



POLAND SYNDROME Support Group
Hand and Chest Deficiency

- Newsletter -

Issue 11 - Summer 2011

Hello to you all and welcome to our latest newsletter. We hope you enjoyed reading our last Newsletter and we can now bring you up to date with what is happening in the group...



The **POLAND SYNDROME Support Group** is here to give
Support, Advice and Information to anyone with Poland Syndrome,
their Families and Friends.

Contact Telephone Line: 01283 551113

Contact Email: polandsyndrome@hotmail.com

www.pssgcharity.org Registered Charity No. 1100794



POLAND SYNDROME Support Group *Hand and Chest Deficiency*

This Issue:
What's happened since the last issue:

2011 London Family Fun Day!



Once again this popular event was enjoyed by all who attended. This year's event was made even more special by **Garry Potts Charity head shave** that took place on they day!

Garry's Son Dakota was born with Poland Syndrome and Garry decided to raise money for the charity by shaving his head! To date Garry's sudden hair loss has raised an amazing **£800** with hopefully more to come!



"Garry before and after the shave!!"

Garry Says:

"My son Dakota was born with Poland Syndrome, when Dakota was about 9 months old we got involved with the PSSG my wife is now Chair Person of the board. I have had long hair for over 20 years and said that if I ever cut it I would do it for charity, so my wife decided to call my bluff and volunteer myself for a charity head shave. After a few false starts we finally got it arranged for the family fun day in London. When I started telling people what I was doing I got a really good response, but as the date drew nearer the enormity of what I was doing started to dawn on me that I would be bald in a few days time. My step-niece Kelly-Marie agreed to do the deed as she wanted to help in any way which she could. We arrived at the Case is Altered and my nerves started to grow. We went round talking to people and explaining what we were about to do and that was it no more staling, no going back I was going to have my locks shaved here and now! Kelly-Marie cut off my ponytail first the whole pub got behind me and cheered when the final strands had been cut. My head was then shaved with clippers and to make sure she got every hair she wet shaved my head!! It felt so strange to have a draft at the back of my neck. Everyone who attended the family day had a great time and we raised over £800. My hair has started to grow back but the original brown colour of my hair is now very few and far between and I don't remember ever having that much grey."



"London Fun Day, Garry mid way through!!"



"London Fun Day, Barry wants a trim as well!!"

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2011 Charity Line Dance!



"Line Dancers at the Line Dance!!"

The **Charity Line Dance** took place on Friday 25th February 2011. Over 80 people attended! The event has so far raised **£463** with thanks to **Lynn Farmer** for organising the event.



"Dakota dancing at the Line Dance!!"



"Line Dance Prizes!!"



Virgin London Marathon 2011!

www.virginlondonmarathon.com

Committee Member **Barry Telling** completed the Virgin London marathon on Sunday April 17th to raise money for The Group! Barry managed to raise **£175!**



"Barry (far left) with club members after the Virgin London Marathon medals in hand!!"

We can also thank Member **P Hopgood** for raising **£100** for The Group.

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This Issue:

Take a Break Magazine article!

Treasurer **Lynn Farmer** has had her Poland Syndrome story published in Take a Break magazine!!



real-life HEALTH

The girl with only one breast

Two worried parents stood over the incubator. Inside it, a tiny life hung in the balance.

A doctor said: 'I'm very sorry but we don't think she'll survive the night.'

The newborn baby was Lynn Farmer. She had a lump on the back of her neck filled with fluid and webbed fingers on one hand.

The doctors thought the fluid would damage her brain and warned her parents Daphne and Richard to prepare for the worst.

That night passed and then another and their baby clung to life. Eventually her parents were told they could take her home.

Lynn was one when the lump of fluid was removed from her neck. When she was three she had the first operation to separate the thumb on her left hand.

Two further operations followed to try to get the thumb to grip but both were unsuccessful. By

the age of 10, Lynn had decided she didn't want any more surgery.

She told her mum: 'I just want to be normal now.'

Lynn settled into the routine of school. But when she reached puberty she noticed that only her right breast was developing. One side remained flat.

Funny, she thought. *The left side — just like my hand.*

At 15, Lynn still had one flat breast and one full one. She padded the left side of her bra and wore baggy tops. Sometimes

other kids at school made cruel comments during PE and Lynn would go home in tears.

'What's wrong with me, Mum?' she'd ask. No one knew. Lynn left school. When

she was 22 she went to see her GP, who referred her to a plastic surgeon.

She had barely stepped into the consulting room when the surgeon said: 'Ah, you're the lady with Poland syndrome.'

Lynn froze. *Poland what?*

The surgeon explained that Poland syndrome affects around one in 30,000 births. A main characteristic is the underdevelopment or absence of chest muscle on one side and webbed fingers are often present.

After the initial shock Lynn smiled with relief.

She said: 'At last I know.'

Months later Lynn had an implant inserted into her left breast. Afterwards she could wear tight tops for the first time.

She even bought a swimwear costume.

She said: 'I feel so much better.'

Lynn tried to find more information on Poland syndrome but there were

no support groups in the UK.

She advertised in local papers. *I'm starting a support group for people with Poland syndrome...*

Within days she had a reply, then another. She found others who were also trying to start a group and they agreed to merge.

The Poland Syndrome Support Group is now a registered charity with more than 300 members.

Now Lynn, 40, of Ladyfields Way, Swadincote, Derbyshire, says: 'Having Poland syndrome used to affect my life because I didn't know what was wrong.'

'But now I know, nothing stops me. I'm not ashamed to show my left hand and I am finally confident with my figure — in part thanks to having a loving family and fantastic friends.'

'I spent 22 years not knowing what my

condition was. Meeting that plastic surgeon changed my life because not only did he give me my confidence back, he also finally gave me an answer.'

Julie Cook

● For information visit www.pssgcharity.org or call 01283 551113.

£200 Tell us your health story — or about your operation. Write to *Heartbeat*, *Take a Break*, FREEPOST LON12043, H Baser Publishing, London NW1 1YU. We'll pay £200 if we publish it.

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Forth coming events 2011:

Yorkshire Family Fun Day !



"The Walnut Tree!"

Is to be held on Saturday **9th July 2011**. The Walnut Tree, Barnsley Road, Wakefield, West Yorkshire. **WF2 6BH**. Tel. 01924 250480.



The Walnut Tree has a **WACKY WAREHOUSE** - Indoor Play Building - for children up to 4ft 9ins tall!!



"Location of Family day, West Yorkshire!"

AGM 2011 !



"The White post Inn!"

The **AGM** is to be held on Saturday **17th September 2011** From 12 Noon at **The White Post Inn**. Farnsfield, Newark. **Nottinghamshire**. NG22 8HN.



"Location of AGM, Newark!"

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Keep Up To Date:



Find us here!!!:

<http://www.facebook.com/group.php?gid=110595298970859>



Find The Group's member's location map here:

<http://www.mapservices.org/myguestmap/map/PolandsPeople>

There are now **150 members** registered on **facebook**, so if you want to chat to other members about Poland Syndrome this is the place to be!

The web page map is interactive so you can add yourself and find other member's local to you!!



"Chat wall is always busy!!"



"Current map showing lot's of members!!"

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Please take the time to complete and return this form if you have not already done so:

PERSONAL DETAILS FORM:

Name:

Address:

Telephone Number:

E-mail Address:

Date of Birth:

Right Side/Left Side/Chest/Hand/Any Other
(Please delete as appropriate)

Is it ok to give your Name/Address and/or Telephone Number to another parent/sufferer?
YES/NO

Any Other Comments you feel relevant:

Please send completed forms to :
Lynn Farmer
Poland Syndrome Support Group
7 Ladyfields Way
Newhall
Swadlincote
Derbyshire DE11 0RH

(Alternatively email polandsyndrome@hotmail.com if you wish to complete a form via email)

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