



Issue 22
January 2010

Autumn/Winter edition **An introduction from the Chair Submitted by Carol Dobbins**

First of all, I would like to say a that I hope you all enjoyed a peaceful and healthy festive period. I hope that 2010 brings you much happiness in your lives. It is difficult to believe that it is now almost 7 years since we started NPSUK. I am proud of what we have all managed to achieve in this time and I look forward to more exciting times in

You may have noticed a slight change in the format on the Newsletter so far. We have decided that the Newsletter will now be issued twice in the year. There will be a spring/summer edition and an Autumn/winter edition. This will allow us plenty of time to add all the interesting stories that are happening within the charity. It also will help reduce some of the printing costs that we have incurred in the past. I would love to invite as many of you as possible to add your stories by sending them to me and I would gladly add them into the newsletter. I would also like to add any of your health issues or questions. Also is you would like others to get in touch with you in your local area, send me a little note to say who you are and where you live and your reason for wanting to be put in touch with others in your area and as long as I have received permission from the other party, I would be more than happy to connect you with others.

Our mailing list is growing and there are always many people who would love to meet others without having to wait every two years for the conference. The Newsletter is for you, so please let me know how you would like me to help you.



So what's inside?

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Runners/cyclists/walkers needed!

This is our year to get our heads down to fundraise as much as possible as we need to get our funds in the charity bank account increased a great deal to allow us to plan/organise and pay for our conference in 2011. Our last conference cost in the region of £9.000 and we were very happy to be able to assist individuals with our Travel Fund. I would love to be able to do this again next year, so if you know anyone or are willing to raise some funds yourself, please let me know and I will work with you. I have enjoyed working with so many of you in the past and I look forward to working with many more in the future. I have all the sponsor forms here and I can also send some t-shirts for your event. Registration for many of the marathons should be open now, so if you think you may know someone willing, please let them know about

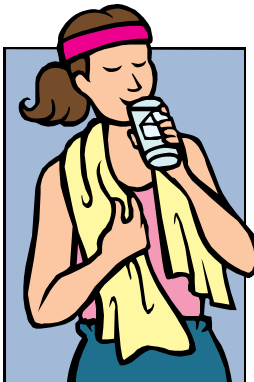


I am pleased to announce that Kathie Pateron managed to raise over £200 in the Women's 10K marathon. She achieved this in an amazing time of 1 hour and 2 minutes!

From all of us, thank you so very much for this wonderful contribution tom our charity.

Many thanks to Jacquie Lawson-McBrien who kindly decided to take a Christmas Aquafit class in Bexhill on 14th December 2009. She then organised a Christmas party afterwards for all who attended and raised £70.00 for NPS!! This is yet another great innovative way of raising funds for this charity and I am so very grateful for your help!

If anyone else has ideas like this, please get in touch!



Submitted by Kath Lovatt NPSUK Project Manager



Firstly I'd like to wish you all a happy, healthy and prosperous New Year!

The 100 Club is ticking along nicely and you can still join in at any point in time. Please drop me an email if you are interested. All we ask is £1 a month! Its nothing is it? Think about it...are you really going to miss a £1? Then what have you got to lose apart from the £25 a month that you could be winning. We have 3 winners already with plenty more to come this year. Many thanks to all who have subscribed to it already. It's such a simple and easy way to raise money.

I would just like to point out that I follow specific guidelines in organising this draw. We have our official license; the numbers are written in the same pen on to table tennis balls, which are the exact same size; and I have an independent person that draws a number out of the bag on the 15th of each month, along with a witness. Thank you to my troop of volunteers!

STOP PRESS! The license is here! NPSUK can now ask for you and your family and friends to support us on this! We need to get the 100 club to have at least 100 members, so please help make this work for your charity!

NPSUK 100 club winners!

Sheila Libberton—October 2009

Ellen Beale—November 2009

Wayne Lovatt—December 2009

Billy & Catriona McLaughlin—January 2010



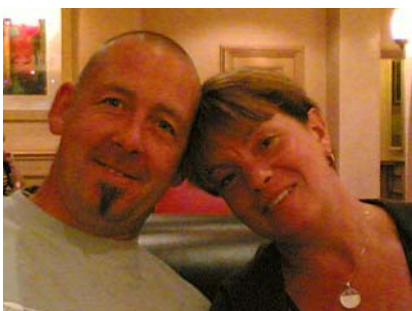
Congratulations to you all and thank you for your continued support!

I have been asked to include a question in the newsletter. If anyone can help or has a similar problem or some great advice – then please get in touch:

“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?”

On a sad note, back in June 2009 Lee Markham lost his battle against cancer and passed away. He was 39. I first met Lee and his beautiful family at our NPS UK Conference in Chester in 2001. Debby, Lee and family quickly became good friends of ours and we have spent many a good time down in Devon where they live. Lee offered to do a fund raiser for NPS UK and proudly cycled along side a friend around the whole of the UK! They raised a huge amount of money for the charity and we will be eternally grateful to him.

As a family, we go to Devon on a regular basis for weekends away, and we always made time to see Lee if we could during the time that he was ill. We last saw Lee at Easter last year, sat and had a coffee in the village and the one thing that I noticed, whenever I spoke to him, was that he never complained about his illness. He just got on with it and lived his life to the full until cancer finally put a stop to it. He was a fine man.



After Lee had passed, Debby, his wife got in touch with me to let me know that Lee had requested that all money donated at his funeral was to be given to NPS UK. He was still thinking of us – even then. I went to the funeral, spoke during the service, which was one of the hardest things I've ever had to do especially when there are 250 people staring back at you. The donations afterwards were pouring in. I had cash and cheques handed to me after the service – it was so heart warming under such sad circumstances. The total raised in memory of Lee Markham was £680! So thank you to everyone.

Lee and Debby Markham at NPSUK conference 2001

NPS UK Finance Report January 2010

Submitted by Shirley Raynor NPSUK Treasurer



Happy New Year, everyone

When I wrote my last report we had just come back from the Chester Conference where we launched the 100 Club. If you haven't already joined, it isn't too late – just let me, Kath or Carol know. It costs £1 a month to join, and you have the chance every month of winning a £25 prize. So far we have had 3 lucky winners, and we are about to draw the next one.

We currently have just under £7000 in the bank. We now get regular monthly donations through Give As You Earn donations, as well as the 100 Club money. On top of that we have received one off donations from sponsored events, and from donation box collections. It soon adds up!

Ways you can help are:

Ask us for a collection box for your local shop or pub

Hold a sponsored event at your school or workplace – ask us for sponsorship forms

Run a marathon(!)

Join the 100 Club

Hold a fundraising event – jumble sale, coffee morning, bring & buy sale etc

Last year's conference cost over £9000 altogether, so we still have a way to go before we have enough for next year's. Thank you to everyone who makes an effort to raise money for us.

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!



As of today, NPSUK has received £2,140.93 from this amazing organization! What would we do without them? Please support NPSUK by using Everyclick as your search engine

"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

Jaquie and Paul Lawson McBrien seem to have caught the exciting fundraising bug! It is such a great feeling once you get on a roll with it all. I have always found it so much fun and the rewards of earning so much money is the best feeling in the world! Paul and one of his mates from work are going to run in their local half marathon in March also for NPS - every little helps! I will send down a couple of t-shirts and some sponsor forms and anything else they need. I am also there for them throughout.

Jacquie's friends are also going to do a summer table sale in their local park - which she will be helping out at too. So watch this space.

Thank you so much to this wonderful family!!!



Many of the marathons have their dates announced for 2010. I am sure that we all know people who do these events. It would be great if we could get as many to support our charity by running these events on our behalf.

Below are a very small list of marathons for this year.

<u>Marathon</u>	<u>date</u>
Brighton	Sunday 18th April
Edinburgh Half	23rd May
Great Ireland	18th April
Women's 10k Glasgow	9th May
London marathon	25th April

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



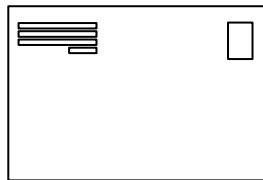
Donations received



Many thanks, once again, to all those donations that keep our charity afloat. Special thanks To Elders Bar, and Julie and Paul Cummiskey's ongoing donations. We have also received many private donations from friends and family over the Christmas period which covers the basic running costs of the charity without us touching our bank account. Many thanks once again to James Kelly for helping us with all our printing costs!!

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 Spring/Summer 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 dobbinssek@btinternet.com

Phone me on 01355 241277