

2ND

meeting of the European Research Consortium on ITP

NEW INSIGHTS INTO IMMUNE
THROMBOCYTOPENIA

Paris Crowne Plaza Paris République

April 23-24, 2026

Quality of Life in ITP

Dr Alice Hart

Imperial College Healthcare NHS Trust

Imperial College London



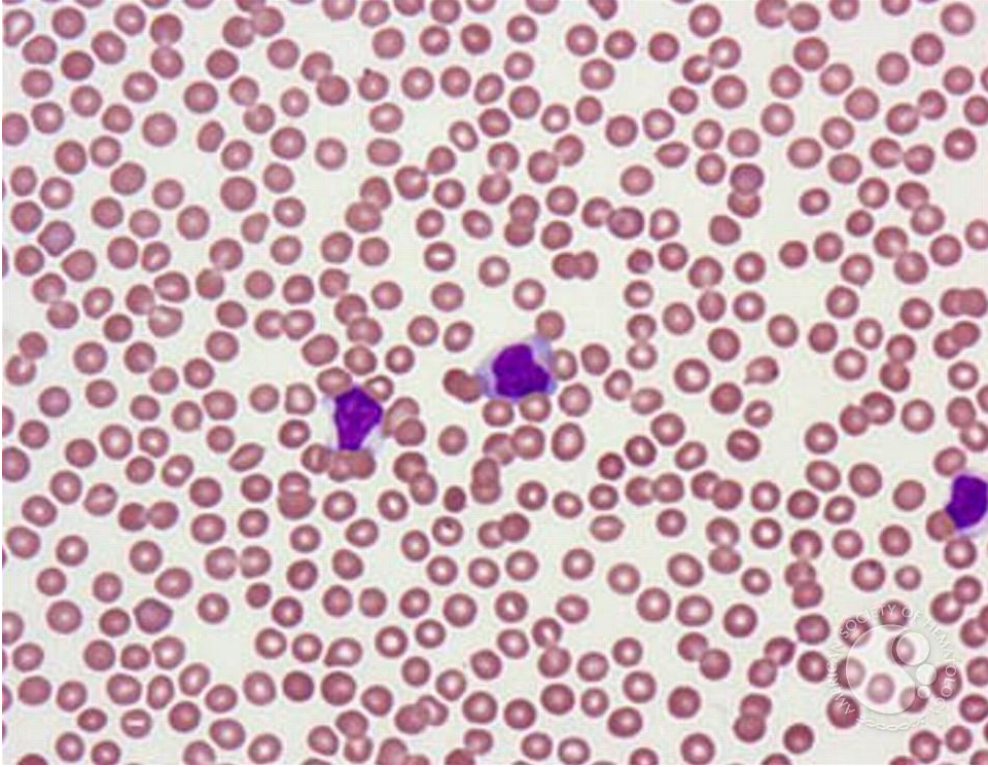
FUNDED BY

Disclosures of Alice Hart

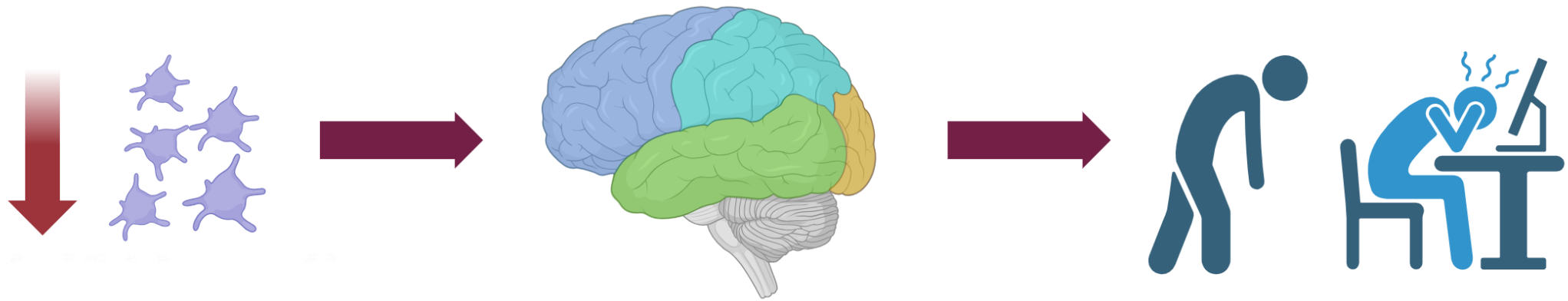
Company name	Research support	Employee	Consultant	Stockholder	Speakers bureau	Advisory board	Other
Sobi					X		
Novartis					X		



Immune Thrombocytopenia



Images courtesy of Prof Nichola Cooper, MDEdge and Dr P. Marazzi/science photo library



Is ITP just a 'low platelet disease'?



ITP Impacts on QoL



- Chronic diseases affect HRQoL
- ITP-specific stressors:
 - fear of unexpected bleeding episodes
 - activity restrictions to avoid trauma
 - anxiety about unpredictable response to therapies
- a state of hypervigilance
- All lead to a distinct chronic stress model
- Heightens anxiety states

ITP World Impact Survey (IWISh)

Am J Hematol. 2020 Dec 19;96(2):199–207. doi: [10.1002/ajh.26036](https://doi.org/10.1002/ajh.26036)

Cooper et al.

- International study of 1507 patients and 472 physicians
- From 13 countries (Canada, China, Colombia, Egypt, France, Germany, India, Italy, Japan, Spain, Turkey, UK, and US)
- >50 questions

(B) Most frequently selected treatment goals

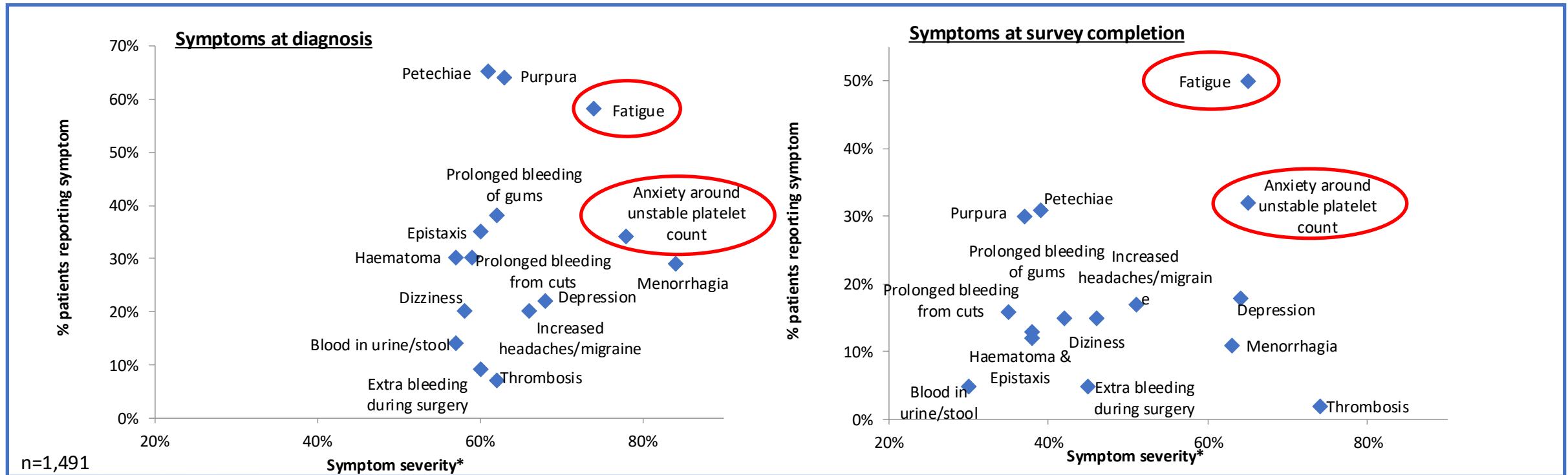


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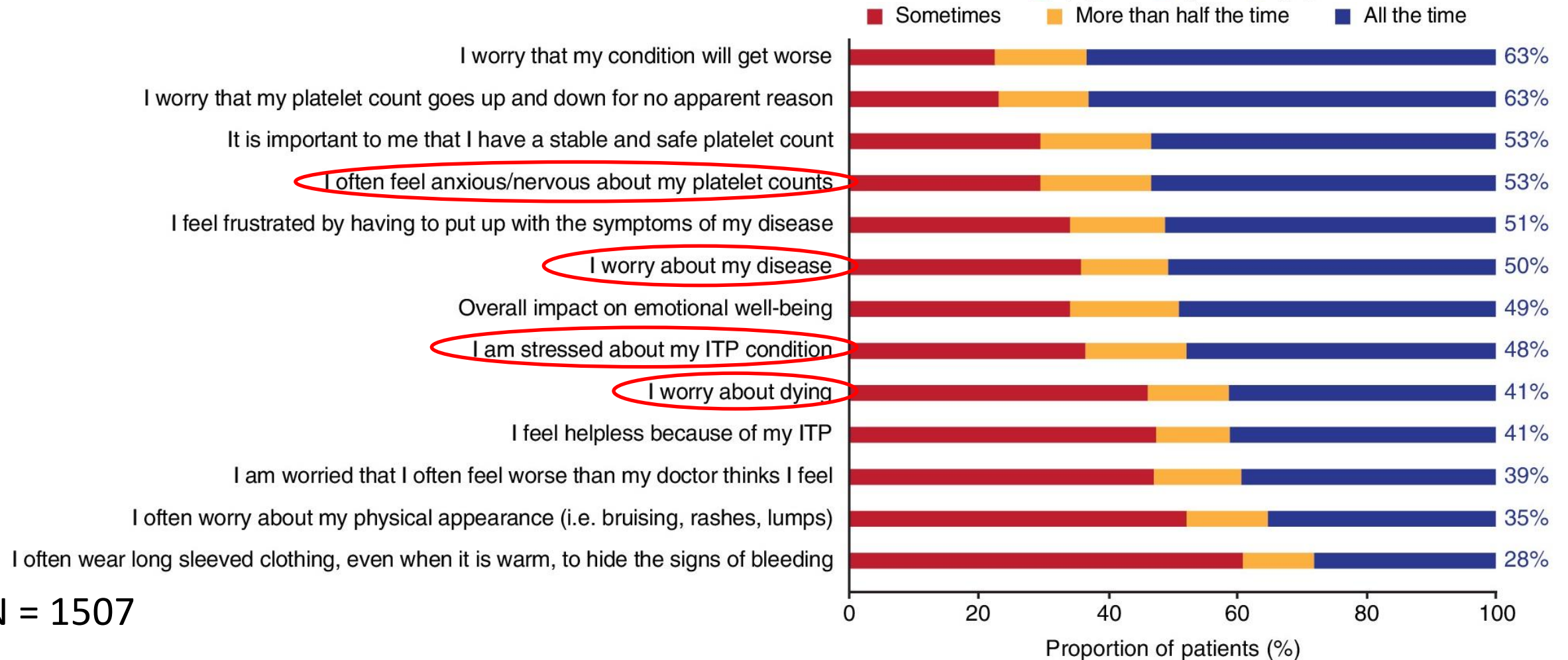
- Fatigue key symptom in frequency and severity (both at diagnosis and survey completion)
- Other key symptoms: petechiae, purpura and anxiety around a stable platelet count



ITP World Impact Survey (IWISh)

Am J Hematol. 2020 Dec 19;96(2):199–207. doi: [10.1002/ajh.26036](https://doi.org/10.1002/ajh.26036)

Cooper et al.



N = 1507

Self-reported health-related quality of life in adults with chronic immune thrombocytopenic purpura

Multicenter Study > Am J Hematol. 2008 Feb;83(2):150-4. doi: 10.1002/ajh.20992.

McMillan et al.



- 73 adult patients with chronic ITP
- Short-Form 36 questionnaire to evaluate HRQoL
- Compared with general U.S. population and patients with 6 other medical disorders
- HRQoL of adult patients with ITP is significantly worse than that of the general U.S. population.
- HRQoL worse than patients with:
 - hypertension
 - arthritis
 - cancer
- Similar to patients with diabetes
- Better than patients with congestive heart failure or a missing/paralysed limb

Air pollution, residential greenspace, and the risk of incident immune thrombocytopenic purpura: a prospective cohort study of 356,482 participants



► *Haematologica*. 2024 Dec 5;110(5):1141–1149. doi: [10.3324/haematol.2024.286328](https://doi.org/10.3324/haematol.2024.286328) [↗](#)

Luo et al.

- Emerging epidemiological studies: long-term exposure to air pollution implicated in RA, COPD, MS and IBD
- Particles/chemicals such as PM_{2.5}, PM₁₀, NO₂, and No_x cause:
 1. Oxidative stress
 2. Inflammation
 3. Disruption of immune regulatory pathways
- Greenspace within 300m and 1000m buffer assessed
- UK Biobank data: 356,482 participants free of ITP at baseline

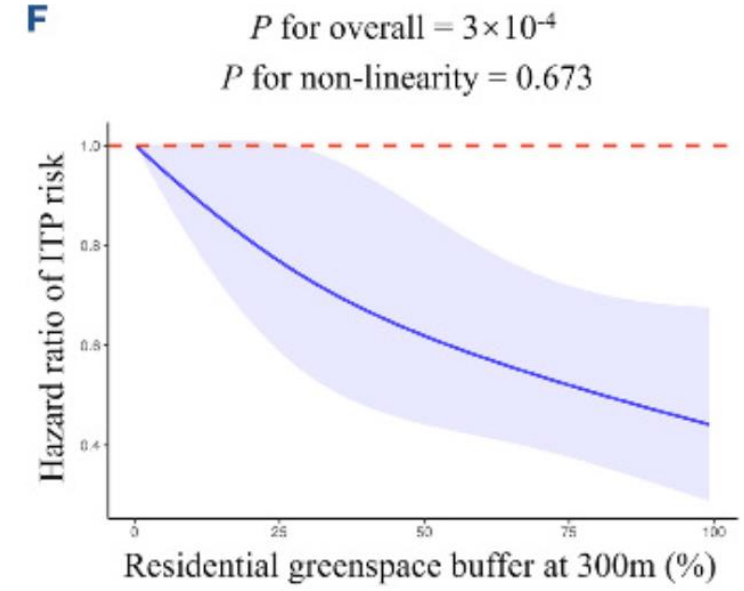
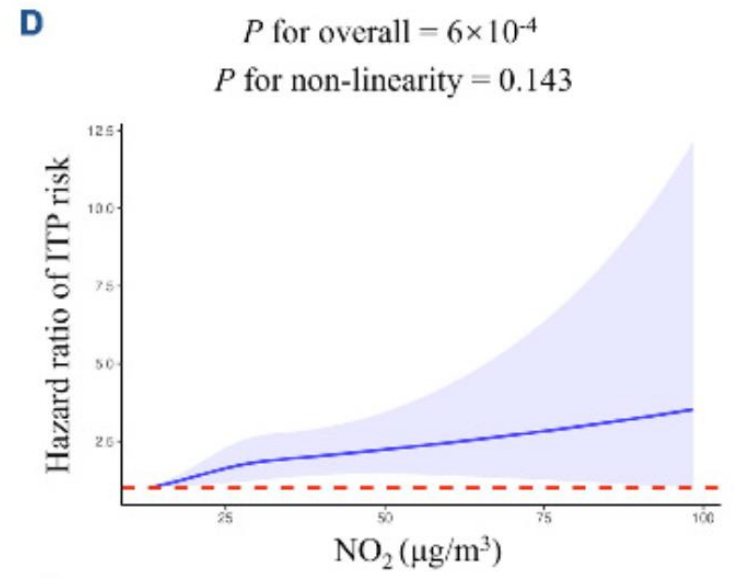


Air pollution, residential greenspace, and the risk of incident immune thrombocytopenic purpura: a prospective cohort study of 356,482 participants

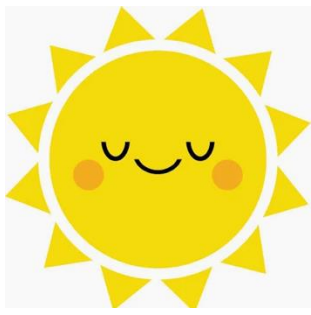
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Luo et al.

- Median follow-up time of 13.54 years:
 - 500 new-onset cases of ITP
- Long-term exposure to high ambient concentrations of PM_{2.5}, PM₁₀, NO₂, and No_x increased risk of ITP
- Lower residential greenspace increased risk of ITP
- The model adjusted for age, sex, ethnicity, BMI, education level, household income, smoking status, alcohol status, physical activity



Immunomodulatory Mechanisms and Therapeutic Potential of Vitamin D in Immune Thrombocytopenia



► [J Immunol Res. 2025 Dec 6;2025:5810208. doi: 10.1155/jimr/5810208](#) ↗

Ma et al.

- Liang et al. clinical data from 160 paediatric ITP patients, univariate and multivariate regression analyses,
 - Lower initial platelet count and higher vitamin D were correlates of remission rates
- Cekerevac et al. retrospectively analysed 152 children with chronic ITP in Serbia
 - only 3 patients had sufficient serum Vitamin D levels

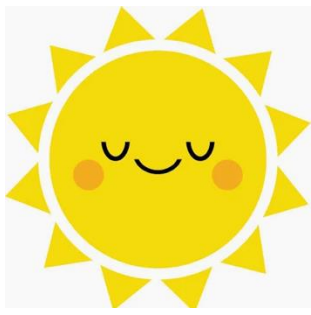


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Immunomodulatory Mechanisms and Therapeutic Potential of Vitamin D in Immune Thrombocytopenia



► [J Immunol Res. 2025 Dec 6;2025:5810208. doi: 10.1155/jimr/5810208](#) [↗](#)

Ma et al.

- Petrovic et al. 45 paediatric patients with newly diagnosed ITP from Croatia assessed bleeding severity
 - lower Vitamin D levels associated with higher SMOG bleeding scores
- Fattizzo et al. 103 adult patients with autoimmune cytopenias, inc. AIHA, Evans syndrome, chronic neutropenia and ITP, compared with 40 healthy controls
 - mean Vitamin D levels were lower in ITP patients vs controls



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Enhancing Immune Thrombocytopenia Education and Support: Insights From a Learning Exchange Program

▶ J Adv Pract Oncol. 2026 Mar 9:1–13. Online ahead of print. doi: [10.6004/jadpro.2026.17.7.7](https://doi.org/10.6004/jadpro.2026.17.7.7) 



Tarantino et al.

- 7 patients, 6 caregivers, and 14 healthcare professionals
- Discussed challenges in chronic ITP management and areas for improvement
- Post-meeting surveys identified shared priorities:
 1. empowering patients to self-advocate
 2. strengthening shared decision-making
 3. improving resources and support
 4. following the evolving treatment landscape
 5. mental health support

Mental Wellbeing

Adult session only

- **Mental Health Integration:** Patients with ITP emphasize the need for mental health support alongside physical treatment, feeling that many doctors focus too heavily on lab numbers rather than overall wellbeing
 - » “It was great to hear [--] say the mental health aspect is so important when treating. My doctor was so ‘by the numbers’ and didn’t really talk to me about how I was feeling or what I was feeling.” [Patient]
- **Access to Counseling:** High-quality counseling for anxiety is often difficult to access; guidelines should highlight the importance of integrating mental health support into ITP care

Influence of Anxiety Level and Degree of Alexithymia on Quality of Life in Adult Patients With Primary Immune Thrombocytopenia



▶ *Actas Esp Psiquiatr.* 2025 Dec 17;53(6):1274–1285. doi: [10.62641/aep.v53i6.2026](https://doi.org/10.62641/aep.v53i6.2026)

Liang et al.

- 148 adult patients with primary ITP
- Hamilton Anxiety Scale (HAMA): 57% (85/148) of patients had anxiety
- ITP-Patient Assessment Questionnaire (ITP-PAQ) to assess QOL

Level of anxiety.

Variables	Score	Negative	May have anxiety	Definitely have anxiety	Significant anxiety
Anxiety ^a	14.31 ± 3.61	2	61	77	8

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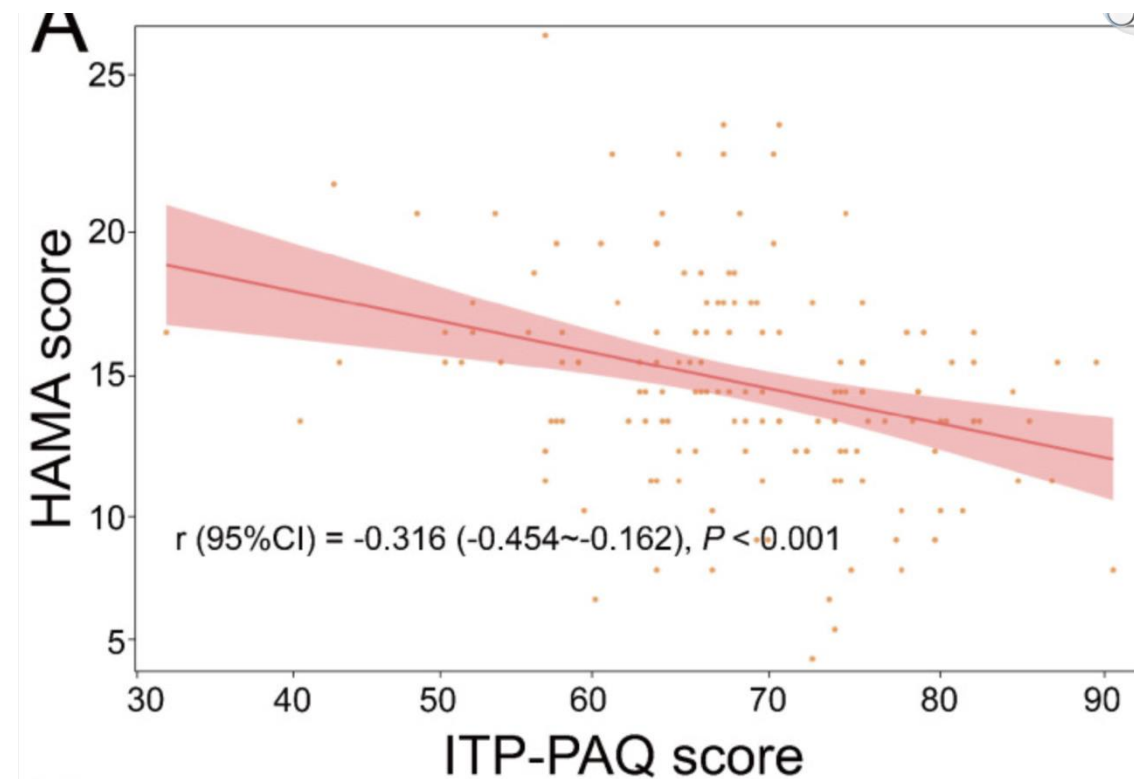
Influence of Anxiety Level and Degree of Alexithymia on Quality of Life in Adult Patients With Primary Immune Thrombocytopenia



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Liang et al.

- Anxiety activates sympathetic nervous system
- Anxiety activates hypothalamic-pituitary axis
- Increases stress hormones
- Higher anxiety score correlated with worse QoL



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Liang et al.

- Toronto Alexithymia Scale-20 (TAS-20)
- Presence of alexithymia negatively impacts QoL (worse ITP-PAQ score)
- ‘Emotional blindness’
- Impacts interpersonal relationships and ability to develop coping

St[†] Level of alexithymia.

Variables	Score	No Alexithymia	Low Alexithymia	High Alexithymia
Alexithymia ^a	56.11 ± 8.41	42	59	47

What about fatigue?



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Definitions of Fatigue

NIH NATIONAL CANCER INSTITUTE

fatigue

 (fuh-TEEG)

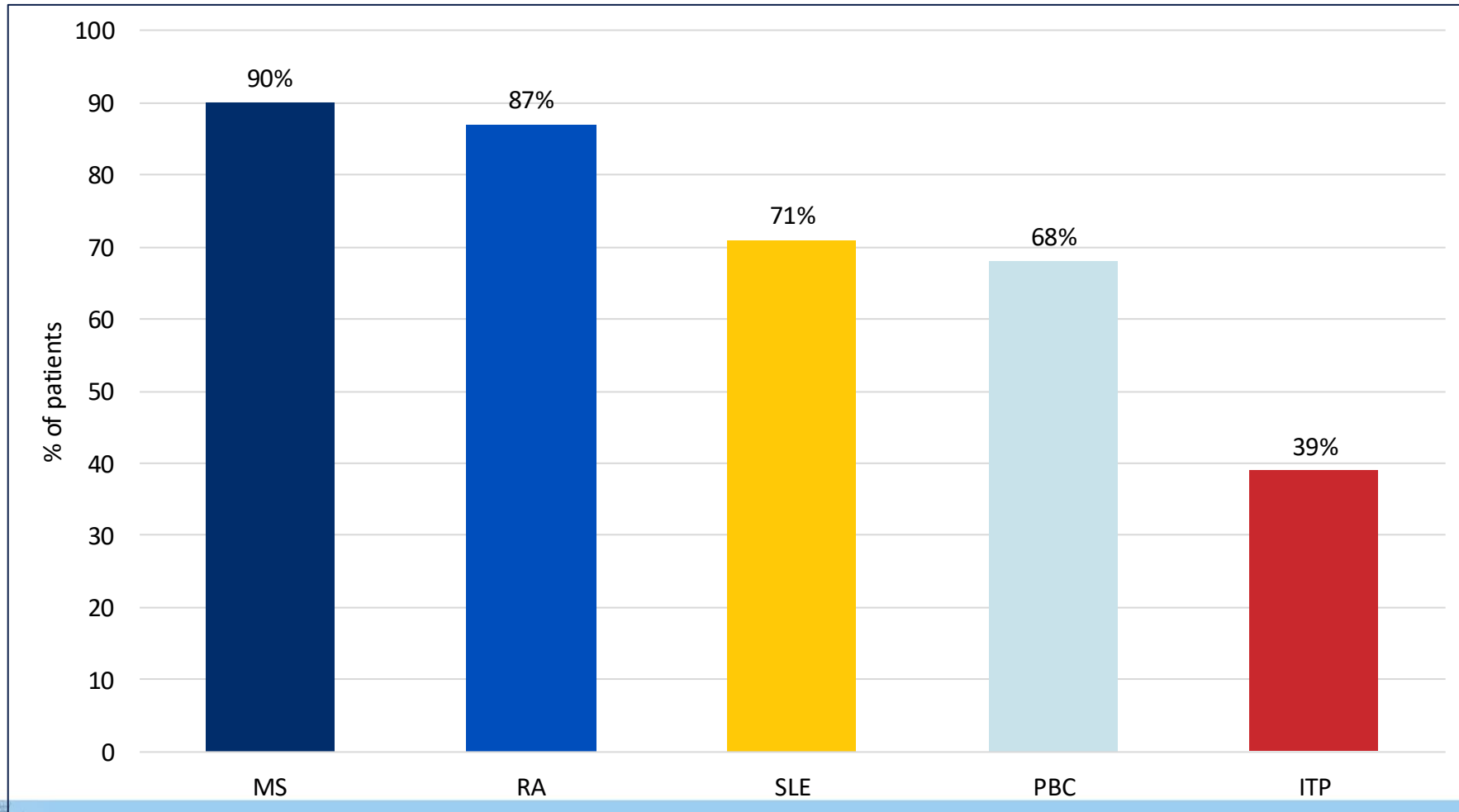
An extreme sense of tiredness and lack of energy that can interfere with a person's usual daily activities. A person with fatigue may feel weak, worn out, heavy, slow, or run down. They may also have trouble speaking or concentrating, short-term memory loss, and mood or emotional changes. There are many causes of fatigue, including anemia, poor nutrition, pain, anxiety, depression, sleep or

NICE National Institute for
Health and Care Excellence

Tiredness/fatigue in adults:

- There is no universal definition of tiredness/fatigue, and its experience and perception are subjective.
 - Fatigue may be defined as severe mental and physical exhaustion, which differs from somnolence or lack of motivation, and which is not attributable to exertion or diagnosable disease.

Fatigue in Autoimmune Disorders



Sources:

1. Zielinski et al, 2019
2. Huyser et al, 1998
3. Schmeding et al, 2013
4. Cauch-Dudek et al, 1998
5. Newton et al, 2011



Fatigue in ITP

- 14/23 patient (Mathias, et al. 2008)
- 39%, n=585 (Newton, et al. 2011)
- 6/10 paediatric patients (Blatt, et al. 2010)
- IWISh: fatigue=top priority symptom 46% (Cooper, et al. 2020)



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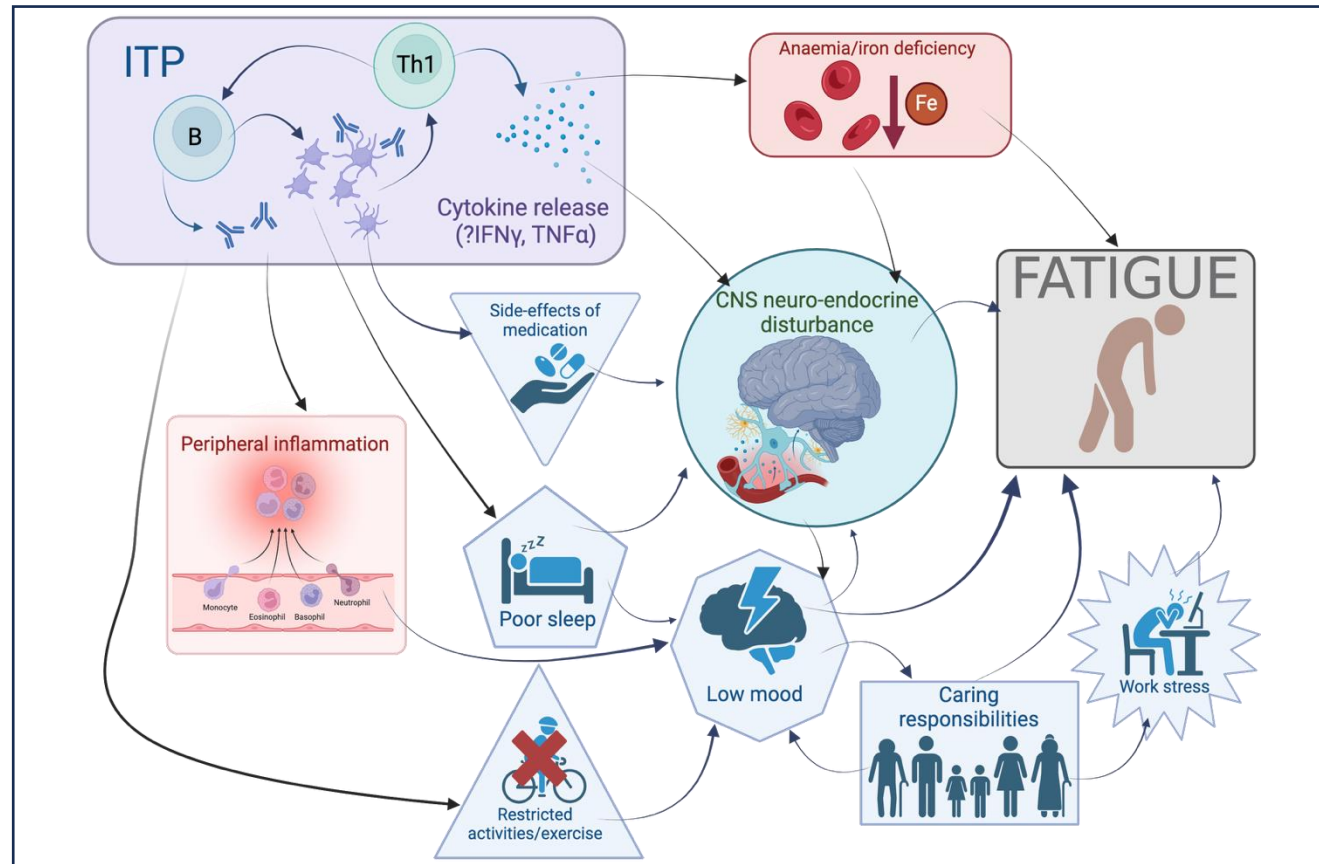
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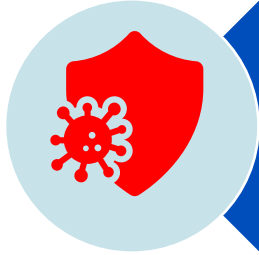
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Possible Mechanisms of Fatigue in ITP



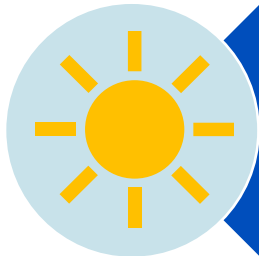
(Adapted from Hill and Newland, 2015. Created in Biorender.com)

Medical Factors



Side effects of treatment

- Steroids/immunosuppression

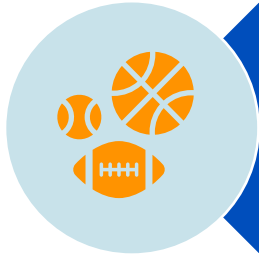


Vitamin D deficiency



Iron deficiency

Social and Emotional Factors



Restrictions on participation in sport



Time spent at the hospital



Effect on mood



What about cognition in ITP?



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311.DISORDERS OF PLATELET NUMBER OR FUNCTION: CLINICAL AND EPIDEMIOLOGICAL | NOVEMBER 15, 2022

Cognitive Impairment Among Patients with Chronic Immune Thrombocytopenia

David J. Kuter, Umer Khan, Paul Maruff, Chris Edgar, Jason Cromer, Gabe Stellman, Lydia King, Kathie Markowski, Ahmed Daak

- Phase 1/2 Adult LUNA 2 study
- Primary/secondary persistent or chronic ITP
- Platelet counts $<30 \times 10^9/L$ on two occasions
- Responded to ≥ 1 prior ITP therapy but unable to maintain adequate response to most recent ITP treatment
- Cognitive and clinical data
- Cogstate™ cognitive testing

Kuter et al. Br J Haematol, First published: 09 May 2024, DOI: (10.1111/bjh.19495)



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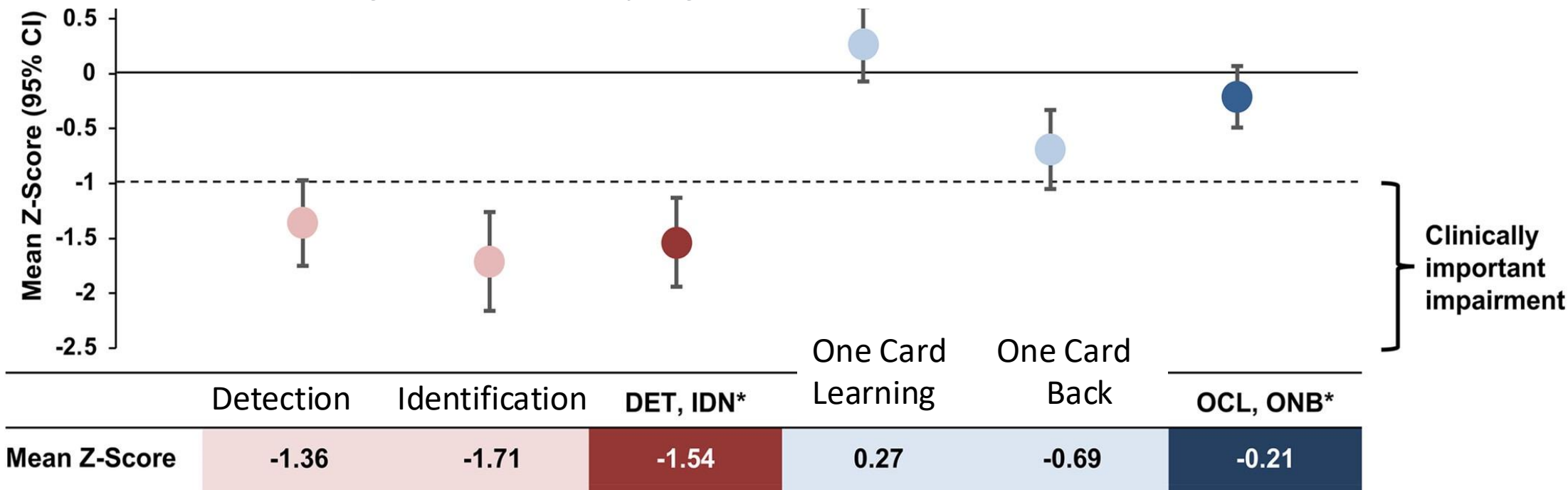


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N=49

- Psychomotor and attention impairment

Kuter et al. Br J Haematol, First published: 09 May 2024, DOI: (10.1111/bjh.19495)

BTK Inhibitor Study



- Similar levels of impairment as give rise to a diagnosis of mild cognitive impairment in neurological disorders
- Impairments of this magnitude:
 - difficulties in employment, education, home/family life

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What about children and adolescents?



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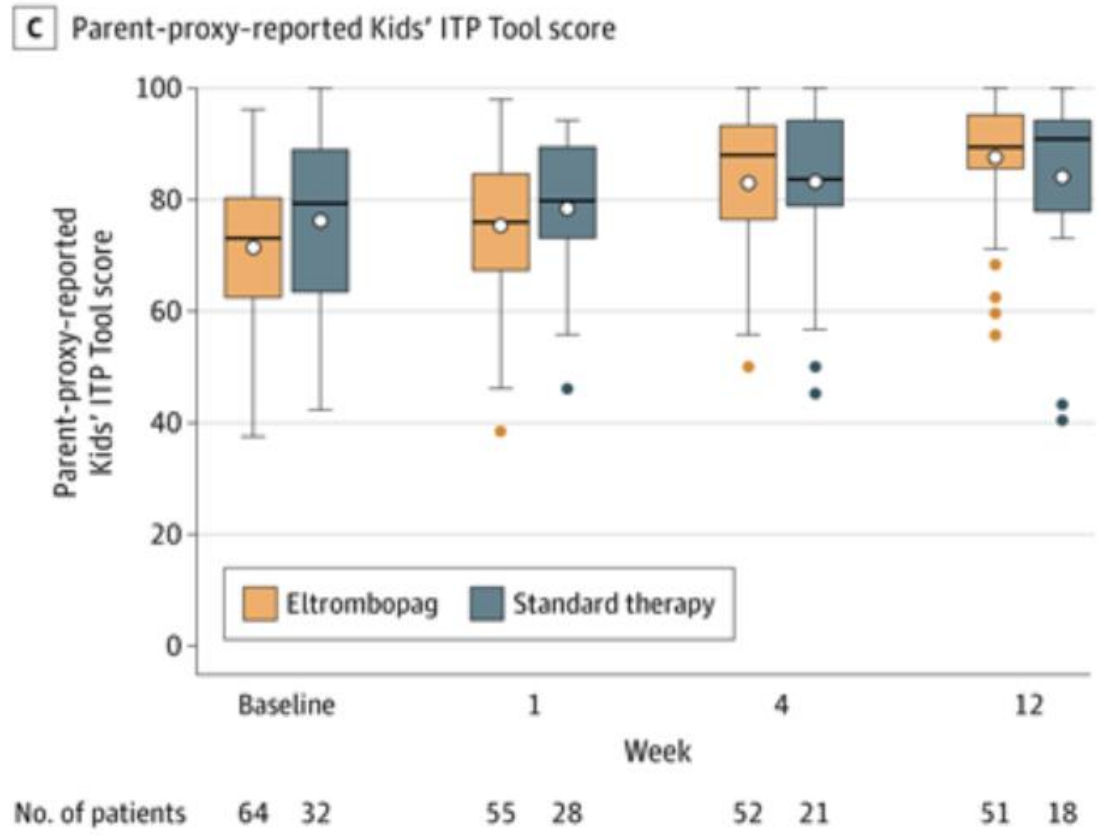
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Eltrombopag for Newly Diagnosed Pediatric Immune Thrombocytopenia Requiring Treatment

The PINES Randomized Clinical Trial

Home | JAMA | Vol. 334, No. 20
Shimano et al.

- HRQoL measured using KIT tool
- Meaningful improvements in HRQoL in pts on eltrombopag and standard therapy



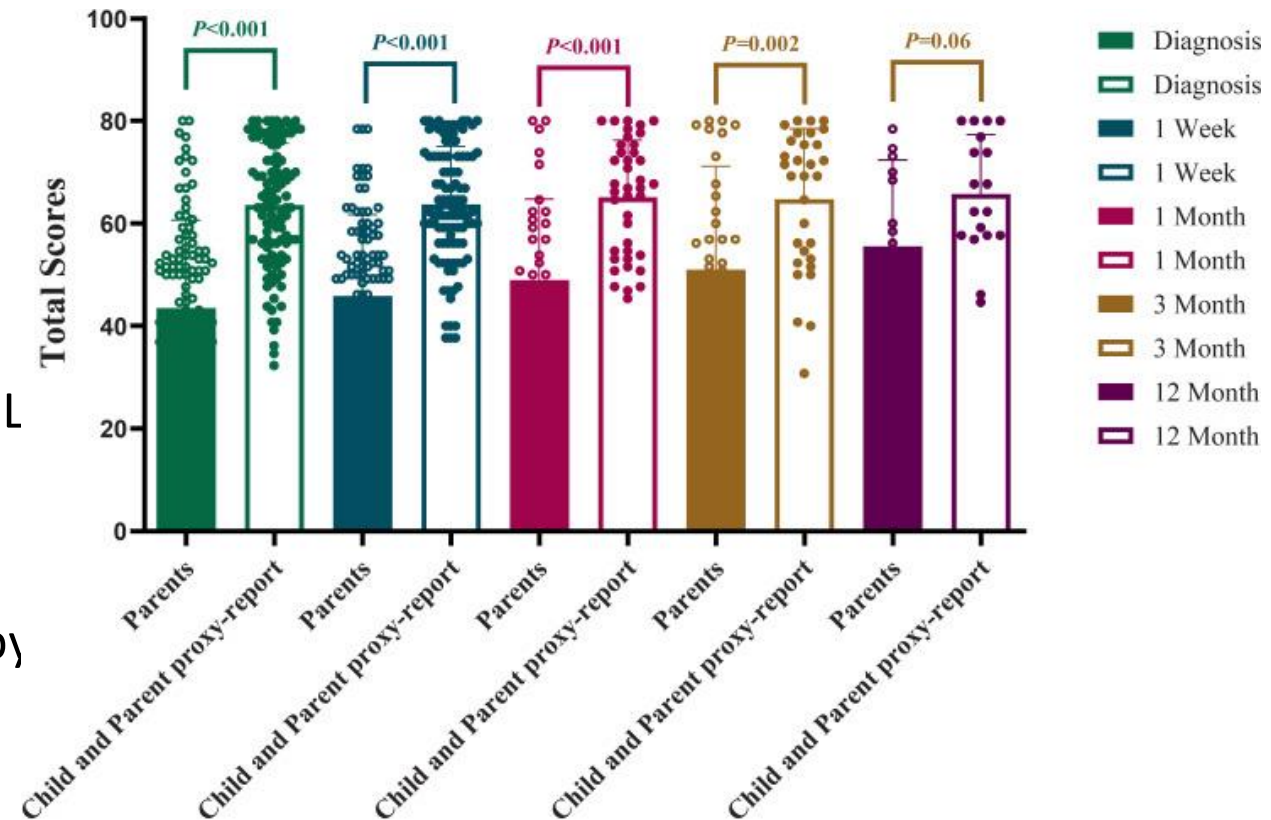
HRQoL in Chinese children with ITP

Multicenter Study > BMJ Paediatr Open. 2026 Apr 1;10(1):e004331.

doi: 10.1136/bmjpo-2025-004331.

Huang et al.

- 303 children with ITP across 9 tertiary centres
- Child self-reported KIT questionnaire ≥ 7 yo, parent-proxy ≤ 7 yo
- Major findings:
 1. significant parent-child discordance in HRQoL
 2. no association between baseline platelet counts and HRQoL
 3. transient HRQoL reductions following bone marrow aspiration and glucocorticoid therapy
 4. age-specific patterns: older children-greater family-related distress, parents of younger children-greater procedural distress



What impact does mood have?



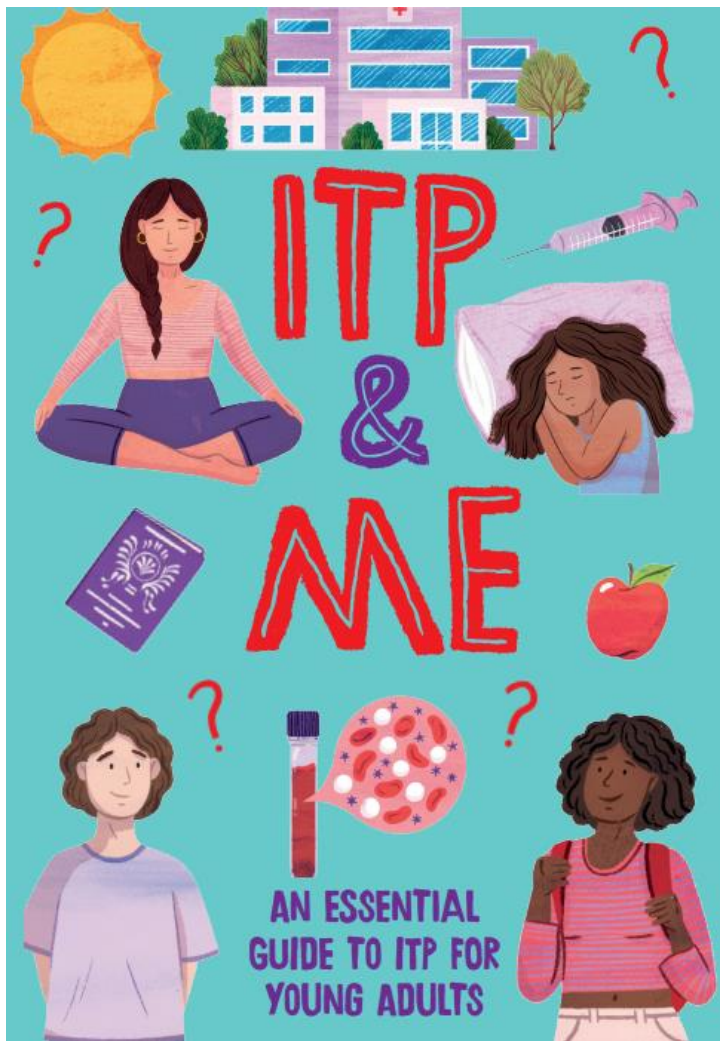
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ITP & ME

Are you a young person who has been diagnosed with **ITP**? Then this book is for **YOU!**

Filled with the real-life experiences of young adults with **ITP**, you'll find everything you need to know about the condition, along with lots of helpful advice. A vital source of support, this book tackles the tough issues and unique challenges that young people face when dealing with a potentially life-changing diagnosis.





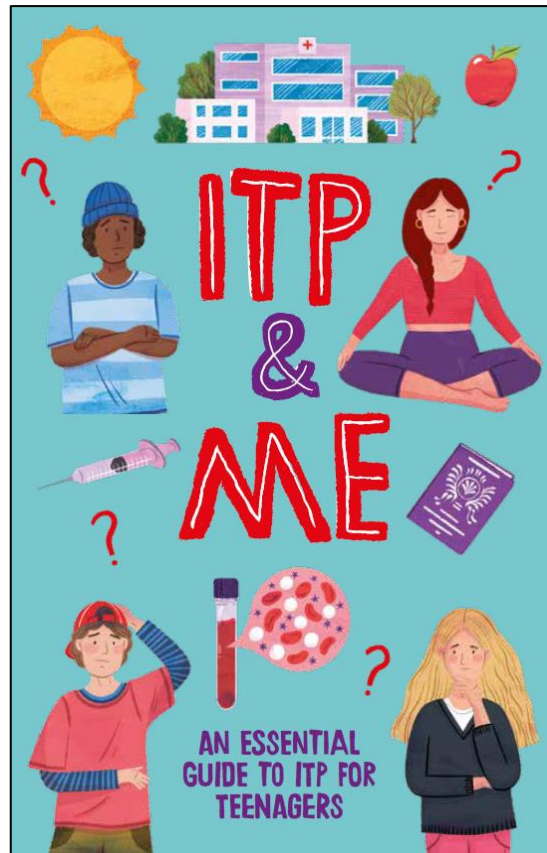
ITP Team Write Book with Teens, for Teens

SCAN ME



Prof Nichola Cooper, Dr Alice Hart and CNS Deena Paul attended a celebration at the House of Commons for 30yrs of the ITP Support Association.

This work came from Dr Alice Hart's PhD findings.



ITP stands for **IMMUNE THROMBOCYTOPENIA**, which isn't the easiest thing to say. But it used to be called *Idiopathic thrombocytopenic purpura* so at least they shortened the name! And from now on we will just call it **ITP**.

I think it's important for those who are just diagnosed to talk to people about it and not panic.

I had so many questions...



The book gives information and encouragement to patients who have significantly reduced quality of life, due to having ITP.

WHAT'S ALL THIS ABOUT PLATELETS?

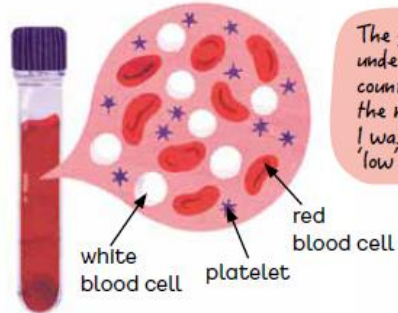
PLATELETS are small sticky cells in your blood whose job is to stop you bleeding. If you cut or injure yourself, your platelets normally clump together to form a seal. This blood clot slows down the flow of blood and eventually stops it completely. But if your platelet count is low, your blood may not clot very well, which means you will bleed for longer than normal. This can be scary – and even a bit embarrassing, especially if you're out and about.



One time I was on a school trip on a coach and had a nosebleed that didn't stop for a while. And I felt really bad for the poor girl sitting next to me!

WHAT IS A PLATELET COUNT?

A PLATELET COUNT is exactly that – the number of platelets that can be counted in your blood. To find out your count, you'll need to have a blood test, after which an electronic machine is used to count the platelets.



The first thing was trying to understand exactly what platelet count meant. That was probably the most confusing thing for me. I wasn't sure exactly what 'low' meant.

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It makes sense that if you feel able to cope with everyday life, you will be able to deal with any effects of ITP treatment much more easily.

WRITE YOUR WORRIES

Spending time and energy worrying about things you cannot control is understandable. However, it is also really tiring, stressful, and can add to your **ANXIETIES** unnecessarily. If you're feeling very anxious, take a piece of paper and write down all the things that are worrying you. Ask yourself for each one: 'Can I do something about this?' Circle those worries as action points for later. Cross out the others. You can't control them or do anything about them – so take a deep breath and **LET THEM GO**.

I worried at first. But after a year and a half I figured that my ITP is unlikely to come back now so what's the point in me constantly worrying about it?

I worry all the time that it might come back. Every time I have a blood test I wonder if my platelets have dropped again. It sounds ridiculous but if I knock myself or any little red dot appears on my skin, I start getting really nervous about it.



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BIG QUESTIONS

Here are the answers to a few more questions that might be on your mind.



I'M SCARED THAT I MIGHT NOT LIVE FOR LONG

There is no evidence to show that people with ITP live shorter lives than anyone else. The only real risk is from a severe haemorrhage (bleed) which is very, very rare. Other lifestyle choices, like smoking regularly, drinking lots of alcohol or being inactive can pose more risk to your long term health than ITP. So now you know!

'I was convinced at one point that I would probably die. Yeah! (Laughs) I think I had very, very low platelets for quite a few weeks, and I was just bleeding constantly. Scary, yeah. But I'm still here!'



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You can download a PDF copy of this book via this link <https://bit.ly/44fwVII> or scan the QR Code below

SCAN ME



If you are an NHS Haematology Unit and would like copies for your patients please email info@itpsupport.org.uk with a contact name and postal address, we will send you some copies.

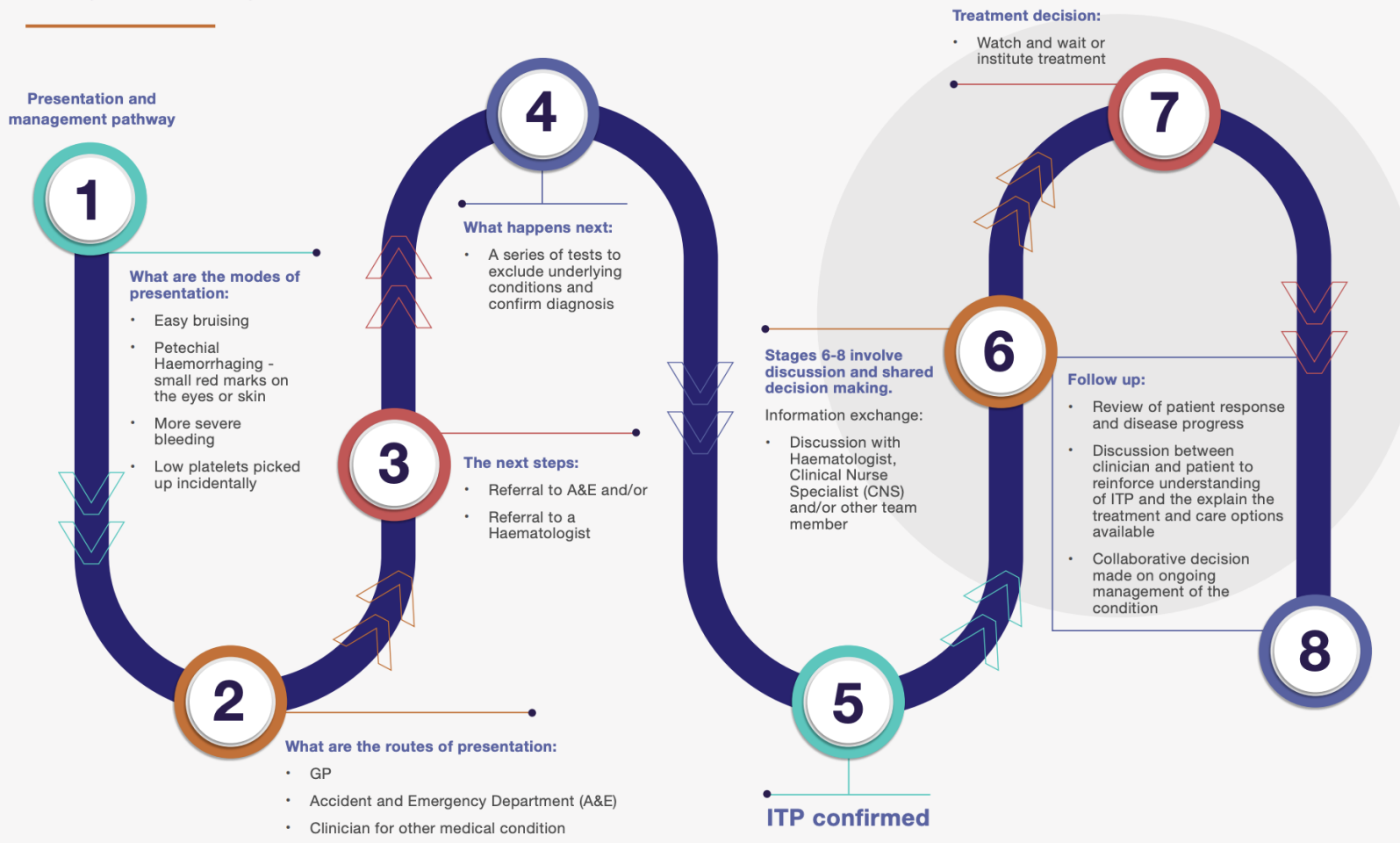
If you are a patient and would like a hard copy, they are free, all we ask is a £3 donation to cover the cost of postage and packing, email us your postal address to info@itpsupport.org.uk and make the donation via our JustGiving page at [Donate – Donation amount – JustGiving](#)

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Best practice in collaborative decision making: step-by-step guide



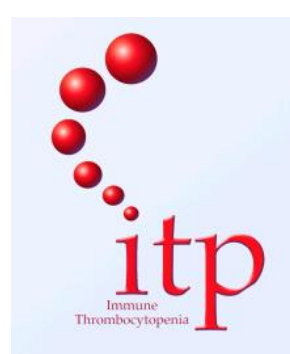
IMPERIAL



HELPING
OUR HOSPITALS
DO MORE



Imperial College Healthcare
NHS Trust



Thank you

Professor Nichola Cooper
Camelia Vladescu
Cooper lab group
Cooper clinical team

NIHR
Imperial Health Charity
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ERCI Committee



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