



DAVID WATTERS

Retiring Executive Director of the International Patient Organisation for Primary Immunodeficiencies (IPOPI)

AFTER A CAREER OF HELPING OTHERS, David Watters is retiring from the International Patient Organisation for Primary Immunodeficiencies (IPOPI) and handing the reins to Johan Prevot, executive director designate. While looking forward to enjoying the next chapter in his life, he will look back fondly on his experiences and continue to educate all who he comes in contact with about primary immune deficiency (PID) and the challenges faced by patients with this disorder.

Can you briefly describe IPOPI?

IPOPI is the global network of national member organizations (NMOs) and it seeks to better equip NMOs to be effective advocates for their patients through the promotion of early diagnosis and effective, safe, therapies. It has been my very great privilege to be involved in the work of IPOPI for over 16 years—first as a Board member, then as a servant of the Board on a part-time basis, culminating in the past six years when, as Executive Director, almost every waking hour has been dedicated to what I see as a great and worthwhile cause.

What are your most proud achievements while working at IPOPI?

It is a deeply humbling experience to work alongside, and be trusted by, patients who are, on the whole, getting a rough deal from their national health agencies and that humility is deepened when you see wonderful things starting to happen in countries where there has been very great disadvantage—I think of Africa, Latin America—but also of Europe. To realize that one has played a small part is very humbling! It has also been very good to see IPOPI grow in strength—now with 41 NMOs—and still growing and showing signs of good health and heart!

How have both the association and patients' attitude changed over the years?

Over the years it has been good to see patients and patient groups become much more assured, confident and empowered to take a lead in affairs affecting their health and the health of

their families. This has not been easy and it comes as a result of many interested stakeholders working together—ranging from affected individuals, national groups, politicians and policy makers, industry, and IPOPI itself. Ten years ago “advocacy training” would be seen as something very threatening—now it is something that people see as essential if they are to adequately represent their patients at a national level.

What are the priorities for the future?

IPOPI has set itself a tough challenge in its objectives and they are lasting objectives that will stay fresh and active for many years to come—early diagnosis, enhanced available therapies, better medical and social awareness of PID, developing more and more NMOs and funding the operation to keep the very busy



ship afloat! Those are enduring priorities—sure we will campaign for early testing for severe combined immunodeficiency (SCID), we will want to influence policy decisions and keep abreast of developments in areas like health technology assessments (HTAs) and other developments in health

policy—but the core priorities will always be to secure the very best for patients through early diagnosis, adequate therapy and empowerment of NMOs.

How has the treatment for PID evolved over the years and what remains to be done?

Sixteen years ago it was so very easy to “spot the PID patient” at any gathering—generally speaking they were in poor health, with racking coughs and, often, poor digestive systems. Today, as a great tribute to all concerned with the provision of health care, it is much harder to tell who has a PID! The availability of therapies, the development of subcutaneous infusions, the development of care programs at national levels—they have all helped to secure a brighter future for people with primary immunodeficiency.

Who was the most significant person you met (or the person that has marked you the most) during your work with IPOPI?

Wow—how do you separate them out! Perhaps the most significant people would be children in a very poor hospital ward in Soweto in South Africa. Their treatment facilities were very limited—their surroundings were far from Western standards—while we were there the water was turned off and there was a massive storm and a power cut—BUT they were being cared for by a dedicated, bright, jovial team of young doctors and nurses who let nothing stand in their way. Those are the significant people who influenced me and kept me going in face of all kinds of local problems in other countries. I would also have to add that at Board level it has been my privilege to work with two very inspiring ladies—Bianca Pizzera and Jose Drabwell—both of whom have driven the work of IPOPI with enthusiasm and very great courage. That, too, is important, along with motivated Board members from around the world. But let’s hope that it is always those highly disadvantaged people who stay in the sights of IPOPI as it heads into the future!

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