



Dear Readers

Welcome to the new PiNSA members. It feels like last week that I was struggling to create our first newsletter.

We had a successful patient and parent meeting at Panorama Hospital on 5 August 2009 and it was well attended.

I would like to take this opportunity to thank NBI and their representatives for their support and Janine Davids from NBI who arranged for a lovely dinner after the talks.

Sincere thanks to Dr Gerrit de Villiers and his secretary Stephanie for arranging the venue. The meeting was hosted by Dr Esser and a variety of issues were addressed.

Sr Anne Gillham from NBI introduced the use of Polygam by means of Sub-cut infusion, Dr Moodley from NBI discussed the manufacturing and use of Polygam and Mrs Rosario introduced PiNSA and IPOPI to our new parents.

Mrs Samantha Jansen has agreed to become the treasurer for PiNSA, and we appreciate her help.

I would also like to thank Katharine McKenzie who has offered assistance with the newsletter.



Dr Sugania Moodley and Ashmita Udita from NBI.





Notes from parents attending the meeting

Building a network and sharing information helps parents and patients tackle the daily challenges associated with PIDs. Here's what some of the parents had to say...

> I would like to firstly use this opportunity to thank the organizers of this meeting. For me it is a privilege to be able to attend these meetings. We as parents of children get the clinical and medical assistance from the doctors that treat our children, but it is at these meetings that we get the emotional support from each other. Just to know that there are more parents that face the same problems that you do, is comforting.

At this meeting we received information on the subcutaneous Immunoglobulin Infusion presented by Anne Gillham. It was explained to us exactly how it works, what the costs are etc. There was also a speaker from the National Bioproducts Institute who explained how safe the polygam is. Gaby Rosario also attended this meeting, who has been using Polygam for many years and is of working age. We got to meet her and chat to her and she also give you hope for the future, as it is possible to have your illness under control and be able to work.

Each time we attend a meeting of PiNSA we leave with something new. During the previous meeting we learnt that Hypogammaglobulinaemia is a PMB condition and we should get our medical aid to also pay for the regular blood test from major risk. We did this and it worked, saving us thousands of rands annually.

Once again thank you for these meetings.

Sunette Odendaal



Mr and Mrs Odendaal

> Thanks for organising a great meeting on Wednesday it was wonderful to meet other parents in the same position and know that there are others out here with the same issues.

Looking forward to another meeting.

Kind regards,

Lisa Arthur

> Baie dankie vir gisteraand. Ek is bly dat ek die geleentheid kon kry om met die ander ouers te kon praat.

Groete,

Nicolene Lourens



*Photos from
our latest
parents
and patient
meeting.*

Upcoming events

■ Outreach in Bloemfontein

We are planning an outreach meeting in Bloemfontein with the help of Dr Jeannette Kriel for February or March 2010. If you know of anybody who would like to attend the meeting please contact me (rina@sun.ac.za).

■ PID workshop for doctors and nursing staff

The South African Immunology Society will be hosting a PID workshop for doctors and nursing staff in Cape Town on 9 December 2009, prior to the annual conference of the SAIS.

Websites

The IPOPI www.ipopi.org and IDF www.primaryimmune.org websites have useful information and Patient and Family handbooks available on different kinds of Immunodeficiencies, should you like to read more on you or your child's or your own diagnosis.

Rina's appeal

Please inform me what topics you would like to hear about at the meetings.

Please also let me know what you would like to see and read about in the newsletter.

If you have any news, stories, photos useful information etc. which you would like to share with us for the next newsletter, please send your contributions to me: rina@sun.ac.za.

■ PID Registry

Another big please! Those of you who have not returned your signed consent forms please let me have them as soon as possible – as I need to keep a signed consent form for the registry.



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