

The following is some notes that I made on the various presentations at IPOPI. The full presentations are available on the IPOPI website and anyone who is interested in more detail should obviously go the site.

<http://www.ipopi.org/publications/congress-presentations/holland-2008-presentations.html>

SUMMARY

Patient organisations.

There was the opportunity to learn about other patient organisations. There is a tremendous diversity throughout the NMOs.

Health Care Systems.

Some of the presentations and exhibitions shed light on how health systems in other countries work. The real highlight for us in Australia is the options available in home therapy in Europe.

Medical Presentations.

There were presentations on CGD (which is not on the IPOPI website), one on Vaccines, and updates from the ESID conference.

IVIg

There was a concern as usual about the supply and demand of IVIg. The talks that concerned this issue were those by Helen Chappel, Jordan Orange and Albert Farrugia. All these are on the IPOPI website.

IPOPI Young Adult

It was stressed that each NMO must be encouraging the young adult program.

What follows in some more details.

DETAILS

Patient Organisations

INDIA

Rubby Chawla outlined the desperate situation in India. People are dying due to a lack of IVIg treatment. The IVIg has increased in price and most people cannot afford the treatment. She mentioned anecdotal evidence of doctors not bothering to diagnose an antibody deficiency PID because they know that the patient would not be able to afford IVIg replacement therapy. In India there is a huge unmeasured pool of people who need treatment and are not getting it.

GERMANY

The German patient organisation DSAI presented the work that they had been doing since the last IPOPI. It was very impressive because they have concentrated on a program which they call Enlightenment. They intend to bring the condition of PID to the forefront of people's attention and so compete with the other issues that are well known. They outlined the series of media events that they have organized. They have employed a part time media organizer.

In addition they outlined a very successful campaign to change a clause 116B in the German health system. This meant that the reimbursement to the clinic for IVIg treatment was changed from €50 to complete reimbursement. The €50 (approx \$100A) was obviously a deterrent to people receiving treatment as it was no where near the total cost.

They are also putting pressure on to have a newborn screening program put in place. They encourage plasma donors to meet the recipients. They have published a cartoon booklet about PID.

They have continual series of patient meetings throughout the country and each of these meetings has a special theme and varies from city to city.

DSAI gets no government funding. They have one major event or show each year involving celebrities which gets most of the funding.

DENMARK

The Danish organisation gets the majority of its funding from the government. It has 94 patients.

The funding received is €56,000 of which €20,000 is free to be used as the organisation wishes. The other €36,000 is earmarked to be spent on educational purposes and is carefully audited by the government. This money can be rolled over to following years if not spent. Thus all activities must have an educational aspect. For instance their family camps always include courses and lectures.

The actual spending each year is approximately €68,000 of which €18,000 goes into overheads and comes from the free money. The other €50,000 is used on the activities and other programs that they have in place. The deficit of €12,000 is made up by charging members a small payment for some of the activities and from the pharmaceutical companies and from corporate sponsors who are given visibility for their contribution.

ARGENTINA

Roberta Penna described some of the activities that her patient organisation is involved with in Argentina and also some of the work she does for IPOPI. Roberta has been elected to the IPOPI board for four years. The main point from what she has been doing is that she actively involves other organisations in Argentina which have a similar program and aims although maybe for quite different groups of people. In this manner it is apparent they have been able to raise awareness for PID in Argentina without needing to find a large amount of funding.

NORDIC COUNTRIES

This group comprises Denmark, Sweden, Norway, Finland and Iceland. They have formed a legal entity which has a proper charter with a chairperson and a secretary with three year terms. This body meets every year and includes representation from the boards of each of the countries involved. In addition, every three years they hold family event over a long weekend which rotates through the countries depending on the ability of the host country to host such an event. Each of the organisations is a completely independent organisation nationally but this strong co-operative link has been forged over many years.

The health care systems.

It was interesting to compare the differences between our system and those in the UK and Europe. It seems that there are many specialized immunology clinics which concentrate on the treatment of PID. In other cases the clinics specialize in the use of IVIg and subcutaneous Ig whether it is immunology, neurology or hematology. In either case it is easy to imagine the benefits that such a system would hold for the patients (and also for the doctors and nurses) over the systems we have here in Australia where each hospital, each area health service, each state create differences. The presentation by Helen Chapel described in part her clinic in London which treats all conditions (including non-immunological conditions) which use IVIg and subcutaneous Ig. There are other clinics which specialize in immunological treatment only.

Home Therapy.

A number of presentations described home therapy and the choice that this allows for patients. In Europe and the UK there is choice for patients on immunoglobulin replacement therapy. They can either have IVIg in the clinics, IVIg at home or subcutaneous Ig at home. We learnt of the home services provided by the Sanquin Company. They deliver the immunoglobulin and the consumables to the home. A nurse is also provided to either set up or monitor the whole procedure or to deliver just what the patient requires. Eg some patients may set everything up and the nurse arrives to do the canulation only and then leaves. Then training and emergency backup procedures are all carefully controlled.

A system such as this would not be easy to establish in Australia. There is a long way to go to have such a choice.

We have a DVD from the Netherlands which outlines how such a service works. The presentation is not on the IPOPI website.

CGD

Professor Andrew Cant from UK gave a talk on his work in the treatment of CGD and please note that his presentation is not included on the IPOPI website.

His presentation was on the use on Bone marrow Transplant for the cure of GCD. His point was that the question should not be "Why should Bone Marrow Transport (BMT) be considered" but "Why is BMT not considered".

He described work where he 20 patients had had BMT – 17 survived. 1 died before the transplant could be carried out. The other two after the transplant but both were over 17 years old. He said that the younger the patient is then the better the outcome is likely to be. He also maintained that the pre-treatment of the original bone marrow must be very thorough and a great cause of failure of transplants is to be too cautious.

He pointed out that Interferon treatment is only effective in those people who already have some residual oxidative burst (ROB) activity. Those that do not have ROB activity do not have any benefit from Interferon.

He also mentioned that in his opinion gene therapy has not produced any significant results as yet. He says the technology is not good enough as yet.

These are just my notes from his presentation and since there is no presentation on the website to refer to I would suggest that if you want to find out more you search for research under Professor Cant's name on the internet or else ask your specialist.

IVIg

Australia's issues with IVIg supply are slightly different to other countries but there were still common issues. Helen Chappel emphasised how important it is to make sure that IVIg is used appropriately through the use of guidelines. She described how in her clinic which is a special clinic for the treatment of IVIg conditions there is a panel made up of neurologists, immunologists and hematologists that evaluates the use. There is a documented system of priorities. One point she made is that those on home therapy are exempt from the shortage priorities. In addition in times of stressed supply then there must be a prioritization of use and of course replacement therapy must always come first.

Jordan Orange described how in the US the reimbursement for IVIg treatment has been cut so that –

1. Changes in sites of care
2. Reduction in frequency of infusions
3. Reduction in dosages

All of which result in adverse health affects.

He as with Helen Chapel emphasised how important appropriate usage is and how good examples of appropriate use must be maintained. Eg in the case of CIDP (not immunological) he maintains that only about 30% of the IVIg used may actually be effective and in the case of multifocal neuropathy this figure may be as high as 70%.

Albert Farrugia pointed out that governments are attempting to reduce costs while providing reasonable care and at the same time staying elected. This creates the fine balance that can be used to ensure that user groups have some influence. It was a very interesting and frank talk and would be worth looking at on the website. One point he made that is relevant to Australia is that he maintains that trying to rely on self sufficiency will always result in shortages. He believes that the only way to go in Australia is to have a multiplicity of providers and be a part of the world market.