

PXE WA NEWSLETTER

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Hello Everyone,
I hope you enjoy our first
newsletter.

PAMPHLETS

Pamphlets have been sent out to all of the Dermatology rooms in the phone book, plus Ophthalmology rooms, Eye Clinics and the Lions Eye Institute. I have had one positive reply from Dr. Ann Halbert, our daughter Caitlin's dermatologist. She has a Genetics Clinic at PMH, so will give them to any new patients with PXE that she sees.

MEDICAL INFORMATION

You can find a four-page summary about PXE, which is great to take to a new doctor. Go to the PXE International website (www.pxe.org) and click on the following headings.

1. Medical Information
2. For Health Professionals
3. PXE and the Primary Care Physician

NEW MEMBERS

I have had enquiries from a few people living in other states in Australia, with one lady from Queensland joining our group. Another lady from Queensland has recently emailed asking how to start a group and she is planning to start one next year. I have had an email from a lady in NSW stating that they have a group of about 20 people and they meet in Sydney once or twice a year.

GENETIC SUPPORT COUNCIL

The refurbishment of the Genetic Support Council building is underway and is not expected to be finished till February / March 2010. It sounds like the meeting room will be a great venue for us to meet once it is finished with kitchen facilities etc.

GENE TESTING

I recently had an email from someone in Australia who thought that their child may have PXE, and they were enquiring about the genetic test. I emailed Sharon asking what the latest was with regard to genetic testing and below is her answer.

"We have licensed the test to a few labs around the world: one in the US, one in Belgium, and one in Italy. No one in Australia has asked to license it, however, there may be labs doing it illegally. In the states, it is \$500 to look for the most common mutations, and \$3500 for a whole gene search. Most people do not need to have it done."

PXE LISTS

I recently found out that you can search old emails from the chat or medical email lists on pxe international re certain topics that may interest you. To do this, you first need to join PXE International which is free. Go to www.pxe.org, click on home. At the bottom of the home page, click on register. On the new page, click on register again. Fill in the form and submit.

To manage any or all of your email lists, go first to: <http://www.galists.org/read/login/?forum>

- Fill in email address, click ok.
- Fill in password (the one you set when you registered online), click ok.

A list of all lists to which you are subscribed will appear. Click on the one you want to manage. There are four lists: Chat, Medical, Announcements and MemberGram.

A list of all the recent postings will appear, in reverse order. You may read any or all of them by clicking on the message.

You may search this list by clicking on "search" in the left sidebar.

Something to remember about the chat list is summed up by a quote from Sharon Terry:

"A reminder, that there are 4000 people on our database with PXE. Of those 4000, very few have anything more than skin and eye involvement.

Remember that the people who stay most active on this listserv are the rare people (about 100) who have more PXE involvement than others...

**MERRY CHRISTMAS EVERYONE
AND HOPE TO SEE YOU IN 2010.**

SALLY GROWDEN
PXE WA