



Building a Global Rare Disease Coalition: Outcomes from the Establishment of an International ITP Alliance Community

Cleveland, Ohio, October 2020. The International ITP Alliance, co-founded by the Platelet Disorder Support Association (PDSA) in the US and the ITP Support Association in the UK, was established in 2016 to support, educate, and advocate for patients with the rare autoimmune bleeding disorder immune thrombocytopenia (ITP). The Alliance is currently comprised of 33 patient groups from 29 participating countries from around the world.

Shared intercontinental partnerships between ITP patient advocacy organizations have led to increased opportunities for ground-breaking research, patient support, a shared skillset for the development of educational resources, and a greater awareness of ITP. Strategies for establishing an alliance among all participating country ambassadors was implemented to build on programs, services and resources that meet the needs of various communities worldwide.

Through annual meetings and an online presence (GlobalITP.org) the Alliance serves as a central hub for available patient support groups and serves as a connection between patients, researchers, clinicians and drug developers. At the time of this press release:

- GlobalITP.org has reaches up to 6,100 visitors per month, from over 157 countries.
- Top countries accessing this online resource include Great Britain, Ukraine, Canada, Italy, Japan, Australia and the US.
- In 2019, GlobalITP.org received 83,760 visits and 1.88 million total hits.
- During ITP awareness month, traffic increased from 3,600 visits to over 30,000 visits.
- Top web pages accessed in 2019 include information on global ITP news, collaborative research projects, information about ITP and ITP in pregnancy, patient support groups, the Global ITP Awareness Week ToolKit, and information on clinical trials.

Comments from patients and ITP experts regarding their experience have been both positive, heartfelt, and thankful and reflect a filled gap in existing ITP communities. PDSA's newsletters, informational brochures and resources have been recreated by ambassadors for use in their communities. PDSA has translated multiple booklets into various languages (including Chinese, French, Spanish, Finnish, and Dutch) that Alliance members can disseminate to patients/caregivers to educate and support them. In 2019, Argentina adopted and promoted the 1st ever ITP Awareness Day based on PDSA's National ITP Awareness Month and Sport Purple for Platelets Day. Several Alliance members serve in an advisory capacity to pharmaceutical companies in various stages of developing new ITP treatments. This allows for the patient voice

to be included to fully understand disease burden and unmet needs while focusing on aspects of clinical research important to patients.

Together, this worldwide initiative is functioning as a gateway to current information on ITP, patient support, and innovative global studies and research. For more information on the International ITP Alliance, please contact **npotthast@pdsa.org**

About PDSA: The Platelet Disorder Support Association (PDSA) is dedicated to enhancing the lives of people with immune thrombocytopenia (ITP) and other platelet disorders through education, advocacy, research and support. Patient-founded in 1998 to educate and empower those impacted by immune thrombocytopenia and other rare platelet and bleeding disorders, PDSA is now a powerful force serving and unifying the global ITP community of patients, practitioners, caregivers, advocates and key disease stakeholders. PDSA is committed to building awareness, educating the global community, and providing critical connections and resources that empower patients to take charge of their disease and encourage practitioners to exercise patient-centered medical care.