

# GPP CHARTER

The GPP Charter defines a collaborative approach to identifying common goals with the aim to enable people living with generalized pustular psoriasis (GPP) the freedom to live the life they choose.

The purpose of the Charter is to unite the community living with, and working for, GPP under a set of agreed principles to improve and change the current *status quo*. Through the co-creation of this Charter, the views from multi-stakeholder perspectives have been considered to ensure a consistent and effective call to action for positive change across all sectors of society.

The Charter takes into consideration how GPP, a rare autoinflammatory skin disease, can have both a physical and emotional impact on people living with the condition. Outlined below are the steps set out to call for and make this positive change and maintain momentum in driving GPP up the agenda.

## AGREED CALLS TO ACTION:

### 1. Increase GPP awareness as a rare, unpredictable, and life-threatening autoinflammatory, systemic disease *that is distinct from plaque psoriasis*.



**Raise awareness of the significant patient burden of this rare, debilitating disease including:**

- ~ Define a clear and distinct GPP lexicon with a consistent narrative for GPP
- ~ Agree the key defining symptoms that identify GPP vs. other forms of psoriatic diseases
  - Raise awareness of the nature and complexity of GPP:
    - Signs and symptoms, triggers, co-morbidities, threat to life (multi-system organ failure)
  - Demonstrate the impact on patients' lives and shared experiences by highlighting the emotional (unpredictable, isolating disease) and physical impact (painful, visible skin manifestations)



**Define the biology behind GPP**

- ~ Improve understanding among physicians and healthcare practitioners of the role of the IL-36 pathway as central to the pathophysiology of GPP
  - Highlight that, unlike plaque psoriasis, the IL-36 pathway plays a key role in the pathogenesis of GPP



## 2. Improve accurate and timely diagnosis by a dermatologist with GPP expertise by setting benchmarks for the *identification, management, and long-term care of GPP.*



### **Actions to reduce misdiagnosis and the implications for people living with GPP**

- ~ Share learnings from other rare-disease experiences on how to pinpoint an individual living with GPP
- ~ Identify and consistently showcase the common symptoms of GPP
- ~ Increase access to accurate and informative sources of GPP support/information:
  - Develop GPP diagnostic and treatment guidelines including defining the referral pathway to accelerate diagnosis via access to dermatologists with GPP expertise
  - Increase access to training across the spectrum of healthcare specialists involved in GPP management



### **Use medical and patient experience to drive thought leadership to improve GPP knowledge and identification**

- ~ Deliver accurate and consistent GPP messaging/symptom descriptions providing access to recommended GPP information e.g. websites, patient experiences via videos
- ~ Define ways to inform and direct decision-makers and patients about GPP
- ~ Empower dermatologists with sufficient GPP knowledge to diagnose and treat effectively
- ~ Leverage a Centers of Excellence model to inform, treat and support improved outcomes



### **Motivate the community to create and disseminate tools and collaboratively raise awareness and improve physician/patient conversations**



### 3. Drive education around the need for appropriate and specific treatment of GPP.



#### Management of GPP

- ~ Set the expectation that people living with GPP should be under the care of dermatologists with experience in managing it
- ~ Identify ways to improve collaboration across multi-stakeholder healthcare personnel and patient organizations to better support people living with GPP
- ~ Identify ways to connect patients through local patient associations and support groups
- ~ Establish benchmarks for the management and long-term care of GPP e.g. leveraging real world evidence and experience



#### Collate existing evidence to support a bespoke GPP treatment to address specific needs and restore patient confidence

- ~ Advocate across multiple stakeholders on a national and global level e.g. patients, patient organizations, physicians, health decision/policy makers for GPP-specific therapies based on the specific inflammatory pathway and clinical evidence



#### Ensure that all stakeholders understand the need for treatment options

- ~ Recognize and address the high unmet need for treatment and significant burden that GPP places on people living with the disease
- ~ Consider the optimal approach to involve multi-stakeholders in a GPP network to improve management and diagnosis at all stages



## 4. Establish excellence in support services to connect the GPP community and improve the patient experience.



### **Connect the GPP community**

- ~ Enable and empower the GPP community through creating connections, networks and communities dedicated to GPP
- ~ Work closely with psoriatic disease associations in establishing knowledge hubs and leveraging on support groups for people with GPP
- ~ Amplify and elevate shared approaches, ideas, and personal experience to support others to manage their condition and to know where to get the best/most appropriate help
- ~ Empower people with GPP knowledge to actively self-manage their condition, including shared decisions around their management



### **Connect rare disease communities to share learnings**

- ~ Connect and support rare disease communities and rare skin disease communities (beyond GPP) to collaborate and learn from existing initiatives to raise awareness of GPP and the need for improved outcomes
  - Leverage global and regional initiatives in rare diseases to create a critical mass for rare skin diseases such as GPP and collectively bring GPP into focus
  - Recognize national variations and build on local initiatives for a model to connect GPP communities globally



### **Empower collaboration to drive thought leadership to improve patient outcomes**

- ~ Develop frameworks and guidance to support patient organizations and HCPs co-develop solutions e.g. registries, guidelines, value propositions
- ~ Support and create Centers of Excellence to upskill physicians who can treat GPP and ensure that people living with GPP gain access to the best care