

Dear Readers,

This year has come to an end and I hope that it has been a successful one for everybody. As always, a warm 'Welcome' to the new PiNSA members.

### **SAIS PID Workshop:**

A very successful PID workshop was convened by Dr M Esser with the assistance of the SAIS Congress and NBI at the opening of the South African Immunology Society Congress in Cape Town on the 9<sup>th</sup> of December.

### **Other Meetings:**

Sr Anne Gillham will update us next year on the patient meeting held in East London in September of this year. She has also successfully assisted 5 patients so far to go onto subcutaneous Immunoglobulin for specific indications.

### **Global Leaders in PID meeting, November, London UK:**

Both Dr Esser (PiNSA medical advisory doctor) and Joy Rosario (PiNSA Chair) attended the GLM in London. Over 50 delegates from all over the world attended the meeting including doctors, immunologists, representatives from the pharmaceutical industry and also other patient groups. The meeting also gave the IPOPI Board an opportunity for a face-to-face meeting. The outcome of GLM is a document of agreed Statements and Actions and both of the South African delegates have been tasked to assist in implementing the actions. The main issues are Diagnosis, Treatment, Communication, Data Collection and the development of Guidelines round all of these.



**Global Leaders Meeting**

### **Upcoming Events:**

A PID medical staff training/information session at Universitas Hospital, Bloemfontein is scheduled for the 19<sup>th</sup> of February 2010.

We are planning another meeting for patients/parents in CapeTown at Dr Pieter Fourie's practice in May 2010. He will be moving to the new Medical Centre at Cape Gate in January 2010 and he is willing to host a meeting as soon as he is settled.

We would also like to have another patient/medical staff meeting in Gauteng but this may have to wait till everything is back to normal after the Soccer World Cup.

### **A Patient's Story:**

Gabrielle Rosario is 32 years old and has Autosomal Recessive Hyper-IGM. She has been on three weekly IVIG Polygam since she was 11 years old and leads a full and normal life albeit managing largely on her own. She has just started sub-cut using the Freedom 60 infusion pump her mother brought back from her from ABC Healthcare in the UK. This has given Gaby a different perspective on her life as she is now free of regular hospital visits, so free in fact that she intends going to Barcelona! The only side effect

has been a slight swelling on the needle sites and it is early days to see whether her health in general improves. The downside is that the medical aid is not acknowledging the lesser cost of no hospital stay and is insisting that the treatment comes out of Gaby's medical savings!

Note from the Chair: I am going to lobby for PID to be on the list of chronic illnesses in the New Year, the present situation impacts negatively on people with the condition and they don't need unnecessary stress.

### **Rina's Appeal:**

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

Please also let her 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 want to share with us for the next newsletter, please send your contributions to: [rina@sun.ac.za](mailto:rina@sun.ac.za).

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

### **Websites:**

The IPOPI [www.ipopi.org](http://www.ipopi.org) and IDF [www.primaryimmune.org](http://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.

We are looking forward to a more substantial Board in the New Year but the distance between cities prohibits regular meetings. Fortunately modern technology will allow us to meet in cyberspace, or at least through telephone conferences.

Finally, we would like to thank our sponsors National Bioproducts Institute, Jeffery Modell Foundation WIN funding, IPOPI and the Binding Site. Without this support we would not have made the headway we have made this year and look forward to an even better 2010.

We wish you and yours a peaceful holiday season and all the best for a busy 2010.

Joy Rosario  
Chair: PiNSA  
0823654663  
[jrosario@mweb.co.za](mailto:jrosario@mweb.co.za)

Rina Nortje  
Secretary: PiNSA  
[rina@sun.ac.za](mailto:rina@sun.ac.za)  
Tel: 021 938 5228  
Fax: 021 938 4005

Dr Monika Esser (MMed Paed)  
Medical Advisory Panel doctor: PiNSA  
Head of Immunology Division  
NHLS  
Tygerberg Hospital Cape Town

Tel: 021 938 5228  
Fax: 021 938 4005

*Merry Christmas and best wishes for 2010*