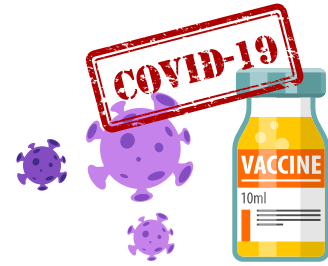


COVID-19 & ITP RESEARCH SURVEY



Have you been diagnosed with ITP

AND tested positive for COVID-19 OR been FULLY VACCINATED?

SHARE YOUR EXPERIENCE!

WHY PARTICIPATE?

These experiences can help us understand if these COVID-19 agents affect platelet counts and bleeding events, **to determine if ITP patients have unique risks for adverse events.**

WHAT IS THE ITP NATURAL HISTORY STUDY REGISTRY?

The ITP Natural History Study Registry is **an international patient-consented registry of individuals with ITP.**

HOW IS THE DATA COLLECTED?

Data is collected **through a secure web-based system** developed and overseen by the National Organization for Rare Disorders (NORD), a committee of leading hematologists, ITP patients and caregivers, and is administered by PDSA.

IS MY IDENTITY AND PERSONAL INFORMATION SAFE?

Yes, **your identity will be protected in this confidential HIPAA (Health Insurance Portability and Accountability Act) compliant registry**, following strict government guidelines to assure patient information is secure.

IS THERE A COST TO PARTICIPATE?

Participation is free, voluntary, and participants may withdraw at any time.

HOW LONG DOES ENROLLMENT TAKE?

It takes **10-15 minutes to enroll** and complete the COVID-19 & ITP Survey.

TECHNICAL ISSUES, ADDITIONAL QUESTIONS?

Contact PDSA Research Program Manager Jennifer DiRaimo, at jdiraimo@pdsa.org.

A complete list of FAQ's can be found at pdsa.org/covid-19



IT ALL STARTS WITH YOU

Take the first step toward brighter futures for ITP

ENROLL TODAY! pdsa.org/covid-19

Learn more about the ITP Natural History Study Registry 



IT ALL STARTS WITH YOU

Patient-powered registries are changing the landscape of rare disease research. However, the success of a registry is dependent upon community participation. PDSA's ITP Natural History Study Registry Program is a powerful opportunity for individuals with ITP and their family members to contribute **directly** to research. Patients, caregivers or guardians enter information from anywhere in the world and complete surveys about personal disease experiences, making the ITP Registry well-positioned to address knowledge gaps and accelerate the development of discoveries for persons with immune thrombocytopenia so they can live better, stronger and more active lives.

A DYNAMIC PARTICIPANT-DRIVEN RESOURCE

The ITP Natural History Study Registry includes a series of surveys developed per study standards and in collaboration with ITP experts intent on connecting the global community of ITP patients and caregivers. It is through this greater collection of patient-powered data in which we hope to identify a more comprehensive understanding of immune thrombocytopenia and its progression over time, develop improved therapies, establish best practices for patient care, and improve overall quality of life for persons with ITP.

COVID-19 & ITP SURVEY:

Captures: Viral infection, vaccine administration, treatments, and platelet counts

PARTICIPANT PROFILE SURVEY:

Captures: Country, race, insurance, education, and employment

MEDICAL & DIAGNOSTIC DATA SURVEY:

Captures: Diagnostic tests, clinical visits, family history, bleeding history, medical history, and pregnancy/childbirth

TREATMENT & REVIEW OF SYSTEMS SURVEY:

Captures: Types of medications and frequencies/dosage, diet, and surgeries

QUALITY OF LIFE ADULT OR PEDIATRIC SURVEY:

Captures: Enjoyment of life, fatigue, sleep, pain, social activities, mental health, physical health, PTSD symptoms, and financial impact

CAREGIVER SURVEY: *(new in 2021)*

Captures: Enjoyment of life, fatigue, sleep, pain, social activities, mental health, physical health, PTSD symptoms, and financial impact

Total
Participants

1,367

Launch
Date

02/28/17

Total Countries
Represented

23



Take the first step toward brighter futures for ITP
ENROLL TODAY! pdsa.org/covid-19

Participation is free, voluntary, and participants may withdraw at any time.

Learn more about the [COVID-19 & ITP Research Survey](#)

