



INGID EJOURNAL – FEBRUARY 2010

Dear Members,

This first eJournal of 2010 is to remind you about the INGID conference in Istanbul in October of this year, but first of all here is an invitation from Gaby Strotmann, the President of INGID:

Dear colleagues and friends,

As the President of INGID, it is an honour and a pleasure to invite you all to Istanbul - the European Cultural Capital in 2010, for the IXth. Biennial meeting of the **I**nternational **N**ursing **G**roup for **I**mmuno**D**eficiencies (INGID), which is held together with the XIth. meeting of the **I**nternational **P**atient **O**rganization for **P**rimary **I**mmunodeficiencies (IPOPI) and the XIVth. conference of the **E**uropean **S**ociety for **I**mmuno**D**eficiencies (ESID).

INGID was formed in 1996 and this is now our IXth. conference. The aims of INGID are, amongst others, to improve and extend the quality of nursing care of patients with Primary Immunodeficiencies, and to increase the awareness and understanding of Primary Immunodeficiencies amongst nurses. This conference will be another important step in our attaining those aims.

At this conference, as with all our previous conferences, we aim to build upon our international network of nurses who will share their knowledge, experience, information and research, and we will also have the opportunity to meet with patients, doctors, scientists, stakeholders and staffs from the pharmaceutical industry.

The INGID 2010 meeting will focus on the challenges of nursing adults and children with Primary Immunodeficiencies. For the first time we will have an educational day for both new and experienced nurses. In addition, we will have our popular round table session with 6 topics, 4 invited guest speakers, 3 joint sessions with IPOPI, and hopefully a lot of oral presentations which will be given by our members, as well as a structured poster viewing session.

I am excited by what we have to offer for this conference and I am really looking forward to welcoming you all in Istanbul in October 2010.

Best regards

Gaby Strotmann

INGID President

INGID Conference - Istanbul 2010

The next biennial INGID Conference will take place in the beautiful and mysterious city of Istanbul in Turkey from 6-9 October inclusive. The biennial conference of INGID is the major event for the group as it is the time when members can meet each other and the INGID Board, exchange information with each other, doctors, patients and pharmaceutical reps., learn what is going on within the field of primary immunodeficiencies in other countries and centres, find out about new therapies and treatments, and, of course, relax and have fun along with other members of INGID from all over the world. This eNewsletter also contains the first draft programme, and you will see how much time we are giving for members' presentations, as well as for invited speakers.

The conference, along with the ESID and INGID conferences will take place in the **Istanbul Convention & Exhibition Centre (ICEC) - Lütü Kırđar Congress & Exhibition Centre**. For more information, access the conference website:

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

Programme of the INGID Conference

At the moment, frantic work is going on to complete the programme of events – both education and social. The INGID Board will regularly update you on the progress of the sessions and other activities that are being planned for you through the coming months. In addition you can also check on the timetable by accessing the conference website:

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

Of course, the final programme will depend entirely upon you, the members, because we need you to present at the conference.

Education half day

For the first time, INGID will be holding an Education half-day in the afternoon before the opening of the conference. There will be two sessions:

1. The Normal Immune System
2. Disorders of the Immune System

Abstracts

What you are doing will be of interest to others, so do submit an abstract for either an oral presentation or a poster presentation. After all, you who work in this field are the 'Experts'

Abstracts on all aspects of the care of people with immunodeficiencies will be very welcome from any of you.

The time has now come for you to submit an abstract so that you can present at the conference and let everyone know of the work you are doing in the field of primary immunodeficiencies. Instructions for submitting an abstract – and all other information on the conference - are to be found by accessing the conference website:

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

Please note that the last date for the submission of abstracts is **June 1st. 2010**. That date is not very far away, so, we do urge you to submit an abstract. This is your conference and we want you to make it a success.

However, do remember that the success or otherwise of the conference depends upon you, the members, whether you are presenting or not, but please do put your 'thinking caps' on and submit an abstract.

If you want further advice as to how to submit an abstract, or if you are not sure if what you want to submit is suitable – although we are sure it will be - then please do contact one of the Board members (contact details of members of the INGID Board can be found on the INGID website). Because all presentations at the INGID Conference are in English, if you have any concerns as to whether your English is good enough, do not worry - submit your abstract anyway, as we will help you with the English.

INGID website – resource web page

As mentioned in the December 2009 INGID eJournal, we want to develop a page on the website that will celebrate the achievements of INGID members. These will initially be placed under the following headings, but these may change as the page develops:

Research Activity

e.g. Vickers P S, Whiting L (2005-2008) Living with Cancer (The effectiveness of palliative care services in South Bedfordshire in meeting the needs of adult patients with cancer and the needs of their families).

Publications

- e.g. Vickers P S (2009) *Severe Combined Immunodeficiency: Early hospitalisation and isolation*. Chichester, Wiley-Blackwell
- Vickers P.S. (2009) Cell and body tissue physiology, in Muralitharam & Peate (Eds.) *Fundamentals of Applied Pathophysiology*. Chichester, Wiley-Blackwell

Presentations

- e.g. Vickers P S ('1996) '*Physical and Psychosocial Development of Children and Families Following BMT for SCID*'. European Society for Immune Deficiencies. Dublin, Ireland

Others

- e.g. Cochrane, S., Salomé-Bentley, N., Toolan, J., Vickers, P.S. (2006) *Immunology/Immunodeficiencies – Antibody Deficiency: Nurse Education Module*. Newbury, Baxters (CD-Rom)

We know that you are all very busy, but this is a wonderful, opportunity, not only to showcase our achievements, but also to provide a resource for other members, so that if they have a query about something, or an interest in developing something, they can look to see who already has expertise and knowledge in their area of interest, so please send your achievements (in the format as above) to the INGID Board.

Rare Disease Day

Sunday, February 28th. 2010 is the 3rd. International Rare Disease Day, and, as you know, many immunodeficiencies are very rare diseases indeed. The theme for this year's Rare Disease Day is "Patients and Researchers: Partners for Life!"

Linked to this, this year, Rare Disease Day will also be the occasion to highlight the achievements of outstanding scientists whose work has helped advance rare disease research.

Why don't you find out what is happening in your country by accessing the website below, and then let us know if you or your hospital was involved in anything to do with this special day.

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

The INGID Board/Peter Vickers (Editor)