

GPP FORUM ARTICLE

Frida Dunger Johnsson, Executive Director IFPA



The fight to improve the lives of people living with Generalized Pustular Psoriasis (GPP) has been boosted by a unique event that brought together medical experts, patients, charities, researchers, industry and policy organizations for the first time. I was privileged to be part of this important multi-stakeholder GPP Forum held recently in Amsterdam and to represent IFPA in laying out the foundations for a new vision and action plan for GPP.

GPP is a devastating and potentially life-threatening rare psoriatic disease that forms visible pustules on a person's skin. It causes significant pain — discomfort that impacts across physical, emotional, social, and economic aspects of a person's life. The distinguishing features are widespread reddened, inflamed skin that is covered with painful pustules. These pustules can cover your entire body and, if left untreated, may lead to a threat to a person's life.

Why were we in Amsterdam?

As is the case with other rare diseases, including other forms of psoriatic disease, and as Rare Disease International representatives confirmed, diagnosis and awareness of GPP is low. This has major consequences even for people who have been diagnosed. We need physicians and the wider community to recognize and fast-track care for people living with GPP.





Emmylou, our IFPA Ambassador from the Philippines lives with GPP. She stressed why we really need to shed a light on GPP. She shared her personal experience on how devastating this condition is, not just in her personal life, but also her family and even work life. She shared how GPP has forced compromises to her life, something we see in many people living with such a severe condition. She described how GPP flares, as well as the uncertainty of flare triggers, had affected her life by saying 'It is not ordinary pain.'

“One day I just woke up with pustules all over my body. Painful, really painful. I cannot move because the pain is excruciating and the discomfort is very extreme, but I cannot stand up. So I cry and ask my husband, please take me to the hospital because I need treatment.”



Her moving address to delegates was echoed by Brandon and Dale, two people living with GPP, who spoke of their excitement around how the Forum had brought together leading figures in GPP and rare diseases and had given them a chance 'to put our shoes on' to learn from people living with the condition.

With poor awareness, no cure, few treatments, and a lengthy time to diagnosis, it is a condition that isolates people both physically and mentally. For too long this rare form of psoriatic disease has had limited focus. But the GPP Forum now offers hope to look at GPP from multiple angles and make positive changes to help people with the disease lead the lives they wish to.

As someone who represents many people who are expert in their own conditions, it was humbling to hear people's stories of courage in adversity. It is inspiring to be part of a new resolve from the medical and patient communities to support them.

The key points for me were how people with GPP struggle to enjoy family lives and how their self-esteem and independence were repeatedly shattered when they experienced GPP flares. It was painful to hear testimonies of suffering, social stigma, and isolation. As is common with many psoriatic conditions, especially with other rare psoriatic disease forms, the impact on mental health was profound.

Despite these testimonies, our direction was for change, that we could make a start for the better – it felt like a moment of positivity, and it was empowering for everyone attending.

We benefitted hugely from an open discussion around every aspect of this rare psoriatic disease — from symptom recognition and initial treatments to how patient organizations can best advocate for better education and awareness to accelerate diagnosis and access to specialists and individualized care. It also brought people from around the world together who do not always have the chance to meet, to form bonds and establish a more powerful united voice and direction.

The Forum crystallized some of the goals IFPA has set in its strategy on the need to improve education and information not only for people living with GPP, but also for families and healthcare professionals. By sharing knowledge and best practices across dermatology and general practice, we can finally unite people who have existed and survived in isolation. In addition, there are experts who are motivated to share more about their first-hand experiences to help others.




With everyone committed and working together, these are achievable goals that will have enormous benefit for the wider GPP community. But what is also exciting is that we can capture the energy from our meeting in Amsterdam and direct it towards a sense of purpose, acting on a number of important ‘next steps.’ These steps have been collated in a GPP Forum, established as a framework for the multi-stakeholder collaboration, with clear goals and ambitions to really make the positive change which is so desperately needed.





Life can be easier, when we are united, when I don't feel alone, when I belong to a patient organization, life can be a bit easier.



But we must not lose this momentum. There are practical steps that can and must be taken to empower decision-makers and influence policy at a global level. These clear calls to action form our GPP Forum. Focusing attention on the biology of GPP is key. We must agree on how we communicate, consistently using the same language to illuminate central, distinguishing symptoms. Furthermore, we must:

- ~ raise awareness of the impact on people's lives;
- ~ share learnings to accelerate diagnosis and upskill healthcare professionals to recognize the signs of GPP;
- ~ support experts who are knowledgeable in the management of GPP;
- ~ establish clear pathways so that people living with GPP are swiftly under the care of dermatologists with experience of the condition;
- ~ advocate for GPP-specific therapies with full access;
- ~ connect the GPP communities with rare skin disease and psoriatic disease communities to learn from each other and improve outcomes.

It is common for people living with GPP to be misdiagnosed or be without a diagnosis for a significant and unacceptably long time. As a result, the individual's quality of life is severely diminished. Living with the fear of a flare — not knowing what this condition is and how to manage it — can be overcome if we achieve our goals set out in the GPP Forum. We must do more and continue our vision to a future where all people living with psoriatic disease enjoy good health and wellbeing, and overcome the stigma and discrimination. We must do everything we can to improve this current situation.

The Forum was a fantastic opportunity to share knowledge, listen to each other, understand different perspectives, and use that focus to make real changes. It was a wonderful experience and I believe we have the power to make these changes.

Emmylou said, ***“life can be easier”*** and that really got to me. In her words, I heard that ***“when we are united, when I don't feel alone, when I belong to a patient organization, life can be easier.”*** As the leader of a global patient organization, I am committed to facilitate as many people with GPP as possible having access to support and resources.

That unity gives us strength.

I want a world where every person with GPP receives the treatment they deserve, and this is their right. I believe the GPP Forum can really unite globally and drive research and collaboration, raise awareness and education as a priority and provide the support that has been missing.

There is much more to do but I am happy to see we are all heading in the same direction. I am convinced that we will make change for the better and continue to grow stronger and become more effective to improve the lives of people affected by GPP.

At IFPA, we are focused on bringing the right people together to collaborate and learn from each other and the GPP Forum that resulted from this special and enthusiastic group of people plays a vital role moving forward.

We don't want anyone to feel alone, and we will not leave anyone behind.



IFPA is a global organization uniting people living with psoriatic disease in every region of the world and every form of psoriatic disease.

FIND OUT MORE ABOUT IFPA'S SUPPORT FOR RARE DISEASES LIKE GPP