



Issue 23
June 2010

Spring/Summer edition

An introduction from the Chair Submitted by
Carol Dobbins

So what's inside?

A wise old lady once said to me that time goes faster when you get older! I won't argue with that!

Welcome to our Spring/summer edition of the NPSUK Newsletter. I hope that you are all well. I have to say that the past few months have been more quiet than ever before in the charity with very little going on. I believe that the current financial climate has a lot to do with this and I sincerely hope that it will improve. Our conferences are so important to us as we can provide many people with information and support that is often needed, so hopefully our fundraising ventures will improve over the next few months. However I am pleased to say that the Kelly family have yet again come to our aid! (more on p.3)



Many of you may also remember that Jackie Lawson-McBrien took an Aquafit class at the end of last year, followed by a Christmas Party. This raised £70 for our funds and was a novel way of fundraising. It proved a success and lots of fun so Jackie has decided to take on another venture! Thanks Jax!!

She wants to put NPS firmly on the Southern Counties map and raise awareness in the South East region!

She has booked to do a joint venture with one of her aqua-fit ladies who is a Huntington's Disease sufferer and is a very keen fundraiser for her particular charity. She has met her son, Toby on several occasions and has learned to love him as we all do!

Therefore, she approached Jackie to do a joint fundraiser in the form of an awareness and fundraiser day in Hastings Town Centre, on Thursday 10th June 2010, whereby they can set up a table and board advertising their charities in the local shopping centre, (10.00 - 4.00pm), with their charity boxes rattling hoping to get lots of pennies!

They have already applied for a street collection permit - in order for them to carry out local collections, and NPSUK have supplied a copy of the NPS public liability certificate to publicly display on the table. I will send Jackie some information to put up on a display board, including the latest NPS newsletter.

I have supplied t-shirts for Jackie and her helpers for the event and some items that can be sold at the table. We have also supplied some pens and pencils that can be given away to increase awareness. They are hoping also to get the local paper taking photos which Jackie can send for the next newsletter.

Jackie has also come up with a wonderful idea for the next conference in which she may be able to use her talents! More on this at a later date, hopefully! More from Jackie on page 3.

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Some of you may ask what is a public liability certificate? Any business or charity which provides any product or service for use by the public or for use in the public domain must have valid Public Liability Insurance to a pre-determined value. This value is set by the company concerned with input from the insurance company. As Jackie is setting up a table in the public domain, NPSUK needed to supply this document. Now that we have it, we could actually do more things like this. Would anyone else like to give it a try? I am more than happy to send what we have for you to display and sell at your table. I would also supply t-shirts for you to wear on the day. It could be a lot of fun and a wonderful way of raising awareness and cash for our charity!



Congratulations



February - Archie Mundegar
March - Anonymous
April - Gail Duxfield
May - Claire Sugden





Submitted by Kath Lovatt NPSUK Project Manager

I want to share with you all a scenario that I had to go through in order to help my 14 year old daughter, who has NPS.

My daughter Rosie is affected by NPS in the usual places, knees, elbows etc I won't bore you with the exact details as I know that when I say those two words to NPS folk they don't need further explanations! She had been at her comprehensive school for the last 3 years and I have been asking for help for her ever since she arrived. The reason being for the help is that her arms are affected which gives a knock on effect when she writes. Her hand

writing is appalling – I know we cannot blame everything on NPS but I'm pretty certain it plays a major role in Rosie's case. From day 1, the school said they would do all they could to help and in certain aspects they were helpful except for the writing problem. They just didn't want to know.

Just before Easter I took up my case as they had a change of staff in the SENCO (special education needs) department and thought that it was worth a shot. The guy said his hands were tied! My reply to him was well at least you can straighten your arms! I spoke to the LEA (Local Education Authority) who after thinking about it for 3 weeks said they couldn't help!

My main frustration in all of this is that in a year from now Rosie will be sitting her first few GCSE's and in 2 years from now she will be taking 11 subjects. If her regular teachers in school can just about decipher her writing, then how on earth will an independent examiner read what she's written in these final exams? As a mother, I had to fight for my child. I looked into changing schools, which after a few enquiries I got so much help in 10 days than I did in 3 years at the school she was at. The new school suggested that if I had a letter or report from an OT (Occupational Therapist) or her consultant then the school would have to act on that as a direct instruction.

Bingo! Back in February this year she had an appointment with her consultant who offered to write to school to clarify a few points on our behalf, after lack of co-operation. I called the hospital and they sent me a copy of the letter that was sent to her school and it clearly stated that she should be using a laptop or a pc for school work due the pain and discomfort it causes by writing. Like I said the school had this on file for 2 months and had ignored it.

By this time I had arranged for Rosie to start at the new school after Easter. I was then able to contact the LEA again and tell them that I had a copy of the letter and I was told they would get back to me by the end of the week. I wasn't happy with that so I rang our local MP and told her about the situation, and she got in touch with the Head of Children's Services. In the mean time I also emailed the Education Minister for Wales who had just been on TV that day and announced they were giving out 500 laptops to under privileged children in Cardiff. I then copied it all to Ed Balls in Westminster who was the Secretary for Education for the UK.

4 days later I finally had a phone call from the LEA to say they had ordered a laptop for Rosie to use at school!

What I want to say from this experience is never give up the fight. If you can see your child in pain and it's affecting their life – then fight for them! I really got the bit between my teeth and didn't let go. When I got the call to say the laptop had arrived, they wanted to deliver it to the old school, so I drove over to the LEA in Bridgend and picked it up myself! Rosie had been at her new school for 4 days by this time and they had lent her an old laptop until the new one for her arrived, which again is far more than her last school did in 3 years.

Recently the old school has had an inspection, so I had to go along to the pre inspection meeting and let them know what had or hadn't gone on. The inspector was appalled. I didn't go along to that meeting just to vent off, but to make sure it didn't happen again to someone else's child.

If you have any stories that you feel could make a difference to someone reading our Newsletter, then please send us your stories!

Sadly, stories like this can still be found within the NPS community. I commend Kath for sharing this story with us. It obviously has been a very difficult time for their family, but through persistence and determination, she has finally got what was right for her child. Please share your stories with us too. I am sure that many of you have endured similar situations. I would love to hear if or when you finally overcame your issues. Have you a message to carry to others who may be in a similar situation? Please get in touch and I promise to add *all* your stories submitted to us. You can email them, preferably to me or if not, write to me and I will type them up for you.

Once again, many thanks for your heartfelt story, Kath.





James has been a wonderful support to the charity over the past few years. He currently prints all our Newsletters and has raised great sums of money in many ventures. He also has signed up for the Give As You Earn scheme and makes a donation to our charity on a monthly basis. This is such a great help

to us when times get tough, as they are right now. This time his lovely wife, Karen decided to run in the Women's 10k in Troon in early May. I am delighted to say that Karen succeeded and finished the race with an impressive time of 58 minutes!! I will update you in the next Newsletter with the final collected donation total, but I have been informed that it may be in the region of £500!!!

Thank you, thank you, thank you!!!

Give as you earn "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.

charities aid foundation

CAF



Submitted by Jackie Lawson-McBrien

I served for 9 years in the Army as a physical training instructor - (but don't let that put you off!) because my aquafit classes are FUN as well as benefitting in fitness!!!!

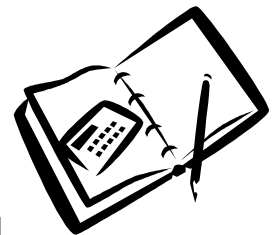
After leaving the Army, I travelled around the world for a year before settling down to have a family. Paul and I have two boys, Robert (13 yrs, non-NPS) and Toby (5 yrs, with NPS). Neither Paul nor I have NPS, so Toby is our little mutant (turtle hero)!!!!!!

I take 4-5 aquafit classes per week along with swimming teaching, admin and reception in our local Leisure Centres, and have worked for over 15 years in the leisure industry, expanding from Cornwall, South London to the East Sussex coast.

In December, I did a special Xmas aquafit class/party raising £80.00 for NPS, and in June I'm doing a fundraising/awareness day here in Hastings town centre - hoping to firmly put NPS on the map!!

More stories

Many thanks to Jackie for sending us her story. I think it is a nice way for us all to get to know one another a little bit more. I would love if some of you would send me your stories. Tell me about yourself. What do you like doing? If you work, what do you do? What are your hobbies? In fact, anything at all. I just feel that our little NPS family need to look out for one another and this is a nice way to do it! I have learned a lot about Jackie in the past few weeks, as I have for many of you in the past few years, and I have loved every minute of it. So go on, share your stories with our little group. I promise to add them all!



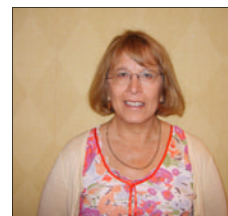
Questions

In our last newsletter, we included a question from an individual who was looking for some help and advice. Unfortunately we received no replies, so I have decided to reprint this letter and hopefully someone may be able to help with this matter. If you think you can help please get in touch. Many thanks. Any other questions, send them to me and I will add them in the next issue.

"As I am very flat footed, I need to wear orthotics or insoles in my shoes. I go to the National Orthopaedic Hospital at Stanmore for these. The orthotics lady told me they fit in any normal shoes. To date, I find they only fit in trainers as they are big enough to take the orthotics. Now I'm a teacher I can't wear trainers to work and I am on my feet for most part of the day. I wear Start-rite shoes, believe it or not, as they are supportive, but after a week on my feet, they really hurt and I feel the need to wear my orthotics. My question is, has anybody got orthotics which are small enough to fit in smart shoes? If so, what do you order? And who makes them for you?"

NPS UK Finance Report January 2010

Submitted by Shirley Raynor NPSUK Treasurer



Here we are again, time for another Treasurer's report – since I last wrote to you we have continued to receive our monthly regular income from our 100 club members, and from our Give As You Earn members donations – thank you to all of you who make these contributions.

Our bank balance is currently standing at £8030. Our fundraising efforts have been pretty quiet over the cold winter months – now that we are beginning to see some nice weather at last we are also seeing the start of sponsored runs. Don't forget to ask us for sponsorship forms if you are planning to take part in a run, and think you could raise some money for our funds. Here's a reminder of some of the other ways that our members raise money for us:

Give As You Earn – by making a regular donation direct from your salary, you can get tax relief for yourself, and we get an extra 28% added on by the Tax Office.

Everyclick – use Everyclick as your browser home page and set us up as your designated charity. It doesn't cost you anything, and we get a penny when you click through to connected websites.

100 Club – a small monthly contribution could win you £25! If you would like to join, just ask us for details.

Collecting boxes – would your local shop or pub have room for a collecting box on the counter, even for a short time? Other people's unwanted change can soon mount up and pay for a new printer ink cartridge, or our phone bill for example.

Organised events – some of our members enjoy organising and hosting fundraising events of all sorts. If you wouldn't feel happy organising a whole event, why not think about taking a table at a car boot sale, or a summer fair, and selling donated items from friends and family, or homemade cakes, or whatever you can think of.

If you are holding a fundraising event, don't forget to take some photos and let us know. We would love to include details in our next newsletter, and who knows – you might inspire someone else!

Thank you for your continued support!



As of today, NPSUK has received **£2,164.76** from this amazing organization! What would we do without them? Please support NPSUK by using Everyclick as your search engine. It is simple to do and easy to use.



NPS UK 100 Club

How many of you buy lottery tickets at the weekend? How often have you won? You may be one of the lucky ones, but let's be honest for most of us, that £1 or £2 a week generally remains in the coffers at Camelot! I stopped it years ago. We placed £2 a week and won about £20 in 4 years! That £104 a year just blew away in the wind! NPSUK have set up a brilliant alternative! For £1 A MONTH, you have the chance to win £25 each month! Only £12 a year and you could win just once and double your money! Many people have decided to buy 3 and 4 numbers to increase their chance of winning! Join in and have fun!



Donations received

Many thanks, once again, to all donations received over the last few months. Special thanks To Elders Bar, and Julie and Paul Cummiskey and their ongoing donations. We also receive private donations from friends and family and this allows us to continue with the running costs without the need to dip into our account very often. In other words without this money, it would be incredibly difficult to continue with the work that we do. Many thanks once again to James Kelly for helping us with all our printing costs!!

As many of you will be aware, NPSUK aim to provide a wealth of information, fun and friendship at our conferences that we host every second year. Our next conference will be held in 2011 and the location is likely to be at the Crowne Plaza in Chester once again. We are familiar with the entire set up now as we have been very lucky to have the use of this venue for years and the staff are always exceptional and cater for every need. We have always aimed to provide some financial assistance i.e. travel costs, to those in need and I hope that we will be able to offer this yet again. It is something that I feel passionate about as NPSUK should support everyone and that help should extend to those who would not have been able to financially attend these events. In the next issue of the Newsletter in December, I will be able to confirm these matters with you. Our only hopes are that we are able to find some more willing volunteers to assist with our funds.



We also hope to provide the opportunity of making some good friends. I know that over the past few years, these events have enabled many people to meet others and as a result, their friendships have grown. I have met the most wonderful people at the conferences and I am always blown away by the fact that I still get so emotional when I have to say goodbye!



The next issue of the Newsletter will include much information on the forthcoming conference.

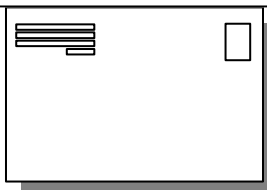
I hope to see many of you there.

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**



Any correspondence, donations, letters can be sent to:-
NPS(UK) / Nail Patella Syndrome UK,
PO Box 26415,
East Kilbride,



Look out for our next edition of the Autumn/Winter edition of the Newsletter. 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 at any time.

**For more information on Nail Patella Syndrome, visit:-
www.npsuk.org**



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