



POLAND SYNDROME Support Group *Hand and Chest Deficiency*

Dear

My name is Ruth Welsh and I am the Parent of Arran who has Poland Syndrome. I would like to take this opportunity to thank you for expressing an interest in the newly formed UK Poland Syndrome Support Group and would like to bring you up to date with the progress that the group has made so far and let you know our plans for the future.

Following our group's get together in August 2002 in Leicester, a committee has been set up and a constitution signed, copies of which are available to any interested party. The primary objective of the group is to provide a network of support for anyone who finds their life affected by Poland Syndrome whether they have Poland Syndrome them self, or are a parent, family member or friend of someone who has Poland Syndrome.

'We strongly believe that everyone has something to offer.'

Whilst the group is becoming more established, the committee is working hard to promote awareness of Poland Syndrome and the existence of the group. There are several very good support websites for people affected by Poland Syndrome but they have a strong American influence. We hope to generate a UK based website which will include information for new members, both parents and adults, surgery experiences, contacts and advise, as well as a directory of the group's members. We are a lot smaller than America so hopefully everyone will be able to find someone close by!

In addition to promotion, the committee members are hoping to find a Patron for the group and are actively involved in fundraising. Any funds coming into the group are primarily to be used to subsidise events for group members. If anyone has any ideas for fundraising then please let us know! We will be holding a further family day in the early spring 2003, a fundraising line dance in May and a more formal annual general meeting in September to mark our first anniversary.

'It is the group's intention to apply for charitable status once it is possible to submit a suitable record of activities and fund raising.'

So, what do we want from you? With this letter you will find a questionnaire, which asks just a few questions about your expectations from the group. It would be extremely useful if you could complete the questionnaire and return it to the address given on the form. You in turn will be kept informed of any relevant dates and activities, as they become available and further details concerning official group membership. Please feel free to get in touch with us if you have any questions or suggestions.

Finally, on behalf of the UK Poland Syndrome Support Group Committee I would like to welcome you to the group and wish you a very Merry Christmas!

Best Wishes

Ruth Welsh (Chairman)

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