PRIMARY IMMUNODEFICIENCY NETWORK OF SOUTH AFRICA

PiNSA Newsletter

May 2009

PiNSA Letter Number 1

Welcome to the first edition of our planned quarterly PiNSA newsletter in which we would all like to get to know each other better.

If you have any news, stories, photos etc. as below, you want to share with us, please sent your contributions to me: rina@sun.ac.za.

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

First Primary Immunodeficiency (PID) Feature story: Sub-cutaneous Infusion

Jared Burger, 14year old from East London was diagnosed with Hypogammaglobulinaemia at the age of six years. He tolerated intravenous immunoglobulin poorly with many side effects following each monthly infusion and was therefore unable to reach treatment levels and suffered from many recurrent infections.

His mom Chantal Burger wrote the following letter:

Jared started the sub-cut infusion procedure to with an IgG trough level of 4.10g/L on the 19th December 2008 with 40ml/Intragam per week and 200ml/Month. We checked his IgG levels a month later and were happy with the result of 5.25g/L... His IgG levels on the 6th of May 2009 was 8.96g/L after only 5 months on Intragam

Jared is in excellent health at the moment with no infections and no use of cortisone or antibiotics.

Anne Gillham, the training sister trained me to do the sub-cut and I can say was a bit nervous at first but have mastered this procedure very well.

I found that Jared has had no side effects with the use of Intragam and he excelled at the swimming Championships in March taking 2 Gold's and Silver Bronze medals.

We feel that the sub-cut procedure is a huge success.

Jared and family list many advantages of the subcut infusion such as lower cost, being at home for the infusion and that Jared can start putting up the needles himself even. Importantly also, with the steady trough levels he has stayed in excellent health and has had no infusion reactions as he had before.

Sr Leendertz, Jared and his sister Erin

Upcoming Events

We are planning more outreach programmes like the IPOPI visit in 2008 in Cape Town, Durban and Johannesburg. This year is already half-way gone and we are working on a meeting still for Cape Town patients in July or August this year.

We would also like to visit Bloemfontein and East London in the future.

I will keep you posted on the dates and events for next year.

If you are interested in such meetings please let us know what topics you would like to hear more about.

Primary Immunodeficiency PID Registry

The PID Register started in 2006 at Tygerberg Hospital, University of Stellenbosch by Dr Monika Esser as medical advisor and Rina Nortje as secretary. It is growing with nearly 90 patients recorded but I am sure there must be many more patients suffering from an Immunodeficiency of whom we have no knowledge or information. This registry will give us an indication of how many patients we have in South Africa and what type of deficiency is seen. This is very important information for motivating with medical aids, hospitals and regulatory bodies for essential treatment. We need you to support this ! Should you be aware of anyone who would be willing to go onto the registry or who would like more information on their PID, please notify me.

For any further information contact, please contact rina@sun.ac.za.

I will be sending out consent forms again to those of you who have not yet signed the written consent form for the registry – as I need to keep a signed consent form for the registry.

Web sites:

The IPOPI www.ipopi.org and IDF www.primaryimmune.org website has 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.

Looking forward to hearing from you.

Kind regards,

Rina Nortjé

Secretary PID and PiNSA Registries.

Note from the Chair

The best news of the year is that we have some funding; two years of funding for our secretary, Rina Nortje. This thanks to the Binding Site. What this means is that the association will have the option of being properly viable and sound, an achievement only possible with the necessary personnel, something we have not enjoyed to date. The second funding comes from WIN, the Jeffery Modell Foundation and this will allow for workshops and training in the bigger centres of South Africa. Finally Tristar, our service provider/hosting service is hosting PiNSA gratis. NBI continues to be a stalwart for our association with Andrea Muller always supportive and positive.

I attended the IPOPI/ESID/Ingid meeting in Den Bosch in Nederlands with Gaby my daughter in October 2008. Dr Esser our Medical Advisory doctor was there as was Anne Gilliam our immunology nurse from South Africa. It was at this meeting that I was privileged to be re-elected to the IPOPI Board for a further two years. The new Chair of IPOPI is Jose Drabwell from the UK. The next IPOPI conference is in Istanbul in Turkey in October 2010, wouldn't it be wonderful to have some South African patients there!

Sister Gilliam, Dr Esser and myself on Holland

I also attended an IPOPI board meeting in Paris in March and brought back material for Dr Esser from the accompanying conference International Plasma Protein Conference (IPPC). Then flew back via Cape Town to meet with Dr Esser and Rina Nortje in order to do some strategic planning. The last international meeting will be Global Leaders in London in October with Dr Esser which IPOPI is organising.

Rina will be taking up the newsletter as one of her duties and I think we can look forward to regular updates. I know she already has her hands full organising workshops around the country for Dr Esser. All of this is excellent news as we try a get the word out there – my letter to the Department of Health never saw light there with two changes of Ministers since. We will plough on…

Joy Rosario 29 May 2009

Membership

Remember that at present there is no fee to join PiNSA. You are invited however, to have your name registered on the national database and thus belong to the PiNSA mailing list. This is a closed list for PID patients and their families.

Alternatively join the PiNSA 'Ning', a private network for registered patients and their families

http://www.pinsasouthafrica.ning.org

Rina's appeal

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Previous IPOPI Chair Bianca Pizzera and myself on the IPOPI South African visit