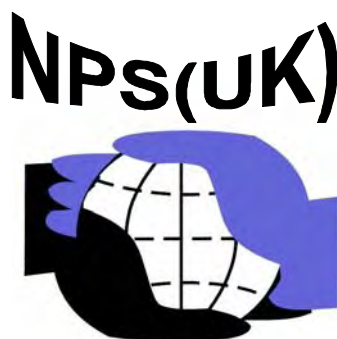


Nail Patella Syndrome (UK) is a charity that provides information and support to those whose lives are affected by this condition and also for the use of the medical profession.

NPS(UK) conference 2005



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May 2004*

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An introduction from the Chair

Submitted by Carol Dobbins

The NPS(UK) 2005 conference is fast approaching. It is now time to seriously consider the location, date and agenda.

My thoughts on this have come as a result of taking into account many points of view from a varied source of people. However, it is not my thoughts that count...it is yours.

Personally, after a great deal of discussion, I feel that Chester should be the place, once again, in the same Moat House Hotel, early August, with an agenda that will closely follow what we had in 2003. I need to book the Hotel very soon to confirm the dates well in advance due to the time of the year we wish to organise the event.

I feel that the Moat House provided us with everything we needed last August and the location was absolutely beautiful. It was easily accessible for wheelchair users and very close to all amenities. The staff were absolutely incredible and there was absolutely nothing that posed a problem for them.

We had a few special diets and they were very supportive on this, ensuring with myself regularly that everything was to our satisfaction

The food was just wonderful and, to be honest, I had loads of positive comments on this. It is always a major

worry that all goes to plan and as Elizabeth, Shirley and I entered into this, the whole sense of responsibility often came to the forefront of our minds.

I also feel that the location is fair to all in the UK, easy reach from the airport, train stations, and all other public transport. I also think it would be a bonus for many to be in familiar surroundings as this may allow many to relax a little sooner.

To be honest, all the boxes in my mind, are ticked in favour of hosting it in Chester once again.

One little drawback is the cost!

The Moat House was not cheap, but there are lots of local Hotels, B &B's that are. I have a great contact in the Chester and Cheshire area who worked very closely with me throughout the entire organisation of the NPS(UK) conference last time and this will be such a positive asset to us this time also. Please feel free to email, call, write and share your views and they will all be accounted for. Up to this point, everyone shares the same views who have come forward.

I look forward to hearing your opinions.

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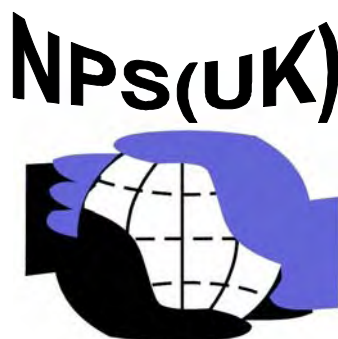
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Stephen Dobbins



NPs(UK)

KIDZ ONLY!!



Ben Sharratt



Rosie Sharratt

- BADGER
- BEAR
- BEETLE
- BUFFALO
- BUTTERFLY
- CAT
- DEER
- DINGO
- DINOSAUR
- EAGLE
- HORSE
- KANGAROO
- LEOPARD
- MARMOSET
- MONGOSE
- OSTRICH
- PENGUIN
- PIG
- RABBIT
- SHEEP
- SNAKE
- TIGER
- WEASEL
- WHALE

Word search

E S O Y S H T X M W O P H D F
 L U L R M R S A W E A S E L F
 A S A D E E M Q Y S A V K E E
 H Q F B R G U P T O V G T A O
 W Z F K U I D U I O D E L F K
 U K U L A T M A B G R K E E G
 Y M B V S N T F B N A A X I G
 H V E H O H G E A O P N P E I
 M W E P N S A R M O S E T E
 T E T M I Y T B R F E A N S L
 P A L N D E E R I O L B G L Y
 G E E I P N U G I Z O Y U C I
 Z E N A B E A R M C A T I P D
 W G V I K J E S R O H Q N E B
 O I L H O B Y K X O Y L E E W

Riddle corner

Answers at bottom of page

1. I don't have lungs or a chest but I need air; I am not alive, but I grow; I don't have a mouth and I'm allergic to water. What am I?

2. I am found in the sea and on land but I do not walk or swim. I travel by foot but I am toeless. I'm never far from home. What am I?

Competition corner

We are running a competition and would love to receive any ideas from you to design a logo for the kids page. The winner will receive £5.00 and all entries will receive a little key-ring. You must be under 16 years of age to enter. Send your entries to dobbinssek@btinternet.com Come on boys and girls, don't be shy!!



jokes corner

Q: What do you take before every meal?

A: A "seat"!!



There are 5 cats on a couch.

One jumped off.

How many were left?

Answer:

NONE, they were all copy cats!

what do you get when you cross a dog with an elephant?

A: a very nervous postman



Q: Why do birds fly south in the winter?

A: Because it's too far to walk!

Q: what is the longest word in the dictionary?

A: the word smiles because there is a mile between each sQ

Pen pal corner

Hi,

My name is Nicola Dobbins and I am 11 years of age. I love Irish Dancing and the pop group, "Blue."

I would love to hear from you.

Please write to me at

40 Malcolm Gardens

West Mains

East Kilbride G74 1QX



Come on, tell me about yourself too.

1. Fire 2.A Snail



NPS(UK) finance report

Submitted by Shirley Raynor

Since our last newsletter, I have put together our first year's financial results as an official charity, and these look very healthy. Here they are, below, for the 12 months to 31 December 2003. These will form the basis of the annual return that I have to send back to the Charity Commission to show how much we have raised and how we have spent it.

NPS UK

Results 2003

Income

		£
Donations		2318.09
Raffles		100.00
Fundraising	3566.75	
Conference income	1159.07	
Sponsored run	1949.50	9093.41

Expenses

T-shirts for sponsored run	90.00	
Photocopying		45.00
P O Box		53.00
Postage		71.14
Collecting tins	104.50	
Conference costs	<u>4447.20</u>	4810.84

Surplus for the year		<u>4282.57</u>
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Surplus brought forward		<u>800.06</u>
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Surplus carried forward		<u>5082.63</u>
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And 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 £6580.21, and I have cheques totalling £45.16 ready to pay in, so we have already have £1600 more than at the end of 2003 – the increase all comes from donations and fundraising. Thank you to everyone who has been involved in helping to raise this wonderful amount.

As well as working towards the funds we need to run our next NPS UK conference, in 2005, we are hoping to invest some of our money in computer equipment to help Carol produce and print our newsletters. We could also use the equipment to produce posters for hospital clinics, raising awareness of NPS even further. If anyone reading this knows of any discounts available to charities buying computer equipment, please get in touch!!

New Report available

At the last conference in Chester, we had the pleasure to listen to many wonderful speakers, including Ketki Desai who works as an occupational therapist in the Pittsburgh area. She has recently had an interesting report published that discusses the variations of NPS symptoms between many people. I found it very interesting and it was a wonderful example of how these conferences help the medical profession and the patient work together to understand the condition even more. If anyone would like a copy of this report, please contact me on the details below and I will gladly send it to you.

John Hopkins research studies

As many of you are aware, an ongoing study is taking place in Baltimore, USA. Dr. Iain McIntosh is always looking for new blood! If you feel that you would like to take part, please contact me for further details. As we all live a fair distance from the USA, it doesn't mean that we can't take part. We can fill out forms, questionnaires and send blood. This is such a valuable aspect to all the research that is happening right now and I would urge anyone who is interested to contact me and I will send you the details necessary.

To quote Iain,

“Come on men, your syndrome needs you!”

Many thanks!

I would like to take this opportunity to thank so many of you for your help with this Newsletter edition. It has been an eventful few months and there were doubts in my mind that I would ever get around to ever completing it, but with many thanks to the kids, Ben and Rosie Sharratt, and Stephen and Nicola Dobbins, we have a kids page to be proud of. Thank you so much to Shirley also for all your hard work in producing our financial report that fills me with great pride. Thank you to all of you who so generously give your time to do whatever you can to help. I honestly would not be able to do this without you.

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 1QX

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

For more information on Nail Patella Syndrome, please check out the following websites.
www.nailpatella.org
www.npsuk.org

Look out for our next edition of the Newsletter which will be issued in September 2004



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