

TITLE OF ABSTRACT:

Patient Community Building in Rare Diseases: The Invaluable Role of Technology as a Lifeline of Information, Support, and Community through the COVID-19 Pandemic

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PURPOSE:

The Platelet Disorder Support Association's (PDSA) ITP Patient Connect program is comprised of patient-led support groups, created to engage and connect individuals and families with immune thrombocytopenia (ITP). Participation in the program reduces the isolation, loneliness, and fear that often accompanies living with this rare bleeding disorder. From 2003 to 2020, our ITP Patient Connect support group community represented an active collection of patient-led support groups who gathered in person regularly across the US, Canada, and New Zealand to offer encouragement, share personal experiences, and learn from one another. As the COVID-19 pandemic advanced around the globe, PDSA committed to sustaining this crucial patient resource and the lifeline of support it offered.

BACKGROUND:

For many, living with a rare disorder like ITP is an isolating and anxiety-inducing experience. Add fears associated with the pandemic, when being with others in person threatened risk of COVID-19 infection, this patient population felt even more closed off from much-needed information and support. ITP patients could no longer attend regularly scheduled medical appointments for blood draws and treatments, and reports of potentially dangerous reactions to both the COVID-19 virus and vaccines triggered concern of drops in platelet counts. Patients and families desperately sought connection and information and PDSA mobilized to respond – to ensure that the ITP patient community felt safe, informed, and connected.

METHODS:

PDSA strategically transitioned its ITP Patient Connect support groups to a virtual format. Virtual events were an easily accessible alternative to in-person meetings and offered us the chance to reach a much wider audience. PDSA executed an outreach plan to build patient engagement and facilitated the participation of ITP experts from PDSA's Medical Advisory Board and Pediatric ITP Consortium of North America (ICON) to share the latest on COVID-19 and ITP and answer patient questions – a benefit not previously possible with in-person meetings. Social media and email communications were utilized to raise awareness of these accessible and information-rich virtual events.

RESULTS:

PDSA's virtual ITP Patient Connect program saw a significant increase in patient engagement. In just two years, the number of support groups increased 29%, from 49 in 27 US states and 3 countries (US, Canada, and New Zealand) in 2019 to 63 in 32 US states and 3 countries (US, Canada, and New Zealand) in 2021. The number of meetings held increased by 78% from 41 in 2019 to 73 in 2021 and patient/caregiver participation grew more than 200%, from 350 participants in 2019 to 1,100+ in 2021. Prior to the virtual format, support groups averaged 40 meetings with 350 total participants per year, 2015-2019.

CONCLUSIONS:

Through the strategic use of technology, PDSA was able to not only sustain but significantly expand the impact of its ITP Patient Connect program to ensure the availability of information, support, and community through the COVID-19 pandemic. Through a robust e-communications plan and schedule of virtual meetings, we successfully reached a wider audience, served as an invaluable and accessible patient resource, increased participation, built the ITP patient community, and provided a safe and helpful space where patients could be fully engaged and supported.