

## **PLUS STATEMENT THE VALUE OF ONE NATIONAL PATIENT ORGANISATION PER COUNTRY**

PLUS is the platform of plasma protein users representing patient organisations including the Alpha-1 Global Foundation, the European Haemophilia Consortium (EHC), the GBS/CIDP Foundation International, the International Patient Organization for C1-Inhibitor Deficiencies (HAEI), the International Patient Organisation for Primary Immunodeficiencies (IPOPI), the ITP Support Association and the World Federation of Haemophilia (WFH).

PLUS member organisations all work to ensure that the views of patients living with rare plasma related disorders and rare bleeding disorders are appropriately included in healthcare policies and legislations, and ultimately to improve diagnosis and care.

Often the national member organisations (NMOs) of PLUS member organisations are involved in similar activities at the national level to defend their rights and ensure that the patients they represent can access proper care and lead active lives.

In order for these efforts at the national level to be as productive as possible PLUS firmly believes that having one recognised patient organisation per condition (or group of similar conditions) per country is key to ensure the patients' voice is taken into account.

Only by having a single recognised patient organisation that channels the views of patients with decision-makers, payers and other stakeholders, can national patient groups efficiently and effectively represent their patient community in a consistent strategic approach. Whilst each country will have its own specific environment and larger countries may need chapters to be established, having one efficient and united national patient organisation is key to adequately and efficiently represent a patient community. PLUS urges its patient communities to always maintain a united national approach when it comes to their representation.

This statement is endorsed by PLUS member organisations:

