



THE ITP NATURAL HISTORY PATIENT STUDY REGISTRY:

PRELIMINARY RESULTS FROM THE IMMUNE THROMBOCYTOPENIA (ITP)
COMMUNITY

ALEXANDRA KRUSE

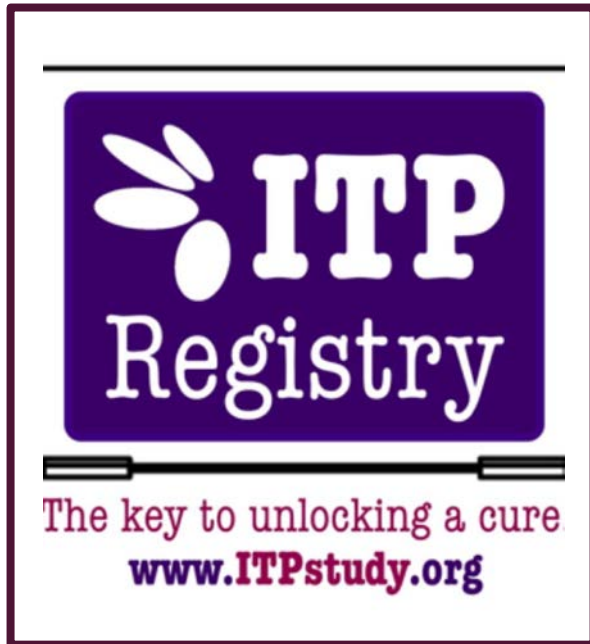
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REGISTRY OBJECTIVES



- Collect data on the natural progression of ITP
- Comprehensively understand ITP and its progression over time
- Characterize and describe the ITP population as a whole
- Assist the ITP community with the development of recommendations for standards of care
- Assist researchers studying the pathophysiology of ITP and interventional outcomes
- Support the design of clinical trials for new treatments

This preliminary analysis seeks to provide an abridged overview of registry findings.

SURVEY METHODS

Adults: 172 questions across 5 surveys

Children: 141 questions across 4 surveys

Enrollment	843
Consented	742
Adults	668
Children	74
Surveys	
Participant Profile	473
Treatment and Review of Systems	329
Medical and Diagnostic Data	378
Quality of Life	
Adult 1	265
Adult 2	251
Pediatrics	38
All Surveys Completed	307

DEMOGRAPHICS

90.3%
Caucasian

76.4%
Female

86.5%
American

9 of 378
patients were
diagnosed with
an additional
disorder

38 years
Average age of
participants

12 ½ years
Average
duration of
disease

20 countries
represented

Range:
1-100 years

Range:
0-69 years

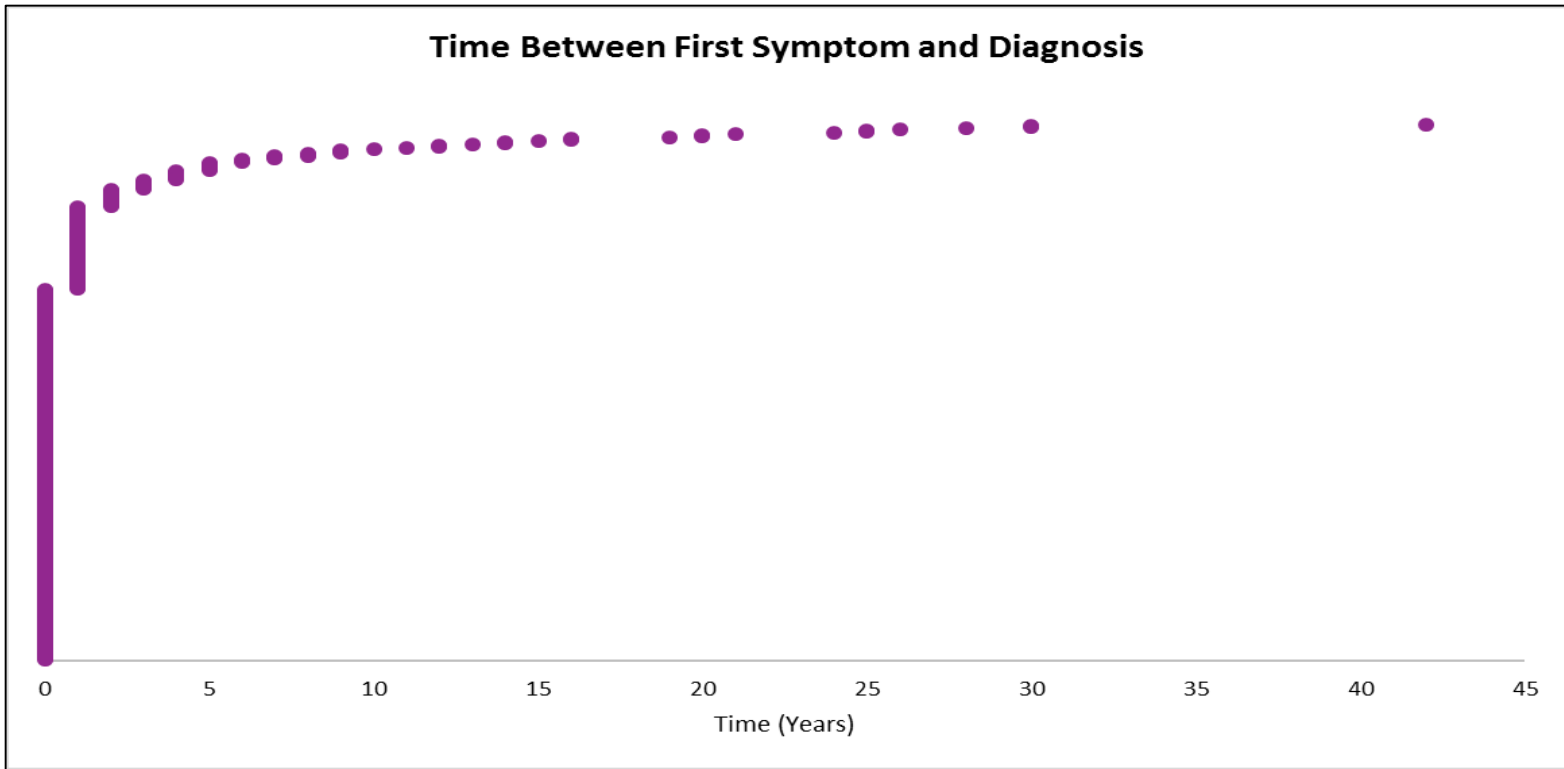


Figure 1. A majority of patients were diagnosed within a year of first presenting with symptoms ($n=328$). 30.7% waited over a year for their official diagnosis ($n=145$; range 1-42 years). ($n=473$).

- 86.6% steroids
- 41.6% IVIG
- 36.8% TPO
- 31.9% rituximab

23.7% Splenectomy

54.7% supplements

12% “special diet”

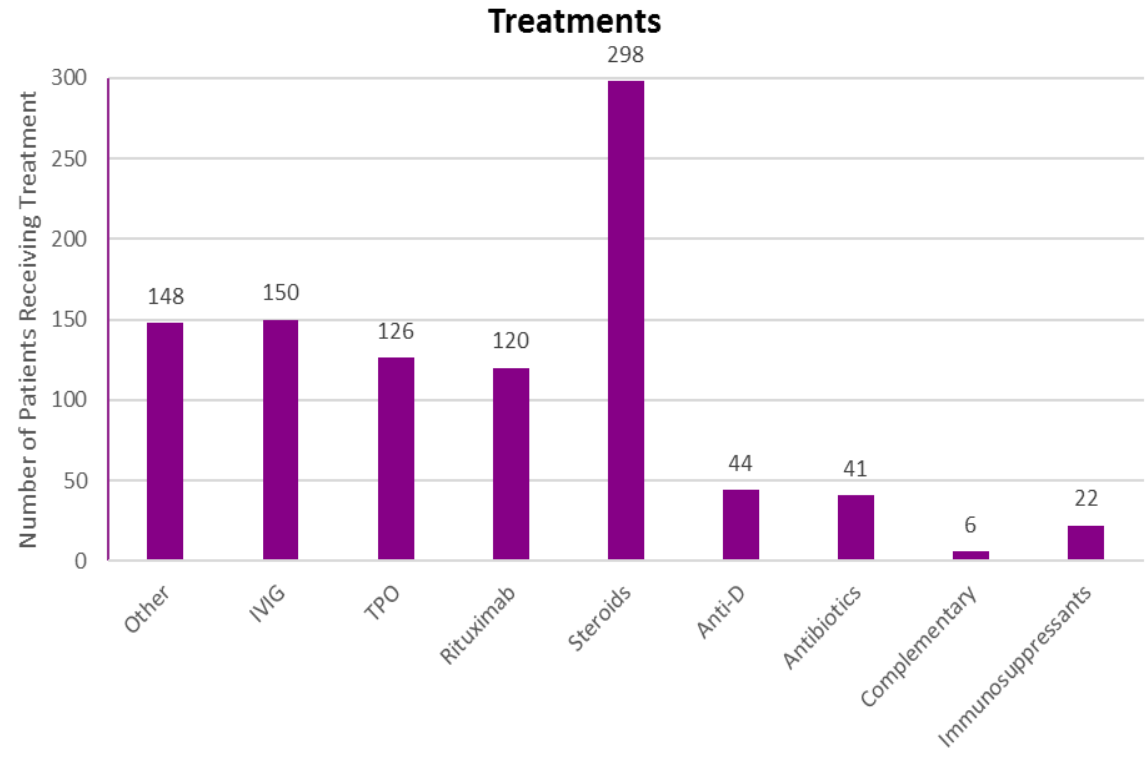
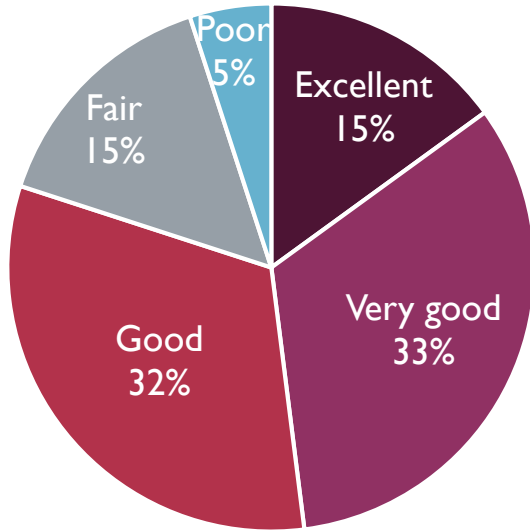


Figure 2. Treatments (n=955) received by patients (n=304) over their current duration of ITP. 25 patients did not receive any therapy.

QUALITY OF LIFE: ADULTS

Overall Quality of Life

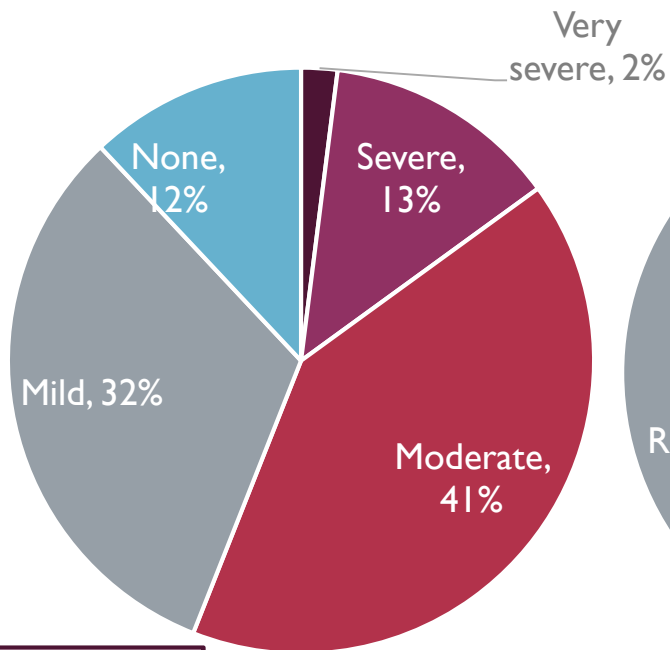


- 65% “good/very good” physical health
- 62% “good/very good” mental health
- 90% pain interferes with QoL
- 88% experienced fatigue that week due to ITP

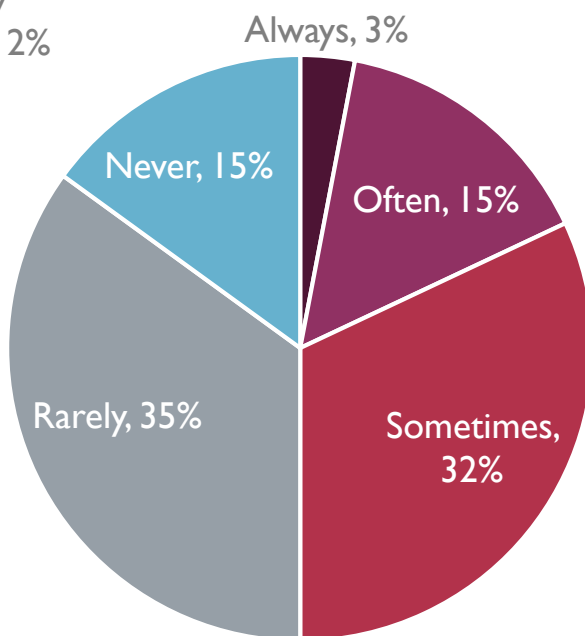
The impact of ITP on an adult patient's health-related quality of life (n=265)

QUALITY OF LIFE: ADULTS

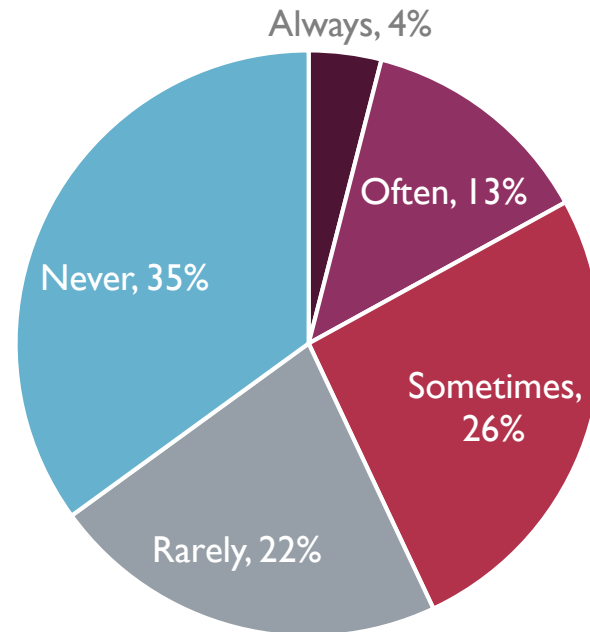
FATIGUE



DEPRESSION



ANXIETY



n=265

QUALITY OF LIFE: PEDIATRIC

84% = Good/Very Good Overall QoL

- 63% = bothered by emotional problems
- 76% = feels nervous about ITP
- 84% = feels sad about ITP

- 71% = tired from ITP
- 39% = experienced pain from ITP in last week
- 7/ 38 children could no longer participate in their favorite activities

n = 38 children

**OVERCOME
THROUGH
SHARING
& RESEARCH**

NEXT STEPS

Continuing to build data set

Examining concurrent medications, patient feelings and responses regarding each treatment, and treatment efficacy and toxicity could guide shifts clinical decision making

Examine differences in disease experience across sub-populations

Comparison between acute, chronic, and patients in remission

Additional surveys in relevant topics

Data access protocol