



An introduction from the Chair
Submitted by Carol Dobbins



Jeans for Genes 2006 Dress to Impress

Hello to everyone and welcome to the 12th edition of our Newsletter! Once again, it has been an extremely busy time and NPS(UK) have become involved in some new and exciting projects. You will be able to read about these in this issue and I hope that many of you will become involved too....but first.....

THE WOMEN'S 10K 2006

The event took place on Sunday 21st May 2006 with an amazing 14,963 women entering! The route made its way round Glasgow's south side, starting and finishing in Bellahouston Park.

I am so pleased to say that the weather was really kind to the runners. The forecast was terrible, but it turned out to be fine. Our nine runners completed the gruelling run through the streets of Glasgow. Each of them wore their NPS t-shirts that I got printed up for them and four of them wore our lovely new baseball caps too!

I am sure that each time someone takes on these challenges on our behalf, we raise a lot of interest.

All of the women were teachers at Saint Leonard's Primary School in East Kilbride where my son Stephen attends. and I hadn't even met some of them! Thanks to these wonderful ladies, the money was collected and we received a total of **£673.50**!! That is a wonderful sum of money and I am so proud of them all!



EAST KILBRIDE HALF MARATHON

On the 25th June, we were very fortunate to have a great friend of mine, Joseph Rossi, run in the East Kilbride Marathon to support our charity. The route is very convenient as it goes straight past my house! The challenge is an arduous 13.1 miles long. It really is a difficult challenge and I am totally overawed by the strength and courage of anyone who takes part!

These events are so important for our cause. They raise an amazing amount of interest in who we are and I have learned to get the www.npsuk.org printed on the back of the t-shirts!! Put it this way, if you are running for a few miles with someone in front of you, that web address will be firmly implanted on your brain!

The unpredictable Scottish weather was very kind to the runners!!

I was very concerned prior to the run as Joe, who was running to raise funds and awareness for NPS, had a back injury. His commitment to our cause was his first priority and he went ahead!

Nicola and I got our NPS t-shirts on and bright yellow NPS cap and walked round to the entrance of our estate. This is part of the route that the runners take and we knew that if we stayed there we would see Joe running past soon. More of my friends and neighbours arrived and before long we had over 20 children and about 6 adults all holding the NPS posters I made, shouting on Joe! We had such a wonderful time cheering on ALL the runners for their various charities.

We saw him and cheered him on the first time round, but when he arrived the second time, we had drums, flutes, whistles, bells and whatever else that made a whole load of noise to show him that we were so honoured to be there for him. Stephen and his little tribe of friends ran about a hundred metres with Joe and cheered him all the way! As we stood there watching, two of my friends looked at one another and said that they would like to do this too! We all met later in the day and it looks like we may have a few possibilities for next year's run! Keith is one of them!!! Stay tuned!!

Thanks to Joe and his commitment to our charity, he raised another **£150**!!

So what's inside?

Marathon runners!	1
FUNDRAISING AND PUBLICITY UPDATES	2
GIG Genzyme J4G	3
KATH LOVATT NPS(UK) NEW PROJECT MANAGER	4
NPS(UK) FINANCE REPORT	5
CONTACT DETAILS CONFERENCE PLANS UNDERWAY FREEPHONE NUMBER	6

Fundraising/Publicity updates



As you will have read in the last Newsletter, the BBC screened a documentary on the 26th April 2006 on BBC4 at 9pm. The title of the programme was "My baby- A life worth living?" It focussed on four other families as we all live our lives with rare genetic conditions and it focussed on the many decisions we have to make in our daily lives.

Thanks to so many of you, the BBC agreed to repeat the programme shortly afterwards on BBC2 at 11.30 pm. This is likely to be as a direct result of so many of you applying pressure to the BBC by letter, emails and calls.

As a result, we have received many calls from people from all over the country looking for help and advice and I am overwhelmed at the response!



As many of you know, my son, Stephen trains at TaeKwon-Do twice a week. He has done this for the past couple of years and has enjoyed it immensely. He has achieved some great success at his competitions and much of this is due to the training he receives from his wonderful instructor, Brian Leckie.

Brian has supported him throughout some very difficult times. Recently he was blessed with a beautiful new addition to his family, little Ava Sarah Louise Leckie. He decided that he would like to ask people to make a donation to our charity at the christening of his daughter, instead of the usual gifts that they were likely to receive. Brian and his family agreed to do this with the support from Father Michael Milton at St. Mungo's Church in Alloa. Even on the mass sheets, the priest drew everyone's attention to the back of it and asked everyone to read about NPS and take a look at the picture of Stephen.

They collected **£250!!!** I am sure that they will also have raised some interest and awareness into this condition. I am sure that many of you reading this will be deeply touched by this gesture.



THE JUNIOR GREAT SCOTTISH RUN

As I type this Newsletter up, my daughter Nicola and two of her close friends, Caroline and Laura are preparing to run the Junior marathon for the benefit of NPS(UK). The run will take place on 3rd September at 1.30 pm in the Glasgow Green. It is a 3k marathon and the girls will be wearing our NPS t-shirts on the day to promote awareness for our condition. They also have sponsor forms and have been collecting some donations for our cause. I am sure that you will agree with me that we wish them all the luck in the world for this day! It is a great challenge and a wonderful experience to attend these events.

For more information on the event please visit www.runglasgow.org

More about this in the January edition of our Newsletter!

PUBLICITY



As a result of working with the Jeans for Genes campaign, our charity is facing much more publicity than normal. We have been asked for stories to be sent to various magazines in the run up to the official Jeans for Genes Day and there should be much more to come.

Many thanks to Debby Markham and her family for taking part in all this.

Debby's daughter Sadie has her story on the shelves at the moment in the "Mother and Baby" magazine October edition.

We have also received publicity in the Celebs on Sunday magazine that comes with the Sunday Mirror and also in the Chat magazine on 20th July. I was not aware of this until it was pointed out to me later. The reason for the article is the launch advert for this year's Goodfellas Family of the Year Award.

In the past two weeks, I have also been contacted by the Glasgow Evening Times journalist, Linda Robertson. They are launching a search for the Scotswoman of the Year and apparently she received a nomination in the post putting my name forward. I have no idea who this is. At first, I assumed it was a joke, but I know that it is legitimate as we have spoke on the phone. It is a huge honour and also a bit bizarre at the same time. My life seems very ordinary to me and I am the lucky one to be surrounded by so many brilliant people who make the charity work a pleasure to do!! I may have some further info on this in the next edition.



At the beginning of June, I was asked by GIG, if we would be interested in participating in a new project. The project would be funded by the Jeans for Genes Campaign and an educational grant from Genzyme for two years. The project is entitled "Family Route Map Project".

GIG have selected 6 groups and NPS(UK) are one of them. I accepted immediately and have been working with them over the past few weeks. It has been an interesting time as I got the chance to meet the Project Officer, Anna Lane and Melissa Winter who is the communications manager at GIG in my home to discuss what lay ahead.

The aim of the Project is to help families and individuals access services and information that is currently available in the UK. GIG will work with the 6 support organisations to assess the current situation, through focus groups and questionnaires. They will also speak to medical professionals to find out what they feel patients are getting and what they should and could receive.

NPS(UK) will have our own route map created, helping families affected to access current services and information available.

As an added benefit, our group is getting involved with the Jeans for Genes Day this year, by helping to promote our charity. At this present time, we are volunteering to tell our stories to the media, national press, TV and radio as well as speaking at local schools to encourage people to take part in the day and raise more money.

FAMILY ROUTE MAP SURVEY

The survey is created to try and build up a picture of the services that families currently receive for Nail Patella Syndrome. She would value as much feedback as possible from as many of us as possible. The questionnaire would only take a few minutes to complete and if anyone is interested in receiving one in the post I will be happy to send it to you. Otherwise, if you have internet access, you can complete it online at www.gig.org.uk.

A Focus Group has been set up for the **2nd of December at The offices of GIG in London**, this year where all the group members feel able to discuss the topic with ease. The focus group is not a question and answer session, but a discussion about being a patient or family member affected by Nail Patella Syndrome. The group may be asked questions to encourage everyone to speak and have their say. The discussion will last between 1-2 hours, depending on the groups' need to talk and contribute. The information you provide during the discussion will be used to help us assess the current services and information. After the focus group meeting, a confidential report will be written. This report may be used to support an action plan for development of the Family Route Map project.

So far, we have a few volunteers and there may be a few spaces left. If you feel you would like to attend, please contact me and I will send you all the relevant details in the post. *Please note that no more than one or two members from a family, or children under the age of 16, may take part.*

What is Jeans for Genes?

Jeans for Genes is a national appeal where everyone in the UK is asked to throw out the usual dress code and throw on their jeans and donate £1 in schools and £2 in companies. This helps children with genetic disorders. This year, it is hoped that 4 million pounds will be raised. In the UK, 1 in every 33 babies born will have a genetic condition or defect

HOW CAN YOU HELP?

You can simply wear your jeans on the day and donate £1 at school or £2 in your company or you could organise a fund-raising event. There are lots of different ways to join in and you could take a look on www.jeansforgenes.com You will be able to read all about Stephen's story on this site as we highlight Nail Patella Syndrome.

Please do what you can to help.



I would like to take this opportunity to let you know that as a result of our charity work increasing over the past few months, it has been necessary to welcome a new member of our team. Her position will be Project Manager, and thankfully in June of this year, Kath Lovatt happily accepted the position. It is wonderful to have her as an official member of NPS(UK) as she has been working incredibly hard over the past few years making a difference to many people's lives. She has also proved time and time again that her keen determination to get a job done always results in a positive outcome. She has enthusiasm to open up new ideas and the willingness to carry them all through. I want to wish her all the luck in the world in her new position within our charity.

More from Kath on the following page.....



First of all I would like to say that I was honoured to be offered the position of Project Manager for NPS UK. It was a total surprise! I am pleased to be able to help as much as possible for “our” cause in raising awareness and helping to make a difference out there.

Being a parent myself to two daughters, Alice 12, (unaffected) and Rosie 10, who has NPS, it naturally concerns me about how NPS will affect Rosie in how she deals with the condition, and does she fully understand why she is like this. She often asks me questions about our condition and I do my best to explain to her about NPS in a way that she will understand. I wish I could have had those answers when I was a little girl but we just thought it was a family trait of knobby knees and horrible nails. But there is more to it than that.

So that inspired me into starting a mammoth task of creating a website just for kids! I like a challenge but it will take me quite sometime to do as I am finding the software (Dreamweaver 8) quite complicated, so if there is anyone in the UK with a good knowledge of Dreamweaver or tutorials then I would appreciate your help!

I am hoping to make the web site a fun place for kids to be, along with a simplistic overview of NPS for kids with explanations of genetics and affected body parts all in pictures etc. I will also include a gallery or mug shots section and I will be moderate the site and put other children in touch with each other to keep it secure.

So calling all children including the ones that haven't got NPS to get in touch with your ideas – as this is YOUR site and not for adults! You tell me what you would like to see on a website and I will do my best to include your ideas!



Another project I am working on is again aimed at children and their families. After all they are our future! Every 2 years in the UK we hold a conference in Chester and have a great time swapping stories with each other and listening to all the medical jargon on why we have so many aches and pains. The kids either stay at home, or go out for the day with a member of the family or stay within the hotel under supervision of our wonderful childminders. I think we should have a day just for them and they can bring the rest of the family along too!

As conference is held every two years I am intending to put on an event the year we don't have a Chester conference. It will be something for all the family – I am aiming at a big top style event with entertainers, street performers, clowns, food and a big disco at the end of the night, without the medical jargon! The venue will be somewhere central and I would love to hear from people that would be interested in attending so I can start to organise a place i.e. on size etc as I don't want to book a huge venue to find out there will only be a handful of people turning up!

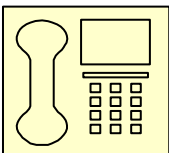
I would also like this event to be free (if possible) so we need to really step up on the fundraising to make it a great day for the children. With this in mind, I have applied for a grant from the HBOS Foundation, (Halifax Bank of Scotland), so I'm keeping my fingers crossed that we get some funds to support this from them. Along with general sponsorship from companies willing to donate especially for this event and we can have a banner with their company details on, so again anyone that can give their support to this, please get in touch with me.

I have written to supermarkets etc asking for their support. One in particular – Tesco. They allow charities to collect funds in their Extra stores and we will be added to their list, to collect sometime in 2007! I have had a volunteer to do parachute jump which would be great to organise in the Chester area so we can cheer him on after the conference! People with children in school – maybe think of approaching your school to donate raffle money to our charity! It a great way to raise awareness about NPS and pulls a fair amount in for NPS too.

Another thing I would like to do is find a celebrity to be the face of NPS UK! I have written to loads of famous people so far with no response what so ever! If anyone reading this knows a celebrity that you think would be prepared to help out, then please do not hesitate to get in touch! It would be a great for us if a famous face showed up at the odd event to boost our spirits or event take part in a charity event for us, such as the London Marathon like Nell McAndrew does!

We would also like to see a new medical brochure put together as I feel that it needs updating tremendously. We would like to see this distributed to the whole of the medical sector, along with schools, colleges, universities etc, so it will be a big task in just the distribution itself. I have been taking photograph's over the summer of affected body parts to include in the brochure, so anyone that has good quality pictures that you don't mind sharing, please email them to me to see if I can use them in the pamphlet.

That should keep me busy for a while! If you have any suggestions, ideas or millions in the bank, then I would love to hear from you! Please email me at kath2167@yahoo.co.uk



We now have a 0800 number up and running, which is being manned by myself! We felt that with all the publicity we will get from this year's Jeans for Genes Campaign, that just including a website address or a personal phone number wasn't good enough. So if anyone needs any information please don't be afraid to call on 0800 1218298 – I won't bite, honest!

NPS(UK) finance report

Submitted by Shirley Raynor

Once again, it's time for another finance report. I'm delighted to tell you that our revised bank balance is just under £11,400. Since April we have received a wonderful amount of sponsorship money, We received £660 from runners in the women's 10km marathon in Glasgow, and another £595 from another volunteer marathon runner.

We are so grateful to everyone who makes this wonderful effort to raise funds for our charity – a big thank you from all of us!!!



I'd also like to take this opportunity to remind you all about Everyclick. You may remember that I mentioned this in my last report – it's an internet search engine that gives us a small amount of money every time it is used. Everyclick accumulate the money in our account and then pay it straight into our bank account every quarter, via the Charities Aid Foundation. We've been registered with this site for less than 6 months, and already we have raised an unbelievable **£1592.95!!!!!!!** Thank you to everyone who has been using this site as their search engine – now you can see how much difference it has made!


If you haven't done so already, why not set Everyclick up as your home page, and use it as your search engine? It is absolutely free to use. The website is:

<http://www.everyclick.com/uk/npsuk>

Even if you don't have access to a computer, please pass the information to your friends and family members who do. I have been blown away by the result of what this can do for us in so many ways. It is a wonderful way of giving money without having to pay a penny or a great deal of time. It is simple and straightforward as each click to the internet means that money generated is distributed to various charities. NPS(UK) HAS BENEFITTED GREATLY, THANKS TO YOU!

Carol Dobbins

Help us spread the word. Tell your friends about everyclick.com
The search engine that helps charity



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

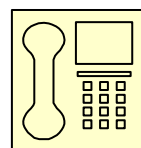
Or write to The NHS Organ Donor Register

PO Box 14
FREEPOST
Patchway
Bristol BS 34 8ZZ



New Freephone number

One of the major issues that required attention was the fact that we, as a charity, did not have a telephone number to issue to the media when giving a story. In the past, I have always given out my own residential number to allow people to get in contact, if need be.



Luckily for me, I have not received any strange callers, but I do believe I have been lucky. It is never advisable to hand out your personal details when going to the press

Within the past couple of weeks, we have set up a freephone account with BT. This will mean that we have a much safer way of getting people to contact us when going to the press.

Our new telephone number is 0800 121 8298

When calling this number, you will reach our new Project Manager's house, Kath Lovatt who will take your query. If need be, you can still get me on my home number.



CONFERENCE PLANS UNDERWAY

It is hard to imagine that it is time to start planning the next conference of 2007! Already, I have been making enquiries in various places and at this early stage it looks like the conference will be set for August and the venue is likely to be the Chester Moat House, once again!

They provide us with the best service possible and the location is as central within the UK that I can find to try and be fair to as many people as possible. There is also a large international airport relatively nearby which helps the speakers fly in from various parts of the world.

I looked into many other possibilities this time, but nothing compares to the service and location of Chester. I have some wonderful contacts in the area who work with us to provide alternative accommodation for those who feel they would not like to stay in the Moat House. In recent years, the places that have been recommended to us have been very comfortable to those who made this decision.

It is not carved in stone yet, but it looks like the Chester Moat House ticks most of the boxes once again.

For anyone who feels they would like to attend, but are worried about the financial implications regarding their travel arrangements, can I remind you all that NPS(UK) have set up a Travel Fund and if you feel that you may need some assistance, please contact us and we can send you the information and forms that you will need to complete.

In the January edition of our Newsletter, I will be able to provide you all with more details of this wonderful event.

For those of you who have never had the opportunity to attend a conference, I highly recommend you to come along. I am sure it will be an experience you will never forget!!

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

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

www.npsuk.org

www.nailpatella.org



Alternatively email me, Carol

Dobbins on :-

dobbinsek@btinternet.com

Phone me on 01355 241277