

Dear Readers,

As always a warm 'Welcome' to the new PiNSA members.

Welcome to Heila Butters, Annie Pienaar and Adel van der Merwe who have all expressed a willingness to be on the committee. This will provide much needed support and strategic direction for PiNSA.

Upcoming Events

The PID meeting in Cape Town at Dr Pieter Fourie's practice at the Cape Gate Medical Centre will be held on the 19th May 2010. Invitations to the event will be sent out in due course.

Please let us know which topics you would like to hear about at the meeting.

A further PID meeting is planned for Gauteng in Mid September of this year. We would welcome any suggestions for a venue and for topics to be discussed.

SAID PID Workshop

A PID workshop was held on 19 February 2010 at Universitas Hospital, Bloemfontein at the invitation of Dr Jeanette Kriel.



Tygerberg Academic Hospital

The Speakers were: Dr Monika Esser – Head of Immunology, NHLS Tygerberg and Stellenbosch University and Dr Trisha Chetty – Pharmaceutical Manager, NBI.

Topics:

1. Recurrent Infections in childhood and appropriate investigation guidelines
2. Indications and usage of IVIG

The talks were well received and interactive. Two patients were also presented, with the diagnoses of Severe Combined Immunodeficiency (SCID) and Agamma-globulinaemia. Both patients were assisted in the diagnosis by the Immunology Laboratory, Tygerberg.

A new SCID patient from Kimberley was presented and confirmed. Guidelines for referral for investigations and work up for bone marrow transplant were discussed and will be standardised and communicated.

The afternoon workshop was attended by Paediatricians, Haematologists and Geneticists and the enthusiasm and dedication of the local doctors made this a very successful Friday afternoon meeting.

We thank Dr Jeanette Kriel for the invitation and NBI for sponsorship.



**Retief Building, Universitas Hospital
Bloemfontein**

Useful 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 Primary Immunodeficiencies, should you like to read more on your or your child's diagnosis.

The Registry and its purpose

Health surveys routinely used to estimate the incidence and prevalence of chronic and acute conditions are used infrequently for "rare" conditions such as primary immunodeficiency diseases (PID's). Established registries like the ESID registry exist for developed countries but very limited information is available for Africa.



Data capture from clinical services at the two medical universities of Cape Town, Western Cape South Africa, describes the spectrum of PID diagnoses and care in a developing country. This and data from North Africa give an indication of prevalence and under diagnosis in a less resourced continent.

Since 2006 patients diagnosed with PID at the two teaching hospitals of the Universities of Stellenbosch and Cape Town are documented, with consent, on a password protected secure server at Tygerberg Hospital.

Patients from six of the nine provinces are reflected on the register with 75% from the Western Cape. Of the more than 130 entries 57% are Caucasian, 37% Mixed Racial and only 6% Black – the racial group representing 90% of the population. Antibody and complement deficiencies are the commonest.

Diagnoses partly identified with research projects were commonly delayed, bone marrow transplantation were difficult to access and molecular diagnostic rarely available.

With your help and support we will be able to identify many more patients with PID to give us a more accurate picture for South Africa. This will give us the urgently required statistics to motivate health funders and national bodies to accept these conditions for benefits.

Again – to those who have not returned your signed consent forms, please let Rina have them as soon as possible – as we need to keep a signed consent form for the registry.

IPOPI Biennial Meeting

The IPOPI biennial meeting will be held in Istanbul Turkey from 6th - 9th October 2010. This is always a joint meeting between ESID, INGID and IPOPI and this particular meeting boasts a very interesting programme – David Watters Executive Director of IPOPI anticipates this will be the best meeting ever! Go the conference website for more information.

<http://www.esid2010.org/>

A note from the Chair: Joy Rosario

PiNSA is a member of IPOPI and I have been on the IPOPI Board for a number of years, not representing the local association but PiNSA has indeed benefited from this contact in many ways. A meeting was recently held in Berlin, Germany whereby I had to give a presentation on National Member Organisations such as ours have benefited from belonging to IPOPI.

If you have any news, stories, photos useful information etc. which you want to share with us or ideas on what you would like to see and read about in the next newsletter, please send your contributions to Rina at rina@sun.ac.za

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Please remember also to use your passports!