



# Building a Global Rare Disease Coalition: Beneficial Outcomes From the Establishment of an International ITP Alliance Community.

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## OBJECTIVE

The International ITP Alliance, co-founded by the Platelet Disorder Support Association (PDSA) and ITP Support Association (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. Together, this worldwide initiative is functioning as a gateway to current information on ITP, patient support, and innovative global studies and research. Through annual meetings and an online presence (GlobalITP.org) the International ITP Alliance group has brought together ITP researchers and clinicians, industry professionals, and patients around the world serving as a global voice and inspiration for those living with ITP. It is also a central hub for available patient support groups and serves as a connection between patients, drug developers, and clinical trials. Partnerships are essential to build community based-research and action plans for improved health care (Israel, et al., 1998; Turner et al., 2017). Here we describe the formation of a large global unified ITP community from smaller isolated ITP communities of patients, experts, and industry for the purpose of improving treatment and support options and working towards best patient-centered practices.

## GOALS

To showcase how shared intercontinental partnerships between patient advocacy organizations and associations have led to increased opportunities for ground-breaking research, further patient support, a shared skillset for the development of educational resources, and a greater awareness of immune thrombocytopenia (ITP). Through analysis of web analytics, patient feedback, and examples of integrated knowledge translation we aim to highlight the benefits of the International ITP Alliance for ITP communities on a global scale.

## METHODS

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. Strategies included the creation of a shared mandate, the development of a web-based space that includes an interactive discussion group, and allows for easy access to unified information on best practices, annual symposiums, breaking news, and provides access to available clinical trials worldwide, along with facilitating collaboration to advance ITP research between patients, caregivers, health care providers, researchers, nonprofits, and key disease stakeholders. Following the 2018 International ITP Alliance symposium, attendees were provided a Toolkit and mentorship to set up local patient groups in their countries where support was lacking. Benefits as a direct result from the formation of these intercontinental partnerships is evident when looking at web analytics, group feedback, emulation of central programs, events, and resources, and increased opportunities for collaborative discussions and research.

## RESULTS

### Web analytics

With up to 6,100 visitors per month, from over 157 countries, GlobalITP.org receives a significant amount of traffic from viewers worldwide. The top countries accessing this online resource include Great Britain, Ukraine, Canada, Italy, Japan, Australia, and the United States (Fig. 1).

### globalITP.org 2019 Website Analytics

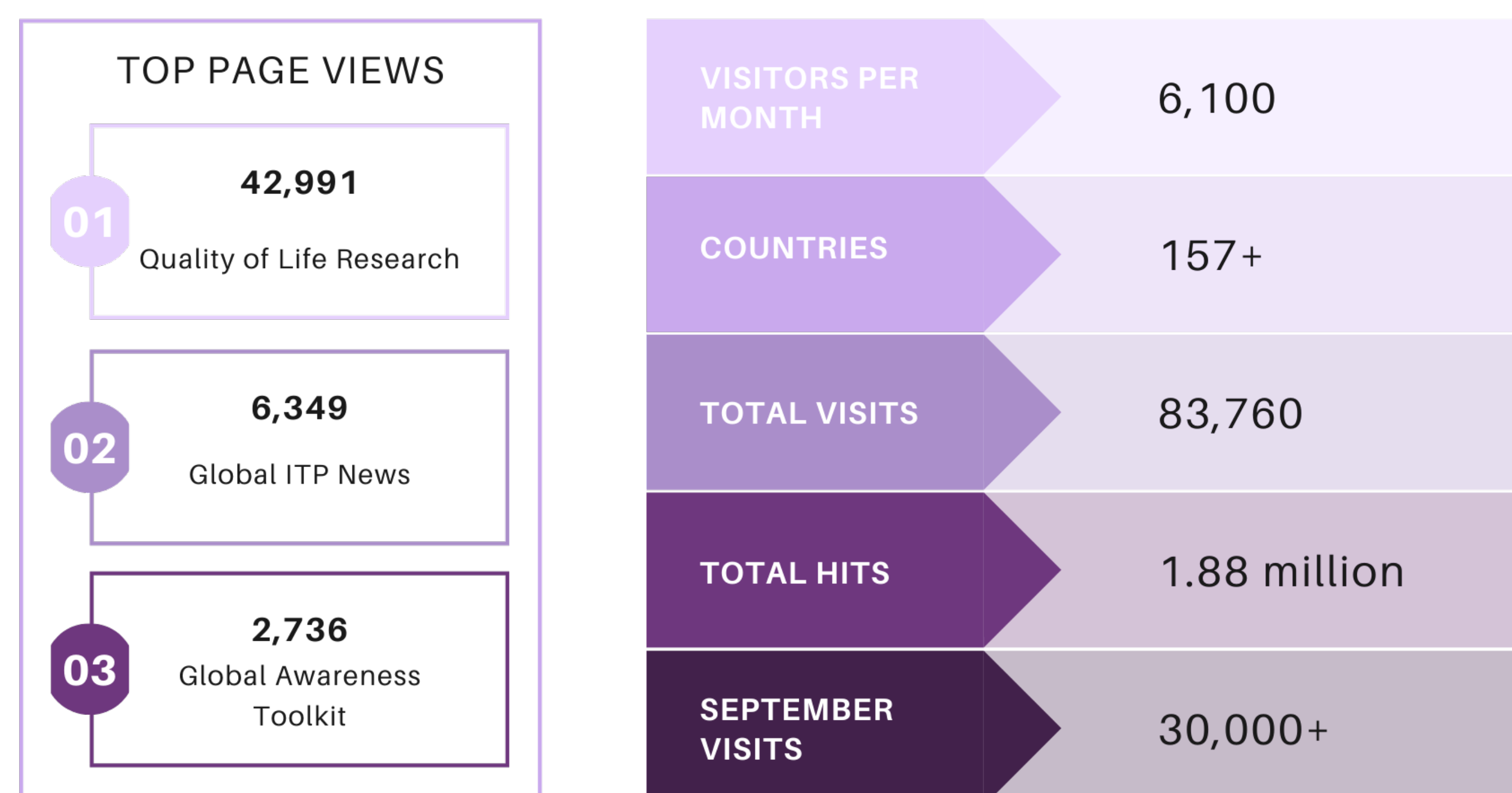


Fig. 1

### Shared Discussions and Research opportunities

International ITP Alliance members are engaging in discussions with ITP researchers, clinicians, and industry professionals on a global scale to enhance patient-centered care. 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.

### Patient and Expert feedback

Establishing a coalition (Fig. 2) that includes international experts allows knowledge to be shared and translated into action plans designed to influence key disease stakeholders and legislative bodies. This is the basis for forward change in the delivery of improved ITP health care.



Fig. 2

Comments collected from patients and ITP experts regarding their experience have been both positive, heartfelt, and thankful and reflect a filled gap in existing ITP communities. A few examples from ITP Alliance members:

- ~ "Thank you to everyone for a brilliant convention, I have learned so much and made some lasting friendships." ~ Mervyn, United Kingdom
- ~ "It was fabulous at the International ITP Alliance Symposium. We're working together to help ITP patients and their families around the globe." ~ Wendy, New Zealand
- ~ "These people are changing the world what a joy to be part of this wonderful alliance full of people of good, with the heart full of love to the next and hope as we are a family!! International ITP ALLIANCE" ~ Marilia, Brazil



Fig. 3

### Emulation of programs, events, and educational resources

The Toolkit has led to the development of over 33 support groups established through the International ITP Alliance. PDSA's newsletters, informational brochures (Fig. 3) and resources have been recreated by international 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 their patients/caregivers to educate and support them. In 2019, Argentina adopted and promoted the 1<sup>st</sup> ever ITP Awareness Day based on PDSA's National ITP Awareness Month<sup>SM</sup> and Sport Purple for Platelets Day<sup>SM</sup>.

## CONCLUSION

The International ITP Alliance has come together to fill an un-met community need on a global scale. This is evident from positive patient feedback, research opportunities, the recreation and use of PDSA's educational resources and tools in other countries, and web-based analytics that show how well GlobalITP.org is utilized internationally. Annual symposiums allow global industry professionals, key opinion leaders and global health care providers treating ITP to collaborate and share new treatment options and drive discussions on better therapeutic plans and improved patient-centered policies. The number of support-groups established across various continents has increased as a result of information sharing, and yearly sponsorship of symposiums have increased validating the need for this groups existence. In summary, the International ITP Alliance has created a networking community of global ITP experts, patients and caregivers, and key stakeholders to share knowledge and experience which has translated into action plans and the development of shared educational tools and resources for best practice, unify knowledge, and awareness of breaking news surrounding ITP-related events, treatments, and research.

## REFERENCES

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- Turner, J. et al. 2017. Community building community: The distinct benefits of community partners building other communities' capacity to conduct health research. Program Community Health Partnership. 11(1):81-86.