PiNSA
PRIMARY IMMUNODEFICIENCY NETWORK OF SOUTH AFRICA

September 2011

Report from the Acting Chair

Dear All

Latest news is that Cally Coldbeck unfortunately felt she had to stand down from the position of new Chair as she has substantial family commitments. We will really miss her as she brought new energy and enthusiasm to the position, but her decision is understandable. Anyway, her time with us was much appreciated and we hope to work together again in the future.

In the meantime, for purposes of continuity and stability, I have taken back the position but on an acting basis until the AGM - date to be decided but certainly before the end of the year. Under the circumstances, another change was that of Secretary who was also based in Pietermaritzburg. This is a paid position and I asked the committee to give me the latitude of appointing somebody closer to 'home'. From past experience I have found it is impractical and inefficient to work with somebody from a distance and I had the good fortune of convincing Mariana du Toit, a retiree who has moved up to Irene, to take this on. She and I worked together in KwaZulu-Natal so we don't have to start training from scratch, something I wouldn't be able to manage at this point. The contract is dependent on whomsoever is appointed as Chair but in the interim, it is great having Mariana on board. Thankyou to Christelle for her time with PiNSA, it was much appreciated.

The committee has continued the work unabated and each committee member has taken on a responsibility, as opposed to a team like before. Dr Monika Esser continues to manage the MAP (Medical Advisory Panel), Adel van der Merwe: Patient Support, Karen Heese: Lobbying, Katharine McKenzie: Advocacy (including the newsletter), Annie Pienaar: Fundraising, Ann Gillham: Nurse Training and Sunette Odendaal: Treasurer. I am managing the website and also Twitter and Facebook along with governance responsibilities. I am still a Board member with the International Patient Organisation for Primary Immunodeficiency (IPOPI).

We are working on a national member organisational manual based on the IPOPI one. This will assist not only the national committee but provincial branches which we intend setting up. There are a number of issues which need clear guidelines including governance on how funds may be raised, a structure for patient support, managing the press etc. It makes sense that local issues can and are managed locally with the national committee having a co-ordinating role.

Other news is that Dr Esser has been to a conference in the US (Jeffery Modell Foundation) and will be reporting in this newsletter. I held a successful fundraiser – a rock and roll party at the Pretoria Country Club – report in this newsletter – and Mariana has requested medical journals all over Southern Africa to profile PiNSA. She has also ensured that our flyers were distributed at the recent South African Medical Association conference

Dr Esser will be at the ALL SA Congress at Sun City in October and will have a session on PID. We would like to have had a meeting there but we don't have the funds or the organisational capacity at this point – PiNSA will have representation there however. Dr Esser and I are both attending the Global Leaders in PID meeting in London at the end of October 2011. We will both be funded by IPOPI, me in my capacity as Board member.

I would like to take this opportunity of thanking every single person on the committee for their ongoing support and commitment. Involvement in a voluntary organisation is never easy as it has to be managed along with other family and work commitments and in the case of chronic disease such as PID, this adds another dimension and stressor. Sustainability is key and this can only be managed if the workload is shared and personal situations understood. We will be putting out a call for nominations when the time comes for the AGM towards the end of the year, also for regional branches, so please give some thought as to whether you would like to be involved.

With best wishes

Joy Rosario
Acting Chair: PiNSA

Lobbying

Meeting with the Council for Medical Schemes

PiNSA has had a breakthrough in recent months, securing a meeting with the Council for Medical Schemes (CMS), which provided an opportunity to table the problems that some PiNSA members experience when making claims with their medical aid schemes.

The Council for Medical Schemes is a body created by an Act of Parliament to regulate all of South Africa's medical aid schemes. Joy Rosario and Cally Coldbeck attended the meeting on 15 June 2011 attended by the CMS's Public Health Economist Ms Sellelo Mametja.

The aim of the meeting was to establish a relationship with the CMS, introduce PiNSA to the CMS and devise a joint strategy for managing complaints.

The PiNSA representatives described the challenges patients face with medical aids. One of the issues discussed was whether the range of diseases is recognised against PMB and also how the CMS can assist patients in managing claims against their respective medical schemes.

Ms Mametja noted that Primary Immunodeficiency is recognised (Code 913 S – and there is a separate code for SCID). She also discussed two strategies for managing problems. Individual patients can submit a complaint to the CMS with supporting documentation and a letter from their physician. The other approach is to do this as a group. Two legal adjudicators evaluate complaints on a case by case basis and there is an appeal board if it is felt that cases are unsatisfactorily dealt with. There is also a code of conduct for medical schemes.

Ms Mametja explained that she is working through treatment protocols for over 800 conditions. A group submission might allow PID conditions to be expedited in the treatment protocol queue.

PiNSA aims to continue building relations with the CMS and to actively lobby this body. An attempt was made to meet with Discovery Health to highlight the issues a lot of our patients face when making claims, we are awaiting a response to our request.

Fundraising

Rocking and rolling in Pretoria

A Rock and Roll fundraiser for PiNSA was held at the Pretoria Country Club and was a great success – it was an evening of dance, fun and an opportunity to highlight PID. We had over 50 people attend and everyone dressed up in the style of the 1950's. The table settings were old LP records, takkies and balloons as a centre piece (the takkies were filled with tips at the end and a pair given to each waiter/waitress). PiNSA blue overlays completed the theme and the menu was popcorn, gourmet burgers and deluxe milkshakes.

The Pretoria Club itself supported the event and their member Ian Fraser was MC/DJ with a wonderful range of 50's music. Joe Aspinall, also a member, managed the prizes for the raffle and the auction. Marius Els, manager of the Pretoria Country Club organised donations of spirits for the milkshakes and Stefmarie of 9ine, the caterers also came to 'the party' with reasonable prices.

Guests enthusiastically

contributed to the event and many donations were received – after costs the event made approximately R7000.00. Amongst other generous people, Roy Devenish donated R1000.00 in the wine auction!

The funds raised will go toward creating awareness in Sub-Saharan Africa and will also be ring-fenced towards a committee member to go to the ESID/INGID/IPOPI conference in Florence, Italy next year. This is an essential event in the calendar of PID as it gives us an international profile and ensures sustainability.

PiNSA thanks everyone involved for making the evening such a success.

- Annie Pienaar is putting together a fundraiser for PiNSA in the Western Cape – we'll keep you posted.

Make a donation!

PiNSA is a voluntary organisation that depends on fundraising to spread the message about PID. We know that thousands of South Africans are still undiagnosed and we have an opportunity to make a difference in their lives. Please inform our secretary at pinsahelp@mweb.co.za if you do make a donation, we would like to thank you formally.

Account name: PiNSA
Standard Bank
Account Number: 07 562 322 6
Branch: Rondebosch
Branch Code: 025009
Swift Number: SBZA ZAJJ
NPO Fund Number 028-020

Contact:
pinsahelp@mweb.co.za
Visit us at:
http://www.pinsa.org.za

PID information sharing in Cape Town

This was the third year that patients, doctors, parents and others had the opportunity to get together and share information at an evening session held at Panorama hospital in Cape Town.

The keynote speaker was PiNSA's medical advisor and mentor, Dr Monika Esser, and the evening was supported by the National Bioproducts Institute (NBI) provided snacks and Panorama Hospital that provided the venue, arranged by Dr Gerrit de Villiers.

Greater Cape Town has a growing community of people affected by Primary Immunodeficiency, with new diagnoses coming through on a steady basis. The range of people present reflected diverse diagnoses, with a notable cohort of teenagers coming through in the Western Cape.

Dr Hilary Lapham

New production capacity at NBI

Dr Sugania Moodley of the National Bioproducts Institute, the section 21 company that produces Polygam and IVIG products, gave a brief overview of the products they produce. South Africa is in the fortunate position of having a blood donation service that is based on voluntary contributions, and the safety of these products is at a very high standard. Dr Moodley explained that one of the reasons that Polygam is expensive is that safety tests `really cost a lot of money' and the NBI laboratory adheres to high standards of Good Manufacturing Practice and Good Laboratory Practices.

Dr Moodley also noted that the NBI lab had recently undergone an upgrade shutdown for six weeks and had installed a new freeze drier. This would help to increase capacity as currently NBI cannot keep up with demand for the product.


Dr Monika Esser and representatives of NBI.


Dr Sugania Moodley, Janine Davids and Zoliswa Siyo from NBI.

Report back from international PID conference

Dr Monika Esser shared information about the recent Jeffery Modell World Immunodeficiency Network conference that she attended in New York.

The Jeffery Modell foundation is a PiNSA partner and has played an important role lobbying on behalf of patients with PID and raising awareness of these rare diseases. The conference took a global view of PID with a presentation on Africa given by Dr Aziz Bousfiha head of the Moroccan PID society. The extent to which PID goes undiagnosed in Africa was underscored by these statistics he presented: Africa which has a population of one billion has just over 1000 patients registered with PID. In contrast Europe, which has a population approximately half the size of Africa has over 13 000 patients registered on PID registries. Dr Bousfiha estimates that there are 108 000 people with PID in Africa.

African PID school at allergy conference in October 2011

The African Society for Immunodeficiency (ASID) of which Dr Monika Esser is a founding member, will be holding an African PID school at the Allergy Conference in October 2011 at Sun City. Patients and parents of patients are urged to attend the conference that will include papers by international PID experts dealing with PID in children, with a range of clinical case presentations, the diagnosis of PID, subcutaneous IG administration and the role of stem cell transplant.
For more information see www.allergysa.org

ASID conference: Cape Town 2013

The African Society for ID will be having its annual conference in Cape Town in 2013. This will be the first time ASID holds a conference in South Africa and will be a great opportunity for global networking and knowledge sharing – make a provisional note of it in your diaries now.


Dirk and Sunette Odendaal and Annie Pienaar