



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 update from the Chair

Submitted by Carol Dobbins

Welcome to our 2nd edition of our NPS(UK) Newsletter.

In this issue, we have many updates regarding the conference in Chester this August; information on fundraisers in the past, present and future; publicity and how we are achieving this; and also the latest information that has become available to us.

Here are a couple of examples of the work that is being done.



Sophie Casper-Gilbank, left, with her mum, Jacquie, and sister Amy, three at home in Hillingdon
Valentine date in fight against Sophie's illness
HAPPY little Sophie Casper-Gilbank is treated for one of the most rare *asthma when they took seven-year-old Sophie to the family doctor after first*



Woman with a mission: Carol Dobbins aims to increase the knowledge and awareness of the rare medical condition.

Jacquie Gilbank (above) has been a shining example for her commitment to raising awareness and funds in recent months. Her efforts have raised more than £1,600. Find out more about her and her family on Page 4

Carol Dobbins (left) with an array of newspaper articles published in the past 3 years.

Our publicity campaign has remained paramount in what we achieve to do. The East Kilbride News has remained an incredible source of support to us and continues to publicise every event that takes place locally. They has spread awareness to the general public about our first NPS(UK) conference in Chester and have asked for support from volunteers on our behalf.

So what's inside?

Front page NPS happenings. 1

Exciting News! Fundraising updates and diary of events. 2

Can you help with ideas and support? 3

Update on the NPS(UK) conference in Chester. A new informative report. 4

Finance report April 2003. 5

Jacquie's story and useful contact details 6



NPS(UK) fundraising updates

Submitted by Carol Dobbins

Great news!

Firstly, I would like to share the wonderful news with you all that NPS(UK) is now a fully registered charity!
Registration number 1095621

We received our charitable status on the 27th of January 2003 and we now have much greater opportunities in raising our funds as a result.

We have recently purchased a number of collecting cans to distribute as far and wide as possible to raise our funds and also increase awareness for this condition. If anyone would like to assist with this, please contact me anytime and I will send you what you need.

At this moment in time, we have nine cans distributed throughout Britain.

We also have the added benefits of claiming tax returns on every donation made by a UK taxpayer. This will increase our funds tremendously as we can receive up to 28% of any donation made to our charity.

Fundraisers galore!

I am so pleased to say that our fundraising attempts over the past four months have been a huge success. Much of this has to be attributed to an incredible lady, Jacquie Gilbank. Her work has been an inspiration to so many and our NPS(UK) bank balance has never looked so healthy!!

Thank you so much and I look forward to doing many more with you!

Fundraiser diary of events

29th March 2003– Disco fundraiser in Stewartfield Farm, East Kilbride, Scotland.

By the time you receive this newsletter, this night will be completed. I have been planning this evening for some time and have received some lovely prizes from many sources. Thank you to so many of you for your support on this. I will be organising two separate raffles on this occasion with a star prize raffle offering a beautiful San Francisco 49ers shirt and cap as first prize. It was sent from California as a donated prize that will hopefully tempt people into digging deep in their pockets for a ticket!

I will also continue with the regular raffle with some beautiful prizes and display a collecting bucket at the bar with a football scratch card and ask people to pick a team, throw in a pound and when the card is complete, I will scratch off the winning team and announce the winner, issuing them with the £20 that could be very useful in a pub!

So far, I have sold approximately 80 tickets and I will be supplying all the buffet myself, so we should make a nice profit.

18th May 2003– Ladies 10K run in Bellahouston Park in Glasgow, Scotland

Angela Mitchell, a dear friend of mine, has volunteered her services to us. She would like to run this event to raise funds and awareness and is already in training!

Angela has been given her sponsor form and is already passing it around to all her friends and family.

Angela, from all at NPS(UK) and NPSW, thank you from the bottom of our hearts!

I look forward to giving you all an update on her success in our next edition of our newsletter.

24th May 2003– 5 munro hike in Killin,
Perthshire, Scotland

Graham is at it again!
You may remember him from our first edition
Newsletter. He ran the Glasgow Half Marathon
for our Charity and now he has come up with
another exhausting, but inspiring idea!

We now have 11 volunteers who are willing to
take on this incredible challenge, including my
poor husband, Keith! Some are complete novices,
but there are experienced walkers with them, so
I plan on seeing them all home safely!

They also have all been issued with their sponsor
forms and they are already being distributed be-
tween work colleagues and family.
Graham, Keith and co, we are eternally grateful to
you all for the incredible challenge that you are
willing to take on our behalf. Just do us all a favour
and return safely
I look forward to updating you all in the next issue
GOOD LUCK EVERYONE!

Fundraising ideas ?

If anyone has any ideas, comments, suggestions, please feel free to contact me at any time on the de-
tails at the back of the newsletter.

You may want to attempt something similar to what has been going on lately and would like ideas on
where to start or need assistance with prizes, tickets, etc....

You may have a novel idea and want to get as many people involved as possible.

Whatever your ideas or comments, they are all appreciated right now.

Do you know of anyone who may be in a position to assist us?

Do you have contacts with companies who may have a Charity Fund and who may support charities
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 contacts, medical journals etc...

If you 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

NPS(UK) conference update

Venue: Chester Moat House
Date: Saturday 16th August 2003

The dates and location are now set. The plans are well underway and there has been a huge interest from many of you who are willing to attend. Thank you to all those who have returned their forms as this enables us to plan much more effectively. For anyone who has not received a form yet, please contact me and I will send it to you in the post immediately.

For more information on the chosen Hotel, click on www.moathousehotels.com

The quality of the Hotel fits all the criteria that we are looking for and is suitable for disabled access. The room rates are £95– single room, £115– double room and we have also been able to issue alternative accommodation to those who prefer to stay elsewhere. All the alternative accommodations that we have provided information on are within close proximity to the Chester Moat House.

We have reserved a room for the Friday evening also and this would be a nice opportunity to meet and greet other guests who wish to attend the conference. Good chance to compare knees, nails and elbows! On the Saturday, talks will begin at approximately 9am and continue until 5pm approximately. NPS (UK) will provide lunch for all and 2 servings of tea. There will be a conference fee of £10 to cover expenses. Children under the age of 16 do not pay. We have also provided a separate room that can be used for the children.

At this moment in time, we have Dr. Iain McIntosh, Dr. Elizabeth Sweeney and Dr.s Jeff and Adele Towers who are hoping to attend. We are planning on organising various talks that will include information on all the relevant areas to Nail Patella Syndrome i.e. kidneys, eyes, bones, joints also.

If any of you require further information or would like to assist in organising the various issues regarding the conference, please contact me anytime.

NPS article goes to print!



Many congratulations to Dr. Elizabeth Sweeney (pictured left) who has carried out an incredible study on Nail Patella Syndrome with 123 people in the UK.

She has worked extremely hard in producing an excellent report on her findings alongside Dr. McIntosh, Dr. Fryer, Dr. Mountford and Dr. Green. The article is hugely informative and can be found by clicking on www.jmedgenet.com/cgi/content/abstract/40/3/153?eaf

If anyone would like a copy in the post please contact me and I will issue you with one immediately.

Many thanks also go to Elizabeth who has helped a great deal in all the preparations for the conference by visiting the Moat House and checking out the area for us all.

Thank you also for providing us with a contact who is working with us to create our NPS(UK) website that should hopefully provide many others with the information they deserve.



Finance Report- April 2003

Submitted by Shirley Raynor

Once again, it's time for an update on our financial position. The last time I wrote to you, and it was only about 4 months ago, we had just over £1000 in our bank account. Since then we have had the wonderful fundraising efforts, which you'll no doubt be reading about elsewhere in this newsletter. I have, today, received the latest bank statement which shows that we currently have.....

£3,200

This is such a brilliant achievement in such a short space of time. I'd like to say a big thank you to everyone who has worked so hard to make this possible. This sum will go a long way to getting our forthcoming conference under way!!

In the last newsletter, I mentioned the benefits of having charitable status – one of them is that the Inland Revenue will themselves make a contribution into our fund, if we receive donations from UK taxpayers who are willing to state that their donation is made as “Gift Aid”. And, as we now actually have our registered status, I'd like to explain this in a bit more detail.

It only applies where a donation is being made, without anything being received in return. So, for example, it would not apply to the conference attendance fee, as conference attendees are getting a service in return for their payment. If anyone wishes to make a voluntary donation, all they would need to do is enclose covering note saying that they are a UK taxpayer, giving their name and address and that the donation is made as Gift Aid. (And if the donor pays tax at the higher rate of 40%, they will be able to enter it onto their own tax return to claim a 20% tax deduction themselves as well.) At the end of the tax year, I will make a claim to the Inland Revenue and we'll receive an amount from them of about 28% of the Gift Aid donations received.

A lot of people don't realise that the Gift Aid scheme also applies to money given via a sponsorship form – so if you are thinking about shaving all your hair off, standing on your head for an hour, or whatever, and asking people to sponsor you, make sure you add an extra column to your sponsorship form. Head it “Gift Aid”, and put a note at the bottom of the page asking your sponsors to tick the box if they are a UK taxpayer and willing to have their donation treated as Gift Aid. And there you are – free money from the Inland Revenue! It's not often you hear that, now, is it?

If anyone needs to contact me for more information about Gift Aid, please feel free to get in touch through the usual address.

Jacquie's story

Submitted by Jacquie Gilbank

We first got diagnosed with Sophie last June. The most frustrating thing off all was it had taken 7 years to find it out, we knew something wasn't right from the day she was born because she hadn't any finger nails, we were told not to worry she had a nail bed & that they would grow, they didn't. Last March we found a lump on one of Sophie's knees I took her to the local GP who when examining her said she couldn't feel her knee cap, to cut a long story short we found out 3 months later she had NPS. It was so scary at first but finally we came to terms with it, I said after Xmas I wanted to try & fund-raise to help the disorder it was something I needed to do to help me. so in Nov. last year I booked the date for the disco with twins Carol & Chris at a local charity event they were doing, they both said they would help me organise it. my first fund-raiser would be 15th Feb. 03. I then got in touch with Carol Dobbins who has really helped & been a good friend. I decided I needed to go to the local paper for publicity, I was very nervous about this because I had never done anything like this before but Carol was great she gave me lots of advice. Anyway it paid off. The day it was in the paper a lady rang me up & said she was so touched by Sophie's story the community centre wanted to hold a bingo to help raise more funds. I was so emotional about this & hadn't expected this to happen. The bingo was to be held 3 days after the disco. We raised £1295.75 at the disco including donations on & before the night, we had a really fun night with lots of things going on we had a Champagne raffle also somebody donated a ten year bottle of malt whisky to win which was brilliant. At the bingo we raised £332 which is excellent for such a small community, so the total raised £1627.75. I never imagined in my wildest dreams it would be that much, but it just goes to show people out there do care. I am so proud off myself & feel so good inside that I am doing something not only to help Sophie but others as well. I plan to do more to help raise funds for NPS later this year.

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 1YW
Scotland

Alternatively email me on dobbinsek@btinternet.com
Phone me on 01355 241277

Nail patella Syndrome website with useful information can be found on
www.nailpatella.org
A new site is being constructed at www.npsuk.org

Look out for our next edition of the Newsletter which will be issued in August

