



XVIII IPOPI GLOBAL PATIENTS' MEETING

an **IPOPI** event

16-19 OCTOBER 2024
MARSEILLE, FRANCE

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UNMET NEEDS

Patient perspective

Martine Pergent

As an introduction

The level of unmet needs for health reported at international level varies across countries.

Is it possible that it also varies across the different perspectives?

Physicians, Patients, Nurses.



Medical knowledge

- Lack of knowledgeable doctors.
- Available doctors with knowledge of PID, including Primary Care Physicians.
- It would be nice if doctors knew from now on that someone with an immune disorder without fever can still have a (serious) bacterial infection.
- It would be great if our disease became more known during medical training. Both for general practitioners and for all specialties.
- More awareness among all doctors about immune disorders. Perhaps more should be written about it.
- Please train hospitalists!
- Doctors and staff not masking to protect vulnerable patients from the most common route of transmission of respiratory diseases - aerosols from breathing.

Patient Follow up / assessment

- **Evaluating patients' mental capabilities** and other holistic approaches that can make the patient feel that his/her life matters and that they can still be an active participant in society aka INCLUSIVITY
- My doctors are all in the hospital in XXX, they work quite well together and have regular consultations with AMC. However, it would be nice if you could also **get patient brochures in regular hospitals**, for example, so that the doctors or employees can help you better after the diagnosis. I had to find you myself
- **Knowledge of what to expect next**
- **More attention to the treatment of physical and mental energy.** The EMC is conducting a long-term study with thymosin alpha 1 and its positive effect on obtaining more energy. I am curious whether other specialists are also working on such research. Thymosin alpha 1 has had positive effects in the treatment of long COVID. The disadvantage is that pharmaceutical companies often find the target group "immune disorders" too small and not interesting enough. Who knows, maybe more interest will come with European awareness/approach.

Coordination/Multi-disciplinary Approach

- As a PID patient you come into contact with many medical disciplines.
- More awareness on the mental burden of disease.
- Better communication between doctors would also be very nice so that you do not have to tell your history every time.
- Often times clinicians focus only on the PID at stake and not the other management issues that also targets the immune system
- How to go to Emergency room if really sick without hospital treating you poorly

Medical/treatment

- Unmet need for treatment and subsequent rejections
- Genetic treatments

Access / Coverage

- Lack of what to do to get medication.
- Timely availability of treatment i.e import restrictions
- More Plasma donors
- Management of long-term dental care conditions (gingivitis, periodontitis, etc.) such as diabetics.
- Financial support to offset cost of treatments

Work - School

- Flexible working hours
- Coping with invisible disease
- Sometimes our difficulties are not understood because our disability is not seen. Sometimes I'm very tired because of my PID, my asthma and my Behcet but people don't understand. Our morale drops sometimes and this is hard to explain. I am a doctor and my colleagues ask me why I am asking for job adjustments if my PID is substituted or cured? In short, I think that the fact that we have a rare and not very well-known disease puts us in a special situation compared to others.
- Enhancing quality of patients' life: home schooling, awareness and training to caregivers and teachers

Importance of patient groups

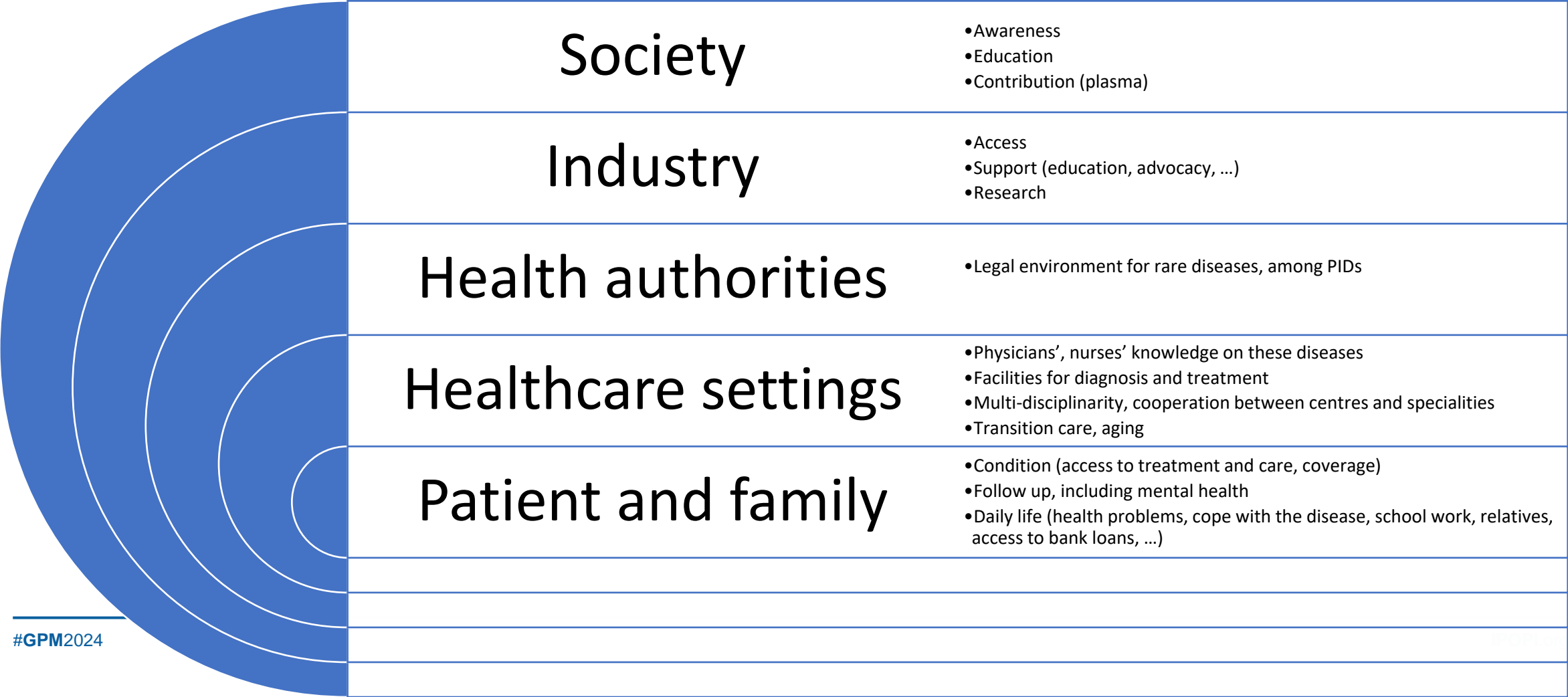
- In any case for me the IRIS association and ARPID (Romania) are real treasures, I have always found help during difficult times.

Research

- **More research on IgA and IgM.** This is a 2-edged sword. They will find out so much illness is due to low levels of both and then there will be shortages of treatment meds.

As a preliminary conclusion

Patient centred care / holistic approach



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