

In the next few months we shall be holding meetings to discuss the next conference for August 2009. This takes up a lot of time to organise, and again any feedback on our 2007 conference would be great if there was something you didn't like or would like to have talked about, or even enjoyed! We are keen to take your ideas on board and try and incorporate them as and where we can. I can't stress enough to someone that has never been to a conference before to go as you will make many new friends and just the experience of being there is enough.

I would like to thanks James Kelly yet again for his support and also the company that he works for as his partner Karen got in touch with me and informed me there was a cheque on its way as the staff had a dress down day and James nominated NPS UK! Many thanks for that it's very much appreciated. At this moment in time we need to get as much as we can in the way of funds so that we can put on another successful weekend conference, so any idea's, suggestion or offers would be wonderful.

I also mentioned in the last article that a database of UK consultants that have helped NPS patients would be great to have on the website or kept on file. I get many phone enquiries for various areas in the country asking for names of helpful consultants and it would be nice to pass on your recommendations. If you can help in this way either call on 0800 121 8298 or email details to [npsuk\\_info@yahoo.co.uk](mailto:npsuk_info@yahoo.co.uk) and I will add the details.

Regards to all,

Kath

■■■ charities aid foundation

CAF

You may remember from the last newsletter that James Kelly was in the process of setting up the "Give as you earn" donation to NPSUK. I am happy to say that James set this up and is now making a monthly contribution to our charity. It is a very simple process to set

up and you get to decide how much you would like to donate. The donation is made before the taxman gets near it!! If you are a basic taxpayer, a gift of £5 will only cost you £4—so you can pass the tax relief onto the charity. Once again, it is a wonderful scheme that is a bit of a life saver for small charities, such as ours. For more information, visit <http://www.cafonline.org/default.aspx?Page=7026>

Or call them on 01732 520 019.

HYMANS  ROBERTSON



Once again, James informed me that his work ,Hymans Robertson LLP, organizes a "Charity Friday", where all the staff make a £1 donation in exchange for not being suited and booted on that day!! James was able to put forward his suggestion that NPSUK would benefit from this and, thankfully, this was accepted.. We received a cheque for **£208** from this, so many thanks for doing this!





## NPS UK Finance Report September 2008

Here we are again with the finance report covering the summer.

We now have just over £8,500 in the bank, so we are well on the way to funding the national NPS conference in a year's time.

Our expenses over the summer have been non-existent (which is good!), but we have received a number of donations. Once again we owe many thanks to James Kelly and his employer's Hymans Robertson LLP. The company has a dress-down day where employees wear casual clothes to work and make a donation which is then sent to a chosen charity – thank you so much for choosing us! The amount they collected and sent to us is £208!!! Brilliant! This is such a great idea to raise money – why not ask your employer if you can organise something similar?

We have also had our first ever Give as You Earn donation, and once again, we are saying thank you to James Kelly!! I have talked about Give as You Earn in previous reports – this is a way of making a regular donation directly from your salary. You get tax relief straight away. The money is collected by the Charities Aid Foundation, who then send it to us every three months together with the tax relief. It was such a nice surprise to get the cheque arrive in the post! If you would like to know more, either ask your employer or take a look at the website:

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

Another good way to help us raise money is to use the Everyclick website, and thank you to all of you who continue to use it.

Thank you to everyone who has helped us so far this year!!

Recently I received a message from Everyclick's founder, Polly Gowers. She thanked us for helping her raise a staggering 491679.81 for charities! What an amazing organization! In case, you are unaware, Everyclick services have added even more ways to raise money for NPSUK. You don't need to change a thing. All your searches will continue to support NPSUK.

Happy searching by using <http://www.everyclick.com/caroldobbins>



As of today, you have helped raise 2,039.60!!!

We need more and more people to use this service, so I ask that you could add this little footnote to all your emails.

"I raise money for charity with Everyclick.com

Join me: <http://www.everyclick.com/caroldobbins>"

If you or any of your friends and family work in large offices, you can distribute little posters now that can be downloaded simply by clicking on the following link.

<http://fundraisers.everyclick.com/docs/A4Poster-TextBox.doc> You will need to personalise the posters and I would suggest

**"Please give your mouse a heart and support NPSUK by clicking on [www.everyclick.com/caroldobbins](http://www.everyclick.com/caroldobbins) <http://www.everyclick.com/caroldobbins>"**

If anyone does not have access to a printer and would like some copies of these, please get in touch and I will send them onto you. Please distribute them as widely as possible.

Everyclick gives you lots of ways to raise more money for charity:

[search the web](#); [shop](#); [collect sponsorship](#); [donate](#), give and reclaim [eVouchers](#)

Help me raise money for **NPSUK**

<http://www.everyclick.com/caroldobbins>

## NPSUK 2009 Conference plans are underway!

It is that time again! As most of you know, the highlight of our calendar is planning these incredible conferences. They are the most amazing experiences for those who have NPS to meet others and learn how from the medical professionals who come along to share their knowledge with us. Personally, I feel that the social aspect is just as important, and I have made some lifelong friends from all over the world as a result of these conferences.



The early talks have started, and it looks like the location chosen will, once again, be the Crowne Plaza, in Chester. I have to finalize this with the staff yet, but I see no reason why we should change something that has worked incredibly well for us in the past. If there are people who feel that the distance to travel may be a financial issue, we are hoping to set up a Travel Fund again this year to alleviate this problem. However, to do this, we need to continue to raise as much money for our charity! Chester has always been a favourite location due

to the easy access to airports, centrality within the UK, and also the service that it provides. There are many places to stay within easy reach of the Crowne Plaza to suit all budgets and I will be happy to provide a list of these nearer the time. If anyone has any questions regarding any of this, please feel free to contact us at any time.



I would also be interested to hear any suggestions you may have for the next conference. Last time, we had a suggestion to host a karaoke/fun night at the end of the talks on the Saturday, and this was a huge success for those who attended.

If anyone has any unwanted gifts (especially over the festive season) that they would like to donate for the raffles that we hold, please feel free to send them to us also.

In the next edition of the newsletter, I am hoping to provide you will a list of the speakers who may attend. Dates also have to be agreed, but it is likely to be early August, 2009. I look forward to seeing you there!!!

### Surgery updates

Lisa Ward, Kath Lovatt and Stephen Dobbins all had their surgeries and I am happy to say that they are all recovering very well. Many thanks for all the kind words of support. If you would like me to add a little reminder for a surgical procedure that you or a family member may be having, please get in touch. I am always interested to hear how you get on and I am happy to say a few wee prayers and send some positive thoughts your way!



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



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