

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.

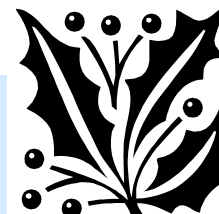
NPS(UK)



*Issue 7
January 2005*



I would like to wish you  joy, health and happiness for 2005. Let's make it a  year to remember!



An introduction from the Chair Submitted by Carol Dobbins

First of all, I would like to wish you all a very happy and healthy New Year.

The last four months of 2004 were extremely busy and many exciting new plans are planned for 2005! We have some exciting plans for our fundraising attempts and we also are well underway with the plans for the 2nd NPS(UK) conference in August.



Jim and myself at the five-a-side presentation



5-a-side annual football Tournament nets a winner!

On 2nd October 2004, we held our 2nd annual football tournament. The weather was slightly worrying as we all got up in the early hours of that Saturday morning. It was forecast rain, rain and more rain, accompanied by heavy winds...just what we needed in this OUTDOOR tournament! No time to worry though as there were loads of jobs to be done and just a small time until some of the official NPS United team were planning to arrive! Nicola got on her domestic hat and was a great help with the food preparation for the buffet, Keith got on the chauffeur hat and picked up some of the players and I got the forms, prizes, gifts, speeches and t-shirts all ready. We packed the car and left at 11.30,am.

When we arrived the East Kilbride News photographer was waiting and I had to ask him to leave as he was too early...not in the habit of chasing the press away!!! He came back shortly afterwards and took some pictures for the newspaper, which were published the week after the tournament. More newspapers got involved to try and drum up some support too.

On the day, I was running a raffle which was to be drawn a couple of weeks later and tickets had been selling for some time. The management at the "Fives" were happy to hang it up behind the Bar for others to buy tickets We sold a few more on the day. Our official team had dramatically improved from the previous year and all that training seems to have paid off!



Stephen, keeping the interest in the Newspapers!

The first game for NPS United was pretty good. We drew 2-2. The second game....all the training showed and they won a convincing 7-2, on the third game, they came up against the eventual winners and lost 4-0. Overall, they just missed the qualifiers by two goals. It was a great effort by them all and I am absolutely proud of them all. Part of my job on the day was to keep a close eye on the scores....difficult job when there are three games being played at any one time on three different pitches. Each time I heard the final whistle I would run round to the match official and get him to give me the final score...on this occasion I turned round and looked directly into the eyes of three great NPS friends! They decided to turn up on the day and surprise me...and my Lord...they certainly did just that!!! I actually thought I was dreaming. Thank you Bill, Anne and Sheila for making this memory so special! So, the speech and the final count came next! It was getting exciting because all thirteen teams arrived and I knew we must have made a few pounds....I was hoping for the thousand pound mark. We made One thousand four hundred and ten pounds!!!! On the day we collected seven hundred and five which will be matched by BOC gases as a result of completing a form which has been posted to the Charities Aid Foundation. We should receive this money some time soon.

So what's inside?

Football Tournament	1
Fundraising and letter from Debby Markham	2
Mick Smith tells all! Please help.	3
Conference plans. Travel Fund ideas.	4
Finance Report	5
Kind donations Fundraising opportunities.	6

Fundraising/Publicity updates

It has been an incredibly busy few months. We have been promoting our charity in many ways and I have to give a huge thanks to all who have been taking part in the fundraising and publicity campaign.

Special thanks this issue must go to our Debbie Markham and her family and friends. They have got together and decided that there is a lot they want to do.

Debbie organised the Webb Ivory Catalogue fundraising idea for our charity and it has been a huge success. We have made a good deal of money over the Christmas period and I would like to thank all who supported this idea and ordered a book from us.

The Ben Nevis Climb brought in a great deal of money and most of this will be put towards some of the conference costs in August.



Many thanks also go to Lisa Threadwell who got together with her husband and asked if the school where he works as a music teacher may support our charity at their school concert in December. They agreed and I am waiting to hear how it all

went. Thank you so much Lisa!

The 5-a-side football tournament pulled in a great deal of money and raised a lot of publicity on the day, once again. This will undoubtedly be one of our biggest annual fundraisers and a date on the calendar that I enjoy immensely. The sales from the signed Rangers FC top raised more money and the story made the papers once again. The winner was a sweet little elderly lady!

The collecting tins have been a huge success with loads of donations from all over the country. Thank you to all who support this important part of our fundraising. We have received some touching personal donations and also many donated gifts for future fundraisers. Thank you all so much!



NPS(UK) cycle marathon 2005

Submitted by Debby Markham



Hi All,

I thought I had better write a few lines to update you all on the Charity Bicycle Ride from Lands End to John O'Groats, which is now changed dates from the previous May dates to June 2005 (due to other commitments on both parties), Mick, who is one of the riders has also added his own information to keep you all posted on the actual route.

The first major change to our plans is that myself and Mick's wife Gill (along with little Taylor) are no longer able to accompany Mick and Lee, as my beautiful daughter Sadie (NPS) has decided to give me a little grandchild, which is due in the very early days of July, and I just have to be here for her, just in case she decides to deliver early, Sadie is very young (she will be just 17 when the baby arrives, and obviously need all the support her mum can give her right now) though we are still hoping to cheer them off at the start line, and maybe do the first few days of the challenge, (but not so far so that I am only going to be a couple of hours away from home in case of an emergency.) So we don't know yet, but there may be a new addition to our wonderful NPS family!!!!

Lee has been cycling the very long way to work every day, he works literally 1 mile from home, but takes the long, but very scenic route which is about 6 miles and then does a few laps around the airfield before he starts work at 7.30 am in the dark, freezing cold weather (Mad!!!) and both Mick and Lee are out on their bikes at every given chance to get fit for this enormous challenge. Obviously because they no longer have a back up car (which was going to be me!!) they have to carry a few extra things on their bikes, which makes things a little more difficult, Mick has just bought a new bike to help with this, and Lee who only bought his bike a few weeks ago, has got to try to sell that one in order to get a new one also. Unless, of course there may be someone out there who is willing to take 3 weeks off of work to drive alongside to help them out, or maybe a few of you could arrange a few days each, come on it would be fun, and what a wonderful way to have a few days break away from home to see our beautiful countryside.

As mentioned in my last letter Lee went to his G.P. to give up smoking for this challenge, and I am pleased to say, he gave up on 6th September 2004 and has not had a puff since, I am very proud of him.

Because myself and Gill will not be going the whole way now we will not be able to jiggle collection boxes and hassle radio stations like we initially planned, so we would be very grateful if you could all take a sponsor form and get as many sponsors as possible, to make all of this worthwhile for NPS(UK). Mick and Lee are not going to be taking out of the charity at all for any expenses, they are doing it all out of their own pocket, so anything that is donated will all be pure profit for our very worthwhile Charity, which we all benefit from so much (Thanks to Carol, Shirley and everyone else involved) Any donations however small would be very gratefully received.

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, we will give more specific dates in the next newsletter, so far we know it is going to take place in June 2005

Love to All

Love Debby xxxx (e mail me on Markhamanon@aol.com if any suggestions or help can be offered on this.)



Submitted by Mick Smith

We need your support

There have been many major achievements by people of the British Isles in the pursuits of long distance travel. Gill and myself spent three lovely days around Lands End in early September. We stayed at the Youth Hostel 5 miles away by St. Just and we walked along the Sea front to Lands end. I visited the End to End Museum and was amazed to find out that one man had walked from Lands End to John O'Groats with a door strapped to his back in memory of his father who was a Carpenter. He must have really loved his Dad. On a humorous side I wonder if any one would dare to try it in recognition of a fisherman. I bet not many people would kiss him at the finish line. Anyway there will be two more additions to the famous end to end club in June 2005 when Lee Markham and Mick Smith cycle this Marathon. Lee is the husband of Debby and father of Taylor who both suffer with N.P.S.

I was doing the ride myself to celebrate my 60th year, but when Gill started working for Debby and Lee, and we found out about NPS, I had no hesitation in doing it for the charity, Then Lee said that he would like to cycle with me, I said Yes, that will be great. I thought then that I could link a metal chain to the back of his saddle for the many uphill climbs!!

Everyone that I have spoken to about the Charity, have said that they will sponsor us.

I have obtained the 'cyclists Touring Clubs Youth Hostel Scenic Route' which covers 1000 miles in 15 days (or maybe 17 or 18!!) It uses mainly minor roads.



This is the route; as briefly as I can make it.

From Lands End we take the A30 to Penzance and then minor roads to King Harry Ferry around St. Austell and then onto Golant Youth Hostel near Fowey.

Next day through Looe to the Torpoint Ferry, through Plymouth and across Dartmoor to Steps Bridge Youth Hostel.

The 3rd day takes us through Exeter, Honiton and the middle of Somerset to Street Youth Hostel.

The 4th day we head up towards the Bristol Suspension Bridge and then across the Severn Bridge, through the Wye Valley to Welsh Bicknor Youth Hostel.

Day 5 we go via Leominster to Clun Youth Hostel

Day 6 we head up to the West of Shrewsbury through Ellesmere to Chester Youth Hostel.

Day 7 we cycle North East through Chorley to the West of Blackburn to Slaidburn Youth Hostel, which is North of Clitheroe.

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

Day 9 we head up and through Carlisle and into Scotland, through the Dumfries to the highest village in Scotland - Wanlockhead Youth Hostel, This will be a difficult overnight stay, as it is Self catering, so we have decided that the last one in cooks the meal of warm Kendall mint cake!!

Day 10 may be a rest day as we go in search of food!!!!!! Well, off we go again along the B7078 alongside the M74 up towards Glasgow to Loch Lomond Youth Hospital

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

Day 12 is the A82 through Fort William, Spean Bridge. (A QUICK WALK UP BEN NEVIS) and then onto Invermoriston Youth Hostel. Self Catering here again.

Day 13 goes up to Duigwall, Alness, Ardgay, to Culrain for Carbisdale Youth Hostel.

Day 14 is up to Tongue Youth Hostel.

Day 15 is the A836 North and East through Betty Hill, Thurso and finally JOHN O GROATS.

Our last four stops are all self catering so if anyone can recommend food houses along the way, it would be greatly appreciated.

Now then how do we get back??????

Shall we visit Cape Wrath???

If anyone wants to join us on parts along the journey please do so.

Any sponsors would also be greatly appreciated.

Best Wishes

Mick Smith.

Can I ask that you all think about how we can contribute to the success of this huge effort from Mick and Lee. If you have any contacts in the press or would like to contact your local radio or TV broadcasting agencies to publicise this event, we would be very grateful. Please contact me with your thoughts on this and we can work together.

If you take a look at the areas that Mick and Lee will be passing through, it would be great if some of you could drum up some support for them and cheer them along. I will certainly be there for them when they are passing through the Glasgow area!

I have enclosed a sponsor form with this issue and ask for your support as best as you can.

Thank you so much.

Chester 2005—NPS(UK) 2nd Conference



NPS(UK) conference 2005



The plans for this years 2nd NPS(UK) conference in the city of Chester are well underway.

The dates are now set for Saturday, 13th August 2005. I have organised another “meet and Greet” room to be made available to us on the Friday evening also where we can meet up and have some fun getting to know one another in a less formal setting. It was a huge success last year and I would encourage as many people to attend this as possible. NPS(UK) lay on a buffet on this night also for all those who attend. I will contact you all again soon with information on accommodation prices and lists of alternative accommodation. We are in the process of contacting the potential speakers for the day and I will inform you as soon as we have this information available. We will also be making a list of the people who would like to attend shortly as we plan the meals for the day.

If you have any ideas on the subject of the conference, please feel free to contact me at any time.

Plans to set up a Travel Fund

It is our intention this year to try and set up a Travel Fund for those who may wish to attend the conference, but who may financially find it too difficult. The entire money that is raised from this year’s marathon cycle ride would go towards this and we would hopefully be able to provide the necessary people with travel costs or accommodation costs in an alternative suitable Hotel or B & B nearby. Last year, many who attended stayed at less expensive accommodation and I have lists of these places to share with you.

The trustees of the charity would make a final decision on what would be offered to anyone who would like to apply for financial support.

It is so important for us to raise as much as possible from this cycle marathon that Mick and Lee are so generously doing for us and I appeal to you all for your support. If you need more sponsor forms, please contact me and I will get them to you immediately. I tend to hand them out to family and friends also and see what they can collect. In the end, each and every one of us benefit from raising as much as possible.



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



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.

NPS(UK) finance report

Page 5



Submitted by Shirley Raynor

Once again it's time for me to pull together an update for you all on the funds we have in our accounts.- since my last report we have gained a further £1500, and our total now stands at £9602.25. About half of this increase came from the football day which Carol organised, brilliant work there! – another sizeable chunk came as further sponsorship for Carol's Ben Nevis climb. We have also had several donations from the generous individuals who collect money for us, either using our collecting boxes or by their own fundraising efforts. We are so grateful to all of you for making the time to raise this money, it really does make a difference.

With the funds we have in hand we are going to be able to hold a really special conference in August 2005!!! I'd also like to think about other ways that we could spend some of this money for the benefit of the NPS community. Carol and I have talked about this from time to time, but it would be great to have input from you, too. Ideas we have talked about are:

- Posters for eye clinics, and other relevant hospital departments
- A wider range of brochures
- Small travel grants for people who might otherwise be unable to attend a conference

Do you have any suggestions to add to this list? We would love to hear from you, either with a new idea, or just to give us your views on how the money we raise should be spent. You can either contact Carol (her details are elsewhere in this newsletter) or me:

Shirley Raynor
84 Winsley Hill
Limpley Stoke
Bath
BA2 7FA

shirley.raynor@gmail.com



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.

Kind donations

My involvement in charity work has opened my eyes to how many kind people there are in this world. We often turn on the television and hear how bad the world is, and yes, there are often some terrible things happening, but I truly believe that the love, kindness and support I have seen, far outweighs the bad in this world.

I have been touched by the kindness shown by people, often as they endure difficulties in their lives, they are still able to open their hearts and give to others in need.

Recently, I received a letter from a lady who I am blessed to call a friend. She shares Nail Patella Syndrome with us and is an active member of our NPS community. Unfortunately, she lost a dear old friend of hers who passed away a week after her 94th birthday. In her memory, a cheque was donated to our charity. Thank you for this very touching gesture.



Website fundraising opportunity

It has been brought to my attention that there is a great website that helps charities raise funds and awareness by an easy set-up process and a little description on an up and coming event. The website is called www.justgiving.com and seems to be an alternative method for people who would like to donate easily online.

I thought it may be a great way to promote the cycle marathon to the public and I would be willing to give this a try. I have checked out the costs of this and I would need £100 approximately for this to happen. Thankfully, I have received a very kind donation from a family member and we could now pursue with this. If any of you would like to work with me on this, I would appreciate it so much as I have very little time left for any other projects right now.

If you have any other ideas, I would be happy to hear from you or you could contact our treasurer, Shirley Raynor.

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
Phone me on 01355 241277

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

www.nailpatella.org
www.npsuk.org

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



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