

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 6
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An introduction from the Chair

Submitted by Carol Dobbins

There are many things I love about what we all do together to raise awareness and funds for Nail Patella Syndrome, but I have to say that I have the most beautiful memories from this year when I travelled down to Wales and spent time at the Lovatt's home. For some time, we had to delay this meeting due to my health problems at the beginning of the year, but it was absolutely worth the wait. Keith and I shared a lovely



Croesty Primary School Headmaster, Mr Hearing with Rosie Lovatt and some school friends.



Kath and myself.

time with Kath, Wayne and their family. It was a very special time as I got to share some memorable moments with them all.

On the following morning, Kath, Keith and I went to Croesty Primary School to meet with the headmaster and receive a cheque, totalling £400 for our charity. The money was raised from the proceedings from the Christmas concert junior raffle.

Mr. Hearing and the staff and pupils at the school were incredibly kind as they welcomed us into their school with a few little songs and the school band playing their little hearts out. It was very moving. Then it was time to say a few words and thank everyone who kindly bought the tickets. I will never forget all those little faces looking up at me as I delicately spoke about living with NPS. Rosie stood up and presented me with the cheque and we stayed for a few photos with some of the other kids.

All in all, it was a beautiful day.

Kath contacted the local newspaper, The Bridgend Recorder, and they put a little article in explaining what happened. I am convinced that every bit of publicity helps and we tend to find someone willing to help or occasionally who may know someone who may share this condition too.

I had a lovely surprise when I arrived at Kath's house. She had organised another NPSer to come to the house. It was absolutely wonderful to put a face to the name of Linda Horlock. What a lovely lady! I have been sending information to her for some time now, but it was lovely to get the chance to meet her in person and I look forward to meeting her again in the future!

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Fundraising/Publicity updates



James Roberts selling raffle tickets at his school in Oxford.

The fundraising efforts of the past few months have been very promising. Many people have come forward to try various ways of increasing our funds and raising awareness. A special mention has to be given to James Roberts.

This bright young man organised a raffle at his school and raised a whopping £289.20! I am so touched and impressed with this young man. We are all so very proud of you.



Rosie Lovatt holding the cheque raised at her school in Wales

As you have previously read, the beautiful Miss Rosie Lovatt handed me the cheque for £400 that was raised from a junior school concert. Thank you so much!

There has been great help with the collecting tins recently with Bill and Anne asking for more labels as they take on the entire community of Galashiels in Scotland! Debby Markham has also been an incredibly busy bee over the past few months. She raised and incredible £171 from collecting tins that she handed out over a period of time. She also has some exciting news which you can read about on page 3!



It has come to that time of the year again where we approach our annual 5-a-side Football Charity Shield tournament. Last year, it was a huge success and the profits were incredible. The publicity we received from this was also very positive and this year we hope for even more!

The event will take place on Saturday 2nd October 2004 at the "Fives" in Nerston. The first games should be played at 12 noon and we hope to complete the entire tournament by 5 pm. This year we are hoping for 12 teams as opposed to the 8 we had last year. Hopefully, our very own NPS United will make it past the first round! They are all in training right now! The current winners "E K Porto Supporters" are holding the shield and will pass it back to me on the day. The winners will receive a prize of £50 and a bottle of bubbly also.

The East Kilbride News will hopefully come along on the day also and take some photos for more publicity. I have also asked for people who want to come along on the day to do so as I will be raffling yet another prize



The winning 5-a-side football Charity Shield



Raffle prize—Signed Glasgow Rangers Football Top

So, what in the world am I raffling now? I am very lucky to be able to say that I have been given a signed Glasgow Rangers FC top (2003/2004 season) I have a second prize of a Bottle of Chivas Regal Premier Whiskey and

A third prize of an NFL St. Louis Rams Polo shirt-kindly donated by our NPS friends in the USA. The raffle draw will take place on the 16th October 2004.



If anyone would like to buy some tickets or want to try their hand at selling some let me know and I will send you the relevant materials.



Submitted by Debby Markham



We need your support

Hi All,

My name is Debby Markham and I have Nail Patella Syndrome, as does my 16 year old daughter Sadie and my 2 year old son Taylor, along with my brother Dave and his 16 year old daughter Sophie. We inherited this 'Special Gene' from our father who unfortunately died 39 years ago when I was 2 and he was at the ripe old age of 32. Like a lot of us we thought it was 'just our family' that had this strange trait of no thumb nails, along with several other things, which we hadn't related together. (we only discovered NPS when I was pregnant with Taylor in 2001.

I have 2 other sons and I married my 2nd (but best) husband last November.

During the winter months I pretty much need a full time, around the clock, carer, I am sure I found the best one and her name is Gill, she is married to a wonderful man called Mick. Where is all this leading I hear you all say (through yawns) well.....

Mick and Lee have decided in a very mad moment to do a cycle ride from Lands End (right down in the very south of the British Isles) to John O Groats (as far North as they can get in the afore mentioned British Isles) Mick has always wanted to take on this challenge, and thought it would be a great way to celebrate his 60th birthday next year, and Lee was happy to go along to keep him company. Myself and Gill (along with little Taylor) are going to accompany them in a much more comfortable mode of transport (my Land Rover Freelander) every inch of the way as their back up vehicle in case of emergencies or injuries.

Lee and Mick have already started their vigorous training and all of this has even spurred Lee to visit his GP to get help with giving up smoking, so that he can reach his peak in fitness.

We are hoping to do this mad cycle stint over a 3 week course starting in the last week of April and finishing around 14th May 2005 (just in time for myself and Lee to fly off to Crete on 18th!!!) and we are hoping to cover about 60 miles every day.

We are in the process of working out the route, and are awaiting information from the cycle club with the best routes, as soon as I know which way we are going you can rest assured that I will be getting onto all of you to cheer us on through your local towns, and we will also be scrounging floor space for weary bodies over night (the majority of sleep will be done in youth hostels right up through the country, which will also determine a lot of our route)

We will also be looking for help from everyone to either sponsor us or we can send sponsor forms to you to get as many sponsors as you can ALL IN THE AID OF NPS(UK).

We will be involving all the local radio, TV and newspapers in as many towns as we can to raise awareness, we will all be wearing the NPS t-shirts for the duration (thanks to Carol) and we are hoping to get a few of the major supermarkets to allow us to shake a few tins, and give out NPS leaflets across the whole of the country.

Myself and Gill, will be in charge of organising all the clean washing and lunches each day, and we will be taking lots of photos and keeping a daily diary recording everything from the weather, to anything that may happen along the way.

For the last half a mile or so of the race, we thought it would be a nice little twist for Taylor (who will be 3 by then) to ride his own little bike across the 'finishing line' where Carol is hoping to arrange for the papers etc. to be there to greet us.

This is going to be a very big challenge for all of us, obviously mostly for the 2 men, but also the fact that I will be driving 60 miles each day (which, as anyone who knows me will tell you, that I NEVER drive outside of my home town, and I am absolutely terrified of driving in strange places!!) also for Gill and Taylor who have to sit in the car with me, while I am panicking.

I hope that we can drum up as much support from everyone as we can, as we move up through our beautiful country, and we look forward to meeting you all.

I will keep everyone informed (through Carol) as our plans pan out.

Thank you for reading this far, as I know I have waffled quite a lot.

Love To all

Debby Markham xx



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.

Chester 2005—NPS(UK) 2nd Conference

NPS(UK) conference 2005



The early planning stages for the next conference are underway. After a great deal of thought and deliberation, it has been agreed that the next conference should be held in the beautiful city of Chester once again. Last year, the conference was a major success in many ways. The location and service was excellent and I hope that we can achieve this once again.

I have been communicating with the Moat House over the past couple of weeks and we are discussing a very rough agenda at the moment.

I am pleased to say that the surrounding area has very many alternative accommodation that is a little less expensive than the Moat House and extremely comfortable. I still have all the lists from before, so please try and come along as this really is a wonderful occasion.

The photograph on the right shows a small number of the people who attended on the day and I am sure that they would back me up on what a great time they all had.



It seems that the date that works best for the Moat House at the moment is the second weekend in August 2005. It is NOT carved in stone yet, but I think that the odds are high.

If anyone has any questions regarding the conference plans, ideas, comments or if they feel that they would like to offer their services

to us on the day, please let me know.

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 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.

NPS(UK) finance report

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Submitted by Shirley Raynor

Time for another update on our financial position – since my last report in April we have managed to increase our funds by an amazing £1541 – and on top of this, I have cheques waiting to be banked of almost £200. This gives us a total in the bank now of £8165. This really is incredibly impressive, nearly all of the increase, apart from a small amount of interest, comes from the efforts of our supporters and fundraisers. Thank you to all of you who have donated or raised money, whatever the amount, it really does make a difference.

Another significant receipt this month was a donation from the Tax Office! We eventually received our tax refund on the gift aid donations that were made in the last tax year, to 5 April 2004, and this came to £457 – well worth claiming!

This whole amount was claimed on donations made through various sponsored events over the past year – if you are planning to hold a sponsored event to raise money for us, please ask Carol to send you the blank sponsorship form, which has the Gift Aid column on it. All sponsors have to do is sign in this column, to say that they pay tax, and that then allows us to claim 28% of their donation as a tax refund.

As mentioned in the last newsletter, we decided to make a small investment in a new printer, which will allow Carol to produce our newsletters much more quickly and efficiently – with more and more people on our mailing list this really is a necessity now. Thanks for all of your donations that have made this improvement possible!

Personal thanks

Submitted by Carol Dobbins

This has been a busy Newsletter! You may have noticed that the Kids page had to be omitted on this occasion, but I hope that we will be back with the usual fun page in the next edition.

I have had to add a note of thanks to so many, including Margaret Woodcock and Elaine Donald for donating very generously to our cause, once again.

Debby Markham, you have been incredible too! This woman has raised awareness and funds by placing collecting tins in various places, and has some great ideas for the future months. The Cycle Marathon is a huge event and I would ask as many of you for some support on this as possible. I would like to think that we could cheer these guys on in the various parts of Britain as they cycle their way through the country for the benefit of so many. It would also be a great help if we could hand out some sponsor forms to friends and family and see what we can achieve with this very brave challenge! I will contact the press and feed them with this story. Debby has also offered help with the Webb Ivory catalogues. These are an easy way to raise some cash and it has worked in the past as Margaret Roberts can vouch.

I want to thank each and every one of you for so much support in the early part of this year as my health took a turn for the worse. However, with your love and support and that from my family, I am back on form! I decided that to prove that I was alive and well, I should do something that I always dreamt of in the past....climb Ben Nevis! I am so pleased to say that on the 1st of August 2004, I was successful in achieving my dream. More on the next page!

Ben Nevis Climb 1st August 2004



This year, I took on a challenge that was incredibly personal to me. I was registered disabled many years ago, but I have never viewed myself as a person who was not capable of trying things. However, in the past I have thought about attempting some physical challenge, but my health has always beaten me! This time was different.

After my surgery on February this year, I knew that I needed to prove to myself that I was mentally strong enough to take this on, so I planned the day.

The weather was absolutely incredible on the morning of the climb and we met some great friends Andy and Clare who decided to take this challenge on also. We had raised some interest locally and some very kind people had sponsored us to complete this climb. This made it much more important to complete.

The trek up was very exhausting and I have to confess there were many moments that I felt that my dream was slowly fading away. However, I looked at Keith, Nicola, Stephen, Andy and Clare and took great strength in knowing that they were doing this too and no doubt feeling the effects too.

At about 2.30 pm we arrived at the highest point of the British Isles, 4,409 feet, after a five hour totally exhausting climb. We were all feeling the effects of the sun and sat for an hour or so to take it all in. I am not ashamed to say that I wept like a baby when I realised just what I had done. I had doctors telling me I was mad to attempt this, but I guess that is just something I have to live with!

Coming down was where all my mental strength needed to come into gear. I reached approximately the 3,000 feet mark in my descent when my left hip dislocated and was lying in a very uncomfortable position. Those last 3,000 feet were almost a blur now as each step hurt more than I have ever felt, but the achievement and realisation of what I have done just blows me away! If there is a lesson to be learned from this I would say it is "There is NOTHING we can't achieve"



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 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 January 2005



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