

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.

**An introduction from the Chair
Submitted by Carol Dobbins**



*Issue 11
May 2006*

**DELICIA
FAMILY OF THE YEAR!**
2005

It has been such an exciting few months for our charity as our publicity campaign has stepped up a gear due to many events including the Dobbins family taking part in a BBC documentary that was screened on BBC4 on the 26th April. Also, many of you nominated our family in two separate awards. This absolutely generated a great amount of interest and I am sure that it will prove beneficial to us in the long run.

In the last issue of our Newsletter, you may remember that Goodfellas had decided our family should be nominated for this award. It was a very touching thought and one I will never forget. So many of you placed your nominations and after a final ten were selected, our family were announced as the overall winners on 19th January 2006! It came as a huge shock to us and we were so happy to receive the award.



I received a call from the organisers to say that Vanessa Feltz would be coming to our house with the media company representative and photographers. It was very exciting as, once again, the NPS media profile was raised. The local newspapers, East Kilbride News and East Kilbride Mail were keen to know if we had won, but I was sworn to secrecy until the day they were due to arrive. Vanessa, understandably, wanted to be the first person to make the announcement to the press. A press release was issued on the 31st January when they were due to arrive and by lunch time I received a phone call from "Scotland Today." This is the TV news programme that many north of the border watch every night in front of the TV. It is on at prime time and they heard that Vanessa Feltz was coming to present the award at my home, so they said that they would be coming too! As if I was not nervous enough!?!

I started pacing the living room at 4.30 when the phone rang. It was Scottish TV wanting to know where we were. They had been given the wrong address and were sitting outside my old house! Two minutes later I received the same call from the photographer who was booked by Vanessa and Katie. I was told by the photographer that they were on their way and would be with us shortly.

A few minutes later, the photographer arrived. He was a nice jovial character who I knew we would have some fun with....and we did!!

A couple of minutes later, the TV crew arrived. This was the first time, I actually felt quite uncomfortable as they were on such a tight schedule to get this filmed and the satellite was down. This meant that we had a 2 minute slot to film as an "as live" and then they would have to race back to the studios to air it for the end of the show.

They were amazing to have done this in such a short period of time as they left my house as 5.30pm. The clip was screened just before 6.30!!!

When Stephen was asked what it felt like to have his leg rebuilt as a young boy, he answered, "Well nothing really. I got a wee jag and was asleep!" Vanessa thought this was brilliant!

Anyway, it was time for them to leave and the photographer came back in and we spent a couple of hours getting photos taken and generally having a great time with them all. Vanessa was a larger than life character. An incredibly honest.....maybe too honest at times.....hysterically funny person. She said that she would take all the calls when the programme finished on the TV and she did!!! She answered the phone to one of Stephen's friends who wanted to speak to him saying, "Hello, Vanessa Feltz here, this is the Dobbins household, to whom would you like to speak?" When his wee friend said Stephen's name she said that she would need to check with his secretary!!! It was such a laugh a minute! She arrived laden with gifts and presented me with a beautiful bouquet of flowers. We received a beautiful trophy and a certificate for the wall which she signed too. We have won a year supply of pizzas in the form of a voucher book and also a luxury family holiday in Italy for 4. We can choose when we would like to go and also we have a say in where we go.

It was a bizarre night, to say the least. It all happened so fast, but I will never forget it for the rest of my life.



Many local and national newspapers ran stories on what had happened and I am very happy to say that NPS will be understood by many others. The Goodfellas website ran the story for some time too and placed a link to our website there. As a result, I have noticed an increase in the hits to our site and this is wonderful news for all of us.

I need to thank so many of you who voted for us in this competition. To be honest the prizes are wonderful, but the honour is far much greater. You are all my heroes! I am so honoured to have friends like you in my life.

Fundraising/Publicity updates



As previously mentioned, 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.

Can I ask a huge favour from you? Would you please put some pressure on the BBC to ask for this programme to be repeated on BBC2? It would be seen by a much wider audience as those people without satellite channels will be able to watch. You can call the BBC direct or you can log onto www.bbc.co.uk/bbcfour and place your comment in the "Have your say" link. Mine is already there and I need many others to do the same.

More about the documentary later.....



On the 19th January, I received a call from Mr Brian Leckie, who teaches my son, Stephen, Taekwon-Do. He had just been in contact with a lady who writes for a school magazine called "Primary Times." She wanted to feature an article with Stephen and a little photo of him as he won his British coloured belt title. The magazine goes out to all schools in South Lanarkshire, so as a result, I believe that many others will read a little about NPS!

As a result of the Goodfellas Awards, many of the local and national newspapers ran a story. The newspapers who supported us were the East Kilbride News, The East Kilbride Mail, The Daily Star, the Daily Express, the Daily Record and the Evening Times! The Daily Record came to the house and took many more photos for their records and ran a separate story.

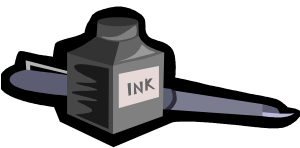


You may remember from the last issue of the newsletter that I wrote an article for the Genetic Interest Group. I am glad to say that it was published in the January edition of their Newsletter and can be viewed on www.gig.org.uk, then by clicking on publications and newsletters. It gives a summary of my experiences as the BBC camera crew followed us around during the filming of the documentary.

If anyone would like to receive a printed copy of this, just let me know and I will print it off for you and post it to you. My contact details are at the back of the Newsletter.



Many donations have been received over the past four months, including a cheque of **£117.42** from our Webb Ivory Catalogue fundraising campaign. This is a simple easy way to raise funds and we will continue raising funds in this way. Many thanks to Debbie Markham for all the work she has done to organise this for the benefit of those with NPS.



I have recently been alerted to another way of raising funds in a simple way, by donating all your used inkjets and mobile phones. At this moment in time, we are looking into this brilliant idea as it is a way of raising funds by recycling your old items that will no longer be of any use to you. Rather than throwing them in the dustbin or into the bottom drawer, you could send them to us and we will generate income by posting them onto the company involved, who, in turn, pay a percentage of all that they receive.



Hopefully I will have more information on this in the next issue in September.

There have been many individual donations recently including a very big surprise from the wonderful Pauline who works at Elders Bar in Tollcross, Glasgow. I knew nothing about her kindness until the last minute when I was stunned to hear that she took part in a five hour sponsor silence on our behalf. From what I hear, Pauline and I share a similarity, we can talk for Scotland! It must have been really difficult for her as I think it would have been impossible for me!!

She raised an amazing **£360** for our charity!

Thank you Pauline, all the Elders staff and everyone who contributed!



A very generous cheque of **£300** was donated by Joseph Woods, from Quality Ceilings in Bishopbriggs, Glasgow. Thank you Joseph for all your interest and support to our charity.

Our bucket collecting raised **£110**, thanks to all the spare cash lying around and donations from friends and neighbours>

Bill and Anne Sneddon, Bill and Sheila Libberton, thank you for your continued support with collecting tins and donations. What would we do without you? You are wonderful.

We also received a very kind cheque from Ballerup Football Club here in East Kilbride, who last year played a tournament on our behalf. They raised **£322.00** for Nail Patella Syndrome UK. Thank you so much from us all!

IMPORTANT FUNDRAISING ANNOUNCE-

Everyclick.com is a search engine that enables you to raise money for NPS(UK) every time you search or shop online. There is no charge to you or the charity and already we have received our first monthly total of **£ 20.48**. It is such a simple way to raise money without even knowing that you are doing it! I have to admit, like everything else I look at, I was sceptical at first, but it has worked out a treat. I believe that it is one of the most exciting ways to raise money as it is so very simple!



The shops that are available through the site are wonderful and I have made a few purchases myself during easter and early spring. I love ebay and that also is one of the sites included.

All you need to do is make the engine your homepage by simply clicking on the icon "Make everyclick your homepage".

Thank you to Bill Sneddon for finding this for us. I would never have known about it otherwise as the charity is growing from strength to strength now and there is little time left for looking into ideas like this.

Can I ask that if you are sending out any emails you add a little tag to remind people. I use the one below:-

Raise money for NPSUK just by searching the web.

everyclick.com is an internet search engine with a big difference - it donates half its revenues to charity!

It does not cost us, or you, a penny. Now you can support NPSUK every time you search the web.

Just make <http://www.everyclick.com/uk/npsuk> your home page and make sure you use it whenever you search the web!



On 8th February, I received a phone call from a reporter at the Daily Record. He explained to me that there was an Awards ceremony planned for the 21st April 2006 at the Hilton Hotel in Glasgow. It was to be a glittering event in their calendar as they pay tribute to many Scots in the "Our Heroes" Awards, hosted by Jackie Bird and Tam Cowan. He went on to explain that he had heard all about Stephen's courage to receive the gold medal in the British Coloured belt Championships and felt it was appropriate for him to be nominated.

On the 18th March I received a letter to inform us that Stephen had made it through to become a finalist in the "Sporting Hero" category and that we were invited to the ceremony.

It was a very exciting night and I was so proud of our wee NPS guy!

Stephen's category was extremely unfortunate in many ways as our Commonwealth entire team was put into it to receive the award. They obviously took it and not only did they take that, they took the overall award on the night. I must be honest it is so worthy of them to receive an award, but poor wee Stephen was up against it with a pack of trained athletes!

The Daily Record staff were wonderful with Stephen though and they gave him some absolutely beautiful gifts. One of the staff came over with a pile of toys and I thought she was asking Stephen to choose what he wanted, but she walked away and told him to keep the lot!!

It was an incredible evening and I will never forget it for the rest of my life. I only wish that we were able to stand up on that stage in front of all those wealthy, powerful people and tell them about NPS and that we need their help. I realised on that night, that I am ready to do that now. Years ago, as many of you know, I wouldn't have stood up in front of my mirror to speak, but now, people NEED to know that our charity needs them too.

We sat at a table with some incredible people who served in the Gulf Wars. They were the 205 Field Hospital TA Unit and I will never forget their incredible spirit. They instantly became friends with Nicola and Stephen and to be honest, I couldn't get a chance to get off the dance floor as they insisted that we dance all night!!!

Stephen received great respect from so many people on the night and it was very emotional to see grown men and women hug him and thank him for his courage. Stephen was so confused and kept asking who they all were!! "Why are they hugging me?" He kept asking. He wasn't complaining when the glamorous women kissed him though!!!

He saw a few famous people and said that he got a hand shake and pat on the head from Dr. Who!!! He got a few autographs, his favourite being "Navid" the shopkeeper in a programme that we love here in the UK called "Still Game". He was so kind to him.

Overall, it was a wonderful evening, and I believe that a few more people have learned about NPS.





The idea of appearing in a BBC documentary was a little overwhelming, to say the least. However so many of you have supported our family on the importance of this documentary being shown. You gave me the strength and courage to go ahead with this and I will never be able to thank you for that.

For the NPS community, it was the best platform we could ever ask for to let the world know about Nail Patella Syndrome. There would also be such a wonderful opportunity to let the medical profession know that we are here and that we need a lot of support too. Little did I know that the journey we embarked on would be so wonderful in many ways.

I met Candida Harris a few months before the documentary when we worked together on a Radio 4 programme that discussed similar issues of living with a rare genetic condition. Almost immediately, I felt like I was sitting beside a woman who I had known all my life. I have the highest regard for Candida and I believe that this programme will show many people that we all have a place in life, whether we fit the perfect mould or not! I think that Candida deserves an award for managing to sit quietly when she interviewed Professor John Harris, as he spoke about his wish to “remove as many of the human diseases as we can” and “avoid bringing inherited conditions into existence”. Sad, in my humble opinion, that there is still such a closed minded attitude such as this in the world today. I agree that every person is entitled to his/her opinion, and I actually respect his opinion, but I absolutely disagree. I have met some incredibly inspirational people in my life, some with disabilities and some without, as I am sure many of you have, and I have to say that I have never thought that those who were “imperfect” should have less rights. We should all be treated and viewed equally, shouldn't we?

The feedback on the programme has been incredible. I hope you all enjoyed the programme. It has made people think, and I think that is good. One lady told me that her family discussed many aspects of the programme and talked about the importance of sharing views of such emotive issues. I hope and pray that anyone out there who may think they have NPS will call and get in touch with me and we can support them in the ways they need.

I would like to say a special thank you to Mr. Des Timmons and all the staff at Saint Leonard's Primary School. Nothing was ever a problem, even when I was turning up at the school with a camera and removing Stephen for, yet another hospital appointment.

I would like to say a special thank you to Mr Brian Leckie who supports Stephen twice a week and has done for almost two years now. He has encouraged him to learn the art of Tae-kwon Do that provides him with great belief in himself and I believe it has built up his physical strength too. Once again, nothing was ever a problem with regards having cameras at the classes.

Another special thanks to Dr. Heather Maxwell and Mr Rod Duncan who have supported us in many ways. They have both played such a key role in Stephen's life and I know that spending time with them in their clinics has never really been a “chore” in his life. I know that Stephen is in great hands!

If anyone needs copies of the recording, just get in touch with me and I will see what I can do. I managed to record it on a DVD recorder last night, and I am in the process of trying to copy from that! I am sure that I will get some! I have some offers of help, so I will likely be taking you up on these! We will try and see how we can convert them to the US format too. If anyone has any ideas, let me know!

Final thanks to the programme director, Dickon Le Marchant, who is such a kind hearted man. It was an absolute pleasure spending time with him throughout the recording of this programme....still feel a bit guilty about the swan bite on the nether regions though!!!

If anyone wants to email me about the programme, feel free.

Please can I remind you to contact the BBC to ask for more shows like this to be shown and also to ask if they would repeat this, possibly on BBC2, terrestrial TV.



The BDF is the UK's leading child health research and care charity. I am in contact with them and receive correspondence from them from time to time. I thought you may be interested to hear that they are now announcing that extra grant funds are available to directly help sick and disabled children and their families. The awards are made under their Child and Family Grant Scheme (C & F)

If you visit www.bdfnewlife.co.uk you can download a sample application form for your information.

The grants can help children and their families in many ways. They have funded special car seats, wheelchairs, bedding, beds, walking aids, to name a few. The grants are not means tested and are awarded based on the needs of the child. They give speedy replies and other than the initial application form, there are no further forms to complete as all follow up is done by telephone. Making an enquiry is simple. Call the Nurse Helpline on 08700 70 70 20.

Why does the BDF exist? Because babies are the future!

Who are they? BDF Newlife were founded in 1991 under the name British Defects Foundation. They were formed by parents, doctors and business people dedicated to fighting the biggest threat to child health—inborn conditions.

What do they do? They aim to tackle inborn conditions from all angles including research, providing services, grants and raising awareness. They do all this without any government funding.

If anyone has no access to a PC and would like an application form, please contact me with your details and I will be happy to send you what you need in the post.

NPS(UK) finance report

NPS UK Finance report Submitted by Shirley Raynor

Since my last report, I have put together our 2005 return to the Charity Commission, which shows our income and expenses for that year. The return shows these results:

NPS UK

Results 2005

Income

	£	
Donations	1994.05	
Interest	120.59	
Fundraising & sponsorship	4276.27	
		6390.91



Expenses

T-shirts for sponsored run	80.00	
Computer costs	255.46	
P O Box	54.00	
Postage	51.55	
Collecting tins	93.00	
Conference costs	6748.45	7282.46

Net expenses for the year		891.55
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Surplus brought forward		9384.29
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Surplus carried forward		8492.74
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Since the end of December we have continued to receive generous donations and yet more fundraising income from our increasing number of active NPSers here in the UK. As I write this, the latest bank statement shows a balance in hand of £9740!!!! **Thank you to everyone who has been involved in helping to raise this wonderful amount.**

A new money raising venture this year has been the “everyclick” search engine. By signing up to use this internet search engine for the benefit of NPS, we get a small amount every time you use it. Every little helps and it is free to join!! Just set <http://www.everyclick.com/uk/npsuk> as your home page.

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



Marathon runners

I am so pleased to say that we had an incredible young woman, Cathy Mellor who ran the London Marathon for us this year. She is a perfect example of someone who gets pleasure and joy out of giving to others. She raised a wonderful sum of money for two charities! The money is still being collected, but it looks to be in the region of **£1,200**!! Not only did she achieve this incredible sum of money, but she ran the entire 26miles in 4 hours, 46 minutes!! Cathy, from all of us, thank you so very much!!

A summary of the day by Claire Sugden

26.2 miles – really !!! Flora London Marathon 2006

Sometimes you're glad when you volunteer to do something without thinking first, and last weekend certainly was one of those occasions for me.

Catherine and I booked Friday off work and set off on the long journey South to the Big City. Surprisingly, it was me who was more nervous about the mammoth task facing her (how **DO** you get an NPS'er, an injured marathon runner with one useful leg and 2 weekend bags across London with no taxis and packed tubes !!?) Questions we luckily didn't need to be answered in the end.

Preparations took the form of 1 or 2 light vodkas on the Friday evening, combined with the most carb-filled meal available on the Japanese menu in front of us. Saturday consisted of registration, a gentle walk by the river in the spring sunshine, alcohol avoidance (clearly!) and, you guessed it, one final carb fest !!

Sunday morning was quickly upon us and even just as a spectator, the atmosphere was like no other live event I've ever experienced. The encouragement from the crowds over the last few miles was incredible, enough to carry the weary athletes (and 'athletes') through to the finish line. I'm not sure how much the lager, cheese (honestly !!) and other weird and wonderful donations would have helped with the task in hand, but the thought was there.

So if any of you are stuck deciding what to do on Marathon Day next year, head on down with your loudest voice and your brightest shirt and you are sure of a great day out !!!



More runners!

I am so happy to say that there are many more volunteers this year who are willing to put on their running shoes for our charity than ever before.

There are a few teachers from Saint Leonards School in East Kilbride who have decided to give the Women's 10K a try. It is a wonderful occasion as many women from all walks of life come together to raise awareness and funds for their chosen charities.

Thankfully NPS(UK) has been chosen by Dawn Torrance and her colleagues and friends at Stephen's Primary School.

The race day is Sunday, 21st May 2006 and I would love to wish them all the best luck in the world!

More on this in the next issue!



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

Look out for our next edition of the Newsletter which will be issued in September 2006!