

# GPP FORUM REPORT





## INTRODUCTION

A unique global event has brought hope to people living with Generalized pustular psoriasis (GPP), a devastating and potentially life-threatening condition that causes pain, discomfort, public stigma and corrodes quality of life.

GPP is often misdiagnosed as an infection, confused with plaque psoriasis or other psoriatic skin diseases resulting in delays in an accurate diagnosis. People living with GPP experience sudden flares that can appear in the form of painful, pus-filled blisters over large areas of the body. They can rapidly develop overnight, and their searing pain is compounded with the stigma of a visible skin disease, which together generate an emotional and mental burden.

Inappropriate medication can be prescribed, particularly when treating an undiagnosed flare, while patients endure months and sometimes years of agony and the uncertainty of not knowing what the condition is. Compounding the uncertainty and impact on mental wellbeing is living with the unpredictability of a GPP flare. Many people living with GPP do not know when or how severe a flare may be and this can have a damaging impact and comprise their life.

At the GPP Forum, dermatologists, patient advocates, patient organizations and rare disease policy makers from around the world met for the first time to share their experiences to create the building blocks of an innovative approach to GPP. They discussed, debated, and tackled every

aspect of GPP to reach an energizing consensus leveraging different expert perspectives. At each step of the condition's journey, the resulting GPP Forum will revolutionize how the condition is viewed and set us on a pathway for positive change.

This united hope stems from a dynamic promise from clinicians, patients, patient groups and industry to banish the era where GPP existed in the shadows, under-recognized and under-served. People living with GPP now have support and a pathway to improvements in diagnosis, treatment and recognition of the rare disease that has blighted lives. The landmark GPP Forum event and subsequent GPP Forum will help replace isolation with a sense of community and desperation with hope.

The agenda-setting Charter captures the energy, purpose and commitment that emerged from the GPP Forum. It also importantly represents an awakening for GPP, a fresh spirit of the possible, a template for better therapies, elevated disease understanding and knowledge sharing. It will also help improve the research and development of bespoke GPP treatments, speed up diagnosis, establish excellence in support services to connect the GPP community, offer access to new therapies and have a transformative impact on quality of life.

***It is a turning point for GPP.***

[View the GPP FORUM](#)



## THE GPP FORUM

Ioannis Sapountzis, Therapeutic Area Head, Inflammation at Boehringer Ingelheim, welcomed the forum attendees to Amsterdam stating: ***“One of the main goals of today is to find ways to make progress for those living with GPP, which we know is a distinct and sometimes very, very painful, even life-threatening skin disease. To do this, we have to listen to each other and, in light of those challenges that we face, work together.”***

The event was characterized by influential moments from two speakers, one living with the condition, Emmylou, from the Philippines and Frida Dunger Johnsson, Executive Director, IFPA. Emmylou, who is also an IFPA ambassador, has been living with psoriatic disease for more than 20 years. She first experienced a GPP flare and its corrosive effect on her physical and mental health 18 years ago. Speaking of its impact, she told delegates: ***“It is no ordinary pain. It feels like the flesh is being ripped from your skin.”***

Her sobering account framed the jeopardy experienced by patients. The resolve to change that was encapsulated by Frida Dunger Johnsson speaking on behalf of IFPA, a global patient organization serving the psoriatic disease community and defining itself as a Global Leader in Fighting Psoriatic Diseases. She stated:

***“This is the day. This is the day we change the future for people living with GPP. It is the moment we have been waiting for and a golden opportunity for everyone involved in GPP to transform care and improve people’s lives.”***

Frida Dunger Johnsson, IFPA



## THE PATIENT BURDEN

GPP is a rare neutrophilic skin condition with a significant burden for patients that can be fatal if left untreated. The prevalence is highly variable around the world, but what we do know is that it is rare.

Most doctors will see a patient with GPP once or twice in their career and the journey to an accurate diagnosis often takes on average five years, during which time the patient will have experienced sub-optimal or even incorrect treatment. Frequent misdiagnoses mean symptoms are often treated as an infection or plaque psoriasis and the reactions, flares and infections can subsequently lead to severe medical complications and even death.

For generations, there has been no global standard management pathway for GPP and patients were left to contend with sudden, painful and unpredictable flares that would cover part or all of their body.

Only the testimony of a patient can do justice to the true burden of living with GPP.

Emmylou Casanova, described her first GPP flare: she was rushed to a public hospital after her body became covered in painful, pus-filled blisters. After an initial misdiagnosis and being given antibiotics, the GPP was identified, and she was prescribed topical treatments.

For Emmylou, the pain of flares was matched by the sting of stigma. She was shunned on public transport, at public swimming pools and spas.

***“The pain is excruciating, and you tend to withdraw from society to hide the lesions. I am a mother, so it was very difficult to care for my family when I had attacks,”*** she told the Forum. ***“You feel so helpless, having to ask people to assist you to go to the toilet or changing your clothes. You have depression and suicide ideation comes to mind. You can only feel the pain and cannot think of anything but pain and hardship, so you want to end it all.”***

***“It is not an ordinary pain. It feels like your skin is being torn or ripped from your body.”***



Emmylou Casanova, IPFA ambassador

***“People with GPP tend to withdraw from society because they don’t want to be discriminated against. They just hide. If they are misdiagnosed and not given the proper treatment that is when complications come in that can even lead to death.”***



Frida Dunger Johnsson, Executive Director, IFPA

**Statistics from a recent survey of GPP patients illuminate part of the challenge: 59% of GPP patients are misdiagnosed while it is estimated that 36% of people live with symptoms for months and 38% for years before they get appropriate help.**



Emmylou, added that patient groups and organizations offered a lifeline to people like her, living with GPP. ***“Sharing my experience can be an inspiration for people to join support groups who can make life easier because you can talk to someone who understands and you can get help to improve your life and better manage your GPP as well,”*** she said.

***“A GPP Forum can do a lot of things because if we have the same common goals it can lead to having the right medication and stop the stigma.”***

Frida Dunger Johnsson said it was vital that all perspectives including psychological burden, burden to families, cost implication surrounding GPP were considered to create a concerted effort to improve the lives of patients. ***“We have to listen, we have to listen to truly understand. That is what brings us here today – we have the knowledge, we have the resources, and we have the power to make change,”*** she said.

***“As a person living with GPP, it is common to feel alone. In my role at IFPA, I have heard stories of people who stay at home when they have flares and cancel activities as well as friends. Others describe how they restart their lives again and again after their flares. One of our IFPA ambassadors explains so well how his self-esteem took a big smash during the times he was isolated. But, I have also heard stories of how people’s lives have changed when they found purpose and belonging in a patient organization. People living with GPP don’t have to feel alone, we can fight this together.”***



Professor Peter van de Kerkhof, Chief Medical Officer, IPC

## THE WAY FORWARD

The need to collaborate across medical experts, patient organizations and policy health decision-makers was identified as the over-arching aim to unite the fragmented field of GPP.

Improving education and awareness for doctors, uniting patient groups, sharing knowledge and best practice across dermatology and general practice are achievable goals that will have a distinct benefit to patients.

Professor Peter van de Kerkhof, Chief Medical Officer at the International Psoriasis Council, said all organizations involved in GPP needed to use their influence and expertise to facilitate a pathway where GPP can be identified much earlier than currently, and provide early access to treatments.

He advocated a range of measures that, with the backing of patient organizations in 60 countries and medical and scientific input, could radically improve patient outcomes:

- ~ **Knowledge Centers:** A resource where people living with GPP, dermatologists, intensive-care specialists, specialist primary-care doctors, psychologists and experts dealing with co-morbidities, can deposit and source information that is aligned across all disciplines
- ~ **Centers of Excellence:** GPP should be acknowledged as a rare disease and specialist centers of clinical excellence established in countries where patients can get optimal treatment. They would also serve to raise knowledge and awareness leading to shorter diagnosis times and encourage rapid access to the highest possible standard of best-available care
- ~ These centers would provide a model of care that also contributes to the generation of real-world evidence to support consensus and guidelines and contributes to disease-awareness education
- ~ **Registries:** These would be driven by the Centers of Health Excellence and provide the data and research content that could enhance clinical trials and underpin research into the disease
- ~ These initiatives can contribute to the harmonising of treatment and creating an environment where patients find it easier to come forward and talk about their condition, therefore minimising the risk of it being misdiagnosed as conditions such as plaque psoriasis or Stevens-Johnson Syndrome

***“I think we can do this and the GPP Forum will be our action plan,”*** added Professor van de Kerkhof.



Matt Bolz-Johnson, Programme Director, RDI and Healthcare and ERN Advisor, EURORDIS

1,000 rare disease patient organizations in 74 countries, pushed the rare disease label further. He emphasized that although aligning under the rare disease banner had distinct advantages in shaping policy, he suggested not to only focus on whether GPP was rare or common but also on the complexity and burden of disease. Reducing the condition solely to prevalence doesn't convey the complexity and true burden of GPP community face living with this condition. Recognizing the complexity of GPP is the first important step to addressing the challenges.

He also underscored the need for partnerships:

***“In rare diseases, we are a community of game-changers and pioneers, and we do that out of necessity,”*** he said. ***“Everything in rare diseases is innovation and when you innovate and drive change, you have to do it in partnership. As no one stakeholder is able to implement innovation by themselves – we have to do multi stakeholder collaboration - a multi stakeholder collaboration for GPP is absolutely fundamental.”***

***“It is a critical element of driving awareness and understanding that can secure GPP patients a brighter future.”***

## THE POLICY CHALLENGE

GPP could get greater visibility if it was officially recognized as a rare disease and find greater traction for its needs within the European Reference Network that specialises on rare skin diseases (ERN Skin). ERN-Skin campaigns for improved recognition and treatment for all rare and undiagnosed skin conditions through sharing of expertise, building knowledge, conducting research and better access to specialist resources. We have positive examples of how other rare diseases have been effectively managed under the ERN system, now it is time for people living with GPP to be able to access the best quality care they need.

But Matt Bolz-Johnson, programme director at Rare Diseases International (RDI) and Healthcare & ERN Advisor at EURORDIS, which represents



RDI's programme to create a global network for rare diseases – which is supported under RDI's collaboration with the World Health Organization – that brings together knowledge, research, expertise and the patient voice will further raise the needs of people living with GPP at national and international level.

***Only by collaborating at a GPP level, then on rare skin disease and ultimately rare disease platforms, will stop the GPP community being ‘vulnerable, invisible and ignored’,*** he stated.

Policy influence can be brought about by aligning GPP with other rare skin conditions and European Reference Networks using the network to raise awareness and understanding of GPP and amplify advocacy for the cause.

## THE ROUTE MAP TO BETTER TREATMENT

Dr Siew Eng Choon, Associate Professor at Clinical School Johor Bahru, Monash University Malaysia, specializing in clinical dermatology, is one of many leading clinicians working towards expanding GPP networks to accelerate accurate diagnosis for patients and improve scientific understanding.

***“We need the international collaboration of all the GPP experts worldwide so that we can do relevant research and improve our understanding of the science behind this rare disease,”*** she told the Forum.

***“We want to grow our expertise in this area so that we can expand this network to enable easier access to the best-available care for patients with GPP.”***

***“The patient voice is so critical in healthcare planning and, as healthcare providers, we can only help our patients best and address their unmet need if we include them in all our decision-making.”***

Dr Choon was instrumental in establishing a Global Expert Working Group, known as PIONEERS. The Global PIONEERS Expert Working Group comprises 14 leading experts in the management of GPP, all healthcare professionals alongside Frida Dunger Johnsson as the IFPA patient organization representative, who are committed to championing evidence-informed excellence in lifelong GPP care.

***“We really need to see whether we can create a clear diagnostic pathway so that every time a patient comes to us, they get their diagnosis on first presentation and receive the proper care they deserve.”***

Frida Dunger Johnsson agreed with the aim and added: ***“Even though we are all experts, we cannot do this on our own. We really need each other. And we need to listen to each other, learn from each other, and see how we can work together and put our knowledge in the same pot.”***



Dr Siew Eng Choon, Associate Professor, Monash University Malaysia

Peter van de Kerkhof, who is also Senior Professor of the Radboud University in The Netherlands, stated: ***“I think we can do it if all the different stakeholders work together; patients, patient organizations, professional organizations, pharmaceutical companies and healthcare authorities. We really have to make the case for GPP.”***

Raised awareness, generated by the GPP sector commitment and the GPP Forum, will radiate around the public, as well as medical communities to raise its profile as a diagnosis distinct from other psoriatic conditions.

It will create a more inclusive environment that will empower the patient and grass roots communities to access information and connect with other patient groups leading to accelerated and accurate diagnosis.





Durhane Wong-Rieger, President and Chief Executive Officer, CORD and Chair of the Council for RDI

## THE GPP FORUM

- ~ Increase awareness of GPP as distinct from other psoriatic skin diseases
- ~ Improve accurate and timely diagnosis by setting GPP care benchmarks
- ~ Drive education around the need for appropriate and specific GPP treatment
- ~ Establish excellence in support services to connect the GPP community
- ~ Establish centres of knowledge and excellence to lift standards and further research

The GPP Forum provides a set of commitments that will deliver for the aspirations of patients, patient groups and clinicians while also creating a reservoir of knowledge, expertise and policy initiatives. It will raise the profile of GPP to improve diagnosis time, the range of therapies available, access to them and the ability of physicians to diagnose and treat.

It represents a paradigm shift and the gateway to a better quality of life for people living with GPP.

Dr Choon Siew Eng believes it will ultimately save lives. She stated: ***“A GPP Forum is really important because it’s going to help GPP patients. Motivated by the commitment for change, the Charter will ensure those involved provide correct information and proper connection with support groups and, most importantly, reduce the GPP knowledge gap, so you can really save lives.”***

Durhane Wong-Rieger, President and Chief Executive Officer of the Canadian Organization for Rare Disorder (CORD) and Chair of the Council for Rare Disease International, added that the Charter will help enshrine better outcomes as a right for GPP patients.

***“A charter is your declaration that says, ‘I have a right to this.’ That is something not easily recognized for people with rare disease because their numbers are so small,”*** she said. ***“You sometimes feel or are made to feel you don’t have a right. A charter can change that. But we also recognize that this is the start to set us on a pathway for positive change at every level from global organizations down to local communities and each individual.”***

Richard Pitt, Senior Patient Advocacy Relations Manager at Boehringer Ingelheim, added:

***“The aim of the GPP Forum was to bring everyone together to learn from each other and to collaborate on improving the future for GPP patients.”***

***“Our goal is to support greater GPP visibility. By bringing multidisciplinary experts together, we can ensure this happens and information reaches all stakeholders sooner. Policymakers need to hear about it, clinicians need to be more aware of it, payors need to hear about it and politicians and the general public need to know much more about it.”***

***“GPP is under-recognized, under-valued and under supported so we wanted to focus on***

***what we could do to address these challenges. The GPP Forum encapsulates the Forum discussions, the commonality of what can be done and what should be done.”***

***“We need to sustain the level of commitment from everyone at the Forum.”***

Frida Dunger Johnsson added: ***“I feel very empowered, but I feel like we are just getting started. There are so many challenges that are unmet and so many people are depending on us. But we have the commitment to go even further to support people living with GPP.”***

The ongoing dissemination around the goals of the GPP Forum and the collaborative commitment from patient advocates, patient groups, physicians, researchers and drug developers, policy makers and regulators will make sure that GPP no longer exists in the dark.