



# Meet the IPOPI Chair: Martine Pergent

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Martine Pergent assumed the role of Chair of the International Patient Organisation for Primary Immunodeficiencies (IPOPI) this year, following several years of involvement within the primary immunodeficiency disease (PID) patient community. Jose Drabwell will remain on IPOPI's Executive Committee and will use her position to continue supporting the PID patient community. We reached out to Ms. Pergent to understand her outlook on IPOPI's future and its role as a leading advocate for patients living with primary immunodeficiencies.

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## 🗣️ What is your vision for IPOPI?

IPOPI is dedicated to improving PID patients' lives, worldwide. In order to do so, we have made it our mission to improve awareness, access to early diagnosis, and optimal treatments for PID patients around the globe. This mission statement is a fabulous ambition when it comes to patients with rare life-threatening conditions, most of whom will need lifelong treatment. It is important in a globalized world, in particular for rare diseases, to have a strong global patient representation that can support the regional and national efforts of its members and to be a strong representative of its community to provide proposals, recommendations, leadership, support or at times to act as a facilitator.

Our efforts and work are aimed at making patients stronger partners in their health care environment so they really benefit from patient-centered approaches, especially those that follow the trend toward personalization in both medicine and pharmacopoeia. In addition, PID patients who live with chronic disorders have become experts on their conditions and how to live with them: In this perspective, we want to ensure that patients are not only listened to, but heard.

**Q What are the most important issues facing the PID community?**

Diagnosis remains a huge issue. Most patients worldwide are undiagnosed, even in countries with reliable health systems. Then access to treatment is also crucial, especially because different options are available, from prophylaxis to palliative or to curative ones. Each of them has its own challenges. Ensuring access to immunoglobulin substitutive therapy (Ig therapy) is also among our top priorities. There is an increasing threat on the access to these lifesaving medicines for multiple reasons. One of them, not the least, is the increasing demand for Ig therapies. However, the world supply relies on a handful of countries that have proven their efficacy in collecting plasma, such including, of course, the United States, but also Germany, the Czech Republic, Austria, and Hungary. In many countries, the collection growth is insufficient, and I strongly think that stakeholders need to change their way of thinking and focus on the safety of patients from a supply perspective in addition to donor safety, for whom we are very grateful, with the ultimate goal that patients have access to their lifesaving treatment.

Of course, beyond this, countries should put in place health systems that allow patients to access the best available treatment option for them to lead normal lives with an optimal quality of life.

**Q The PID field is fascinating, and thanks to successful research, we're gaining an amazing body of knowledge more quickly than ever. From the patients' perspective, the question is how will they benefit from the new research in their daily life?**

Diagnosis and treatments are there, but the key word remains **access**: research, clinical knowledge, diagnostics, availability, affordability, and quality of life. There you touch upon a large range of stakeholders who need to cooperate for the sake of patients' health. This is key to ensuring constant progress of knowledge and research, which translates into a better life for patients.

**Q Developing solutions is critical. Can you highlight key IPOPI initiatives that are making a difference to improve patients' quality of life?**

IPOPI has achieved a lot in the past decade, thanks to its efficient and wonderful staff, sustaining continuous efforts to develop patient leaders who can act at national or regional level. Moreover, I have to say that I am very proud of my board members, each of whom has such a strong commitment to his or her own region. IPOPI works hard to launch new national member organizations, supporting them in their awareness, advocacy, and social outreach. As a case in point, just have a look at what has happened in Africa and Latin America. When it comes to Asia, our Bob LeBien Programme has allowed IPOPI to make outstanding

progress with new patient representatives committed to their communities and working hand-in-hand with their physicians to obtain better access to diagnosis, treatment, and reimbursement.

IPOPI also works at the regional level, including Europe, to foster policies that take into account PID patients and interests. Through its European Policy Forums, IPOPI has raised the patient's voice among members of Parliament and set up frames of what should be gold/good practices when it comes to PIDs as a model for rare diseases. Our work on newborn screening for PIDs, and broadly for rare diseases, is also telling.

IPOPI works as a global and regional partner among many different stakeholder platforms and fora, including physicians and health care professionals, industry, decision-makers, institutions and agencies, as well as other patient groups. To illustrate this, I will mention the International Primary Immunodeficiencies Congress, our clinical conference that has been so successful in spreading the knowledge and experience on clinical care that are so vital for patients and important for physicians, including the youngest who commit to work in this amazing but complex field.

**Q Could you share with our readers what motivates and inspires you?**

For me everything began by chance: Close friends of ours were having a child with PID, more than 20 years ago, in France. As a small group, we decided to set up a patient organization under the advice of Prof. Alain Fischer. Since then, I have done nothing else except learn, listen to people with unbelievable experiences, set out projects, read, write, and meet with fantastic people. Then came IPOPI, with its global scale and its fantastic evolution. The PID community is truly a special one, full of amazing people! Being a volunteer can be demanding when you really commit, but it is well worth doing. When I look over my shoulder at the 20 past years, I can see how life has dramatically improved for PID patients, how today lives of people who would have died yesterday are being saved. I feel proud and rewarded to have been a small part of this! And then, when looking toward the future, I can see all the improvements that remain to be implemented, patients in some countries still have such difficult lives. I also know that nothing is ever won forever and that we need to monitor carefully and continue advocating, supporting, and cooperating as an active, even proactive, stakeholder. Is this not enough to be thrilled? First, I feel privileged to be part of a great organization like IPOPI, and now to have the honor of serving as its chair. Second, I am fortunate to be part of such a noble and irreplaceable mission with many successes and so many challenges left to turn into new successes! ●