

Aims and Background

Living with immune thrombocytopenia (ITP), a rare autoimmune bleeding disorder, is challenging and often accompanied by anxiety (1-2). When the COVID-19 pandemic was declared by the World Health Organization in March 2020, health precautions and priorities everywhere changed.

Viruses and vaccines have been found to cause primary ITP and have the potential to lower platelet counts among those with pre-existing ITP (3-4). As a result, fear of a platelet count decrease following vaccination against COVID-19 has caused vaccine hesitancy within this patient population.

To quantitatively assess the impact of COVID-19 infection and vaccination on ITP patients, we developed a COVID-19 & ITP survey to help reduce anxiety and educate patients and caregivers on the changing landscape of COVID-19 as it relates to thrombocytopenia. We planned several educational webinars and provided resources via social media outlets that also promoted the survey.

Here, we illustrate how the implementation of a self-reporting patient survey and an aggressive marketing campaign allowed for the timely collection of current global data specific to a rare disease group, all while community building through education and connection.

Methods

On February 13, 2021, the COVID-19 & ITP survey launched within our ITP Natural History Study Registry. It was made available to those with active disease and those in remission. The survey collects data on how platelet counts are affected by infection and vaccine receipt and the role of other co-morbid conditions (particularly multiple autoimmune or immune disorders). The survey is designed to capture whether ITP patients truly have increased risk of adverse effects.

PDSA hosted several educational webinars with our medical advisors, infectious disease and vaccine experts, and provided space for patients to discuss questions and concerns regarding ITP and COVID-19 on our closed social media group.

The COVID-19 & ITP survey was promoted during these educational events and on social media as part of our comprehensive global marketing, communication and education outreach campaign leveraging both online and in-print materials.

Results

As of June 4, 2021, 338 ITP patients had completed the survey. Due to our aggressive marketing campaign, a steady number of participants filled out the survey each week.

In 2020 and 2021 the top keyword search was 'COVID' and 'COVID-19 & ITP' on both GlobalITP.org and PDSA.org. On the PDSA site, the COVID-19 Updates & Resources page was viewed over 84,000 times in 2021 (Figure 1). This same webpage on both PDSA.org and GlobalITP.org is now one of the top ten viewed pages, and both contain the link to the survey.

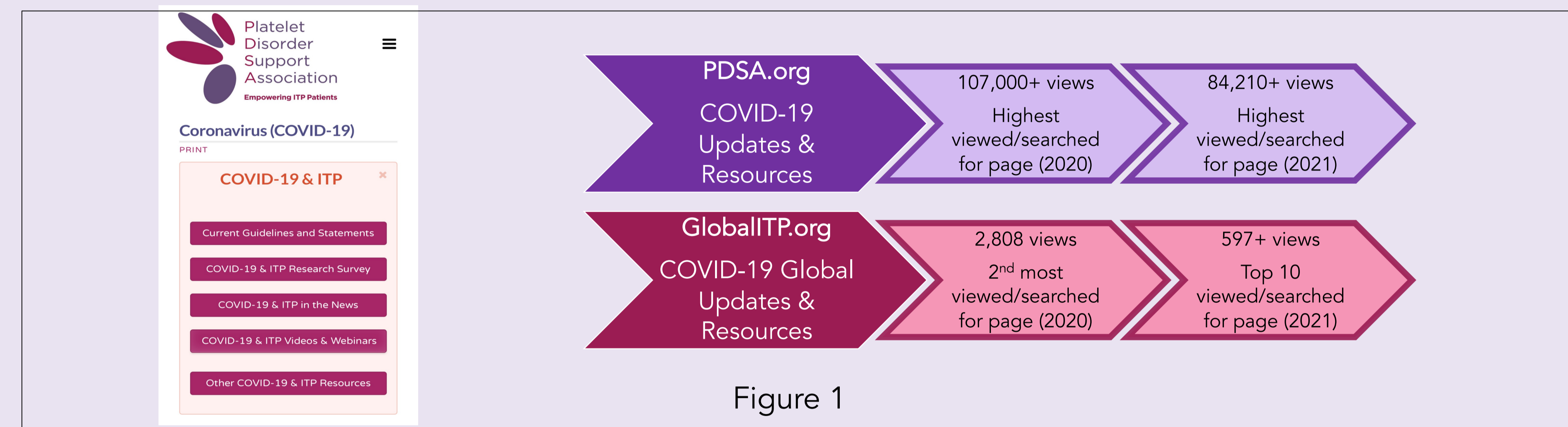


Figure 1

Over 2,000 people attended our COVID-19 & ITP Town Halls and various educational webinars. These events were recorded and later made available through social media channels and to date have received over 36,000 views. Between July 2020-May 2021 approximately 10-15 new Facebook group members (closed group) per day noted they were looking for information on both the COVID-19 virus and vaccines. Approximately 60-80% of our close group posts were about COVID-19 and vaccines (Figure 2). The Facebook group has now reached 16,000 members.

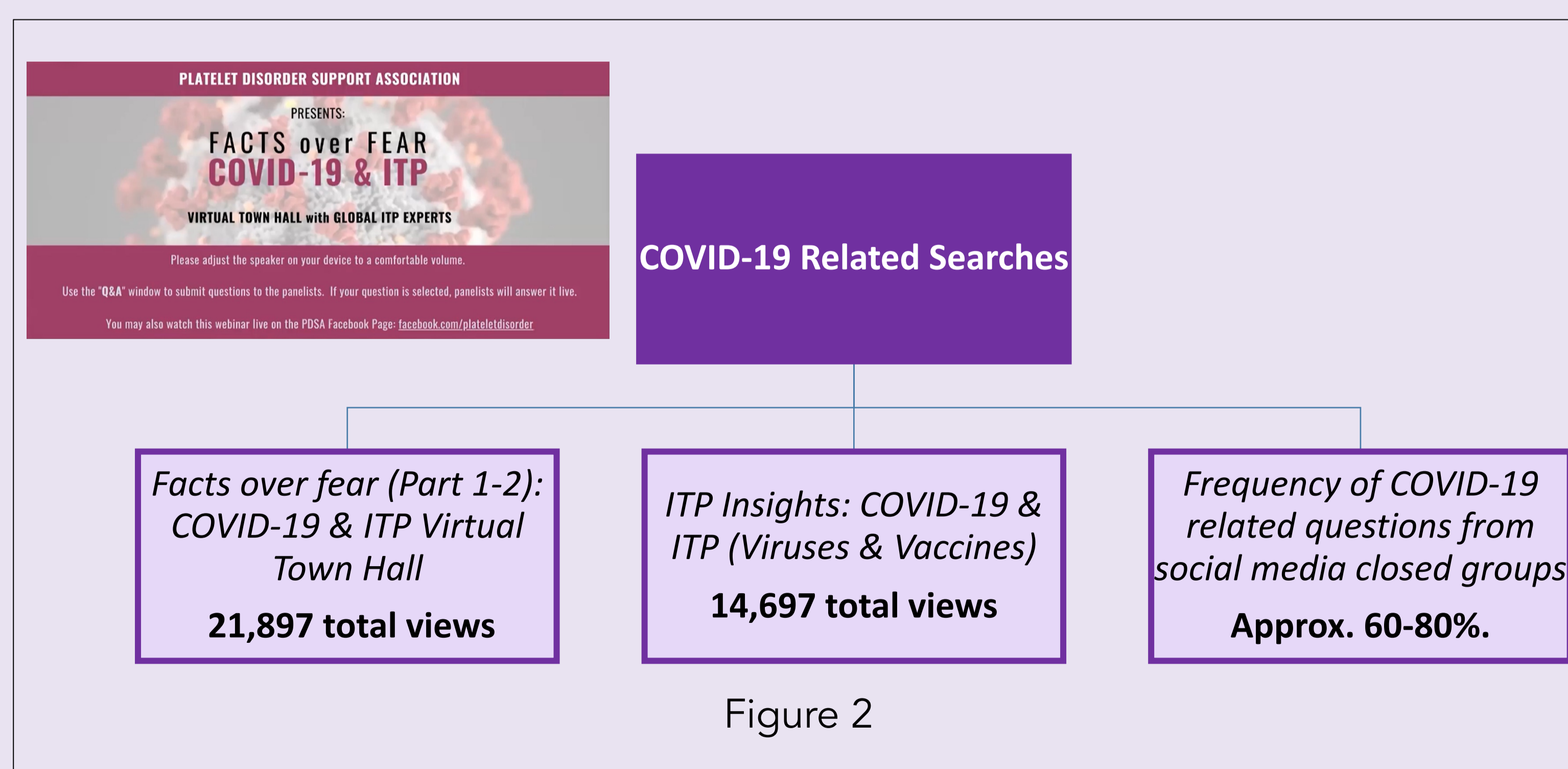


Figure 2

The survey's results have increased patient support and confidence in global vaccination efforts and a greater understanding of the pathogenesis of thrombocytopenia complications following COVID-19 infection and vaccination. This is evident from the patient feedback we have received from our constituents (Figure 3).



Figure 3

Conclusions

In a time of uncertainty, both globally and personally, it is important to utilize patient-reported data to enhance basic and clinical research. The COVID-19 & ITP survey has been promoted internationally and has enrolled an incredible number of patients in a short period of time.

Results from our survey have been utilized by the scientific community to understand the relationship between thrombocytopenia, viruses and vaccines (pending publication). Our survey results have led to increased patient support and confidence in global vaccination efforts. The survey has also led to a greater understanding of how the SARS-CoV-2 virus and vaccines uniquely impacts individuals with ITP, in addition to enhancing patient education, enhancing health care provider education, and contributing to reduced vaccine hesitancy.

Positive patient feedback, research opportunities, and the use of PDSA's COVID-19 educational resources on a global scale illustrate the current priorities of our patient community, in addition to the growing number of COVID-19 & ITP survey participants as allowed for the capture of timely and targeted patient experiences that help others living with ITP.

References

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