



PATIENTS' PERSPECTIVE ON

ITP

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DISCLOSURES

Received consultancy fees/honorarium as Advisory board member and speaker for Swedish Orphan Biovitrum AB, Novartis, Sanofi, and Argenx

Barbara Lovrencic

ME



ITP PATIENT



**MOTHER AND
PARTNER**



WORKER



CAREGIVER

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MY CHILDHOOD

Diagnosed with ITP at age of 4.

My mother was told to go home and
prepare for a funeral.

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MY CHILDHOOD



OTHERS



ME

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MY ADULTHOOD

"Life is like a box of chocolates. You never know what you're gonna get."

Forrest Gump

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DILEMMA

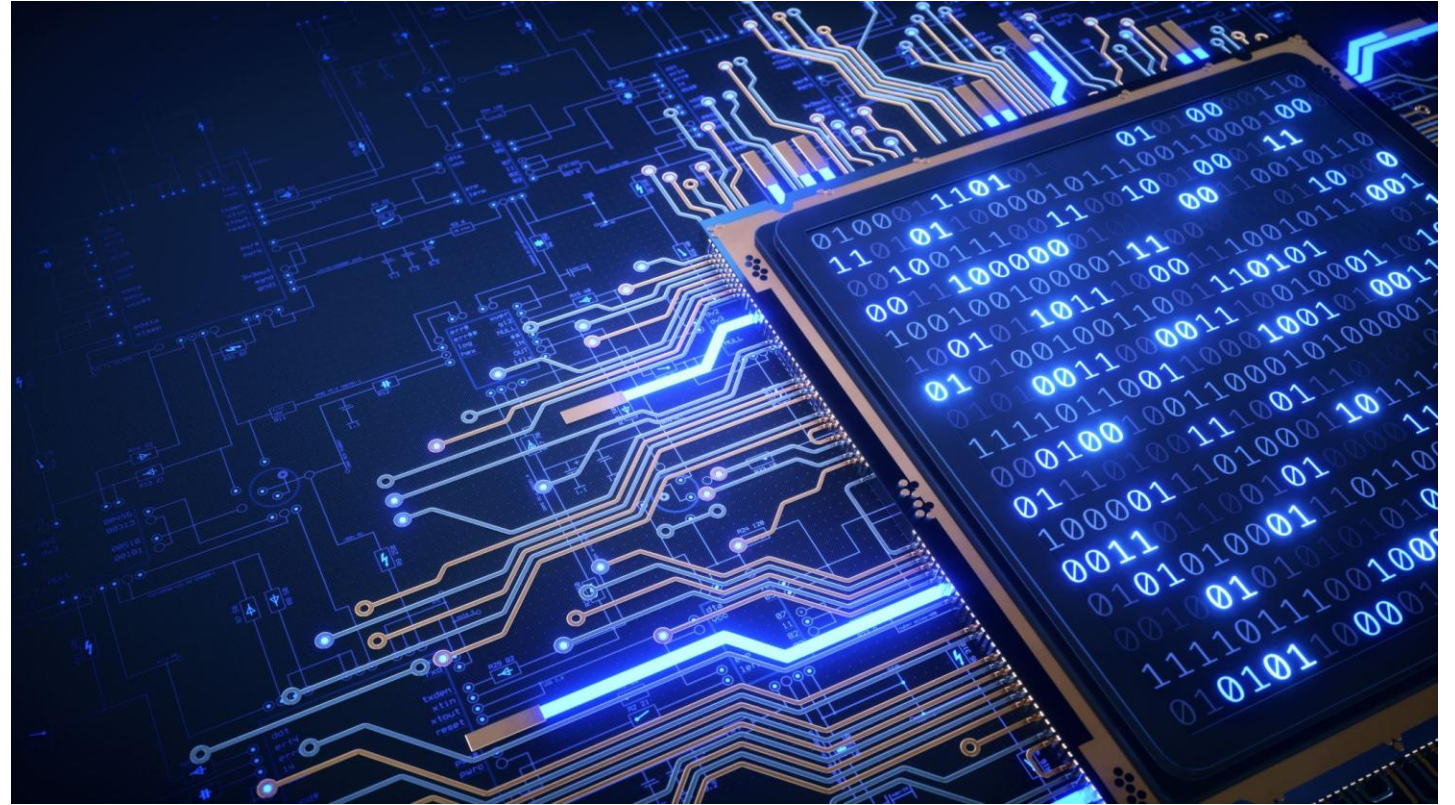
ITP is so complex.
What should I bring to the table?



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ASKED AI

Summary of unmet needs in immune thrombocytopenia (ITP) and patient challenges with current treatments



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AI KEY UNMET NEEDS IN ITP

Lack of durable remission

Up to 70% of patients do not achieve sustained response off treatment. Less than 40% on TPO-RAs, ~20% on rituximab, and $\leq 20\%$ on fostamatinib reach treatment-free remission.

No disease-modifying therapy

Current approved treatments manage symptoms or platelet counts but do not address the underlying immune dysregulation driving ITP.

No reliable predictive biomarkers

There are no validated biological or clinical markers to predict which patients will achieve remission, relapse, or respond to a given therapy — making personalized treatment impossible.

No diagnostic test

ITP remains a diagnosis of exclusion. Around 30–40% of patients lack detectable autoantibodies, complicating diagnosis and mechanistic classification.

Refractory disease

A significant subset of patients fail multiple lines of therapy including splenectomy, rituximab, and TPO-RAs, with limited evidence-based options remaining.

Patient-reported outcomes underweighted

Treating physicians typically prioritize platelet counts over quality of life. Patient experience, fatigue, and cognitive burden are systematically underrepresented in clinical research.

AI PATIENT CHALLENGES WITH CURRENT TREATMENTS

Corticosteroid toxicity First-line corticosteroids cause high relapse on dose reduction. In one study, 66.8% of patients reported adverse effects — fatigue, emotional disturbances, and physical appearance changes — worsening with duration of treatment.	Fatigue & cognitive impairment ~ 50% of ITP patients experience significant fatigue (ITP World Impact Survey). A 2022 study found 50% of patients had cognitive impairment across memory, executive function, processing speed, and attention.	Splenectomy risks & reluctance While splenectomy achieves durable remission in 60–70% of patients, it carries surgical and post-operative bleeding risks, and long-term complications including sepsis and thromboembolic events.	Mental health burden Patients report anxiety from platelet count unpredictability, fear of bleeding, depression, and frustration. Emotional side effects of steroids (insomnia, depression, anger) further compound mental health burden.
Platelet count fluctuation Unstable platelet counts are a major source of patient anxiety and treatment burden, disrupting daily activities, work, and social life regardless of which therapy is used.	Indefinite treatment dependency ITP requires lifelong treatment in a significant proportion of adults. The majority of TPO-RA responders require ongoing therapy — there are no validated criteria for safe discontinuation.	Thromboembolic paradox Despite low platelets, ITP patients face an elevated risk of thromboembolism — partly driven by proinflammatory pathways (NLRP3 inflammasome). This complicates treatment decisions, particularly with TPO-RAs.	Unmet need for shared decision-making Patients want greater involvement in treatment choices and access to educational, psychological, and digital healthcare support — areas largely absent from current clinical care pathways.

WHAT'S MISSING?



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MISSING

- Impact of “Try and error approach” in finding the right therapy and correct dosage
- Treatment side effects (not just steroids)
- Treatment availability
- Loss of response to the treatment
- Lack predictive biomarkers for bleeding risk
- Impact of ITP and its management in psycho/social development in Kids and Teens
- Treatments approved in 2nd 3rd line but data suggest would be more efficient if used earlier
- Pediatric patients have less treatment options compared to adults
- True meaning of fatigue and cognitive impairment in patient lives
- Lack of awareness that ITP impacts entire family
- Comorbidities and drug interactions
- How ITP changes during patients' life
- Fatigue why some yes, others no? How to treat it?

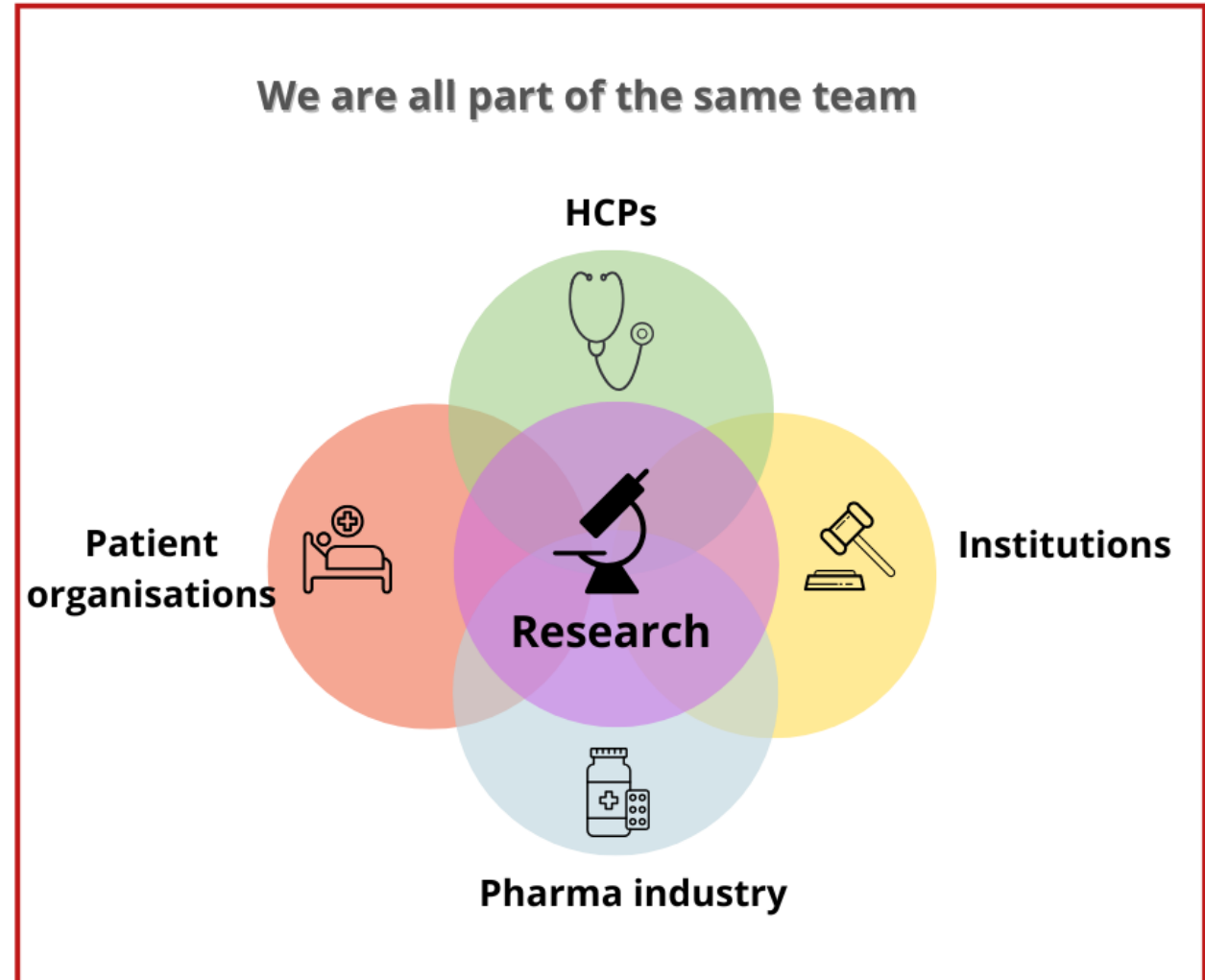
CLINICAL TRIALS CHALLENGES

- Trials are designed without patient input
- No accessible language
- The logistical reality
- The invisible cost
- The cultural shift
- Bureaucracy



TEAMWORK

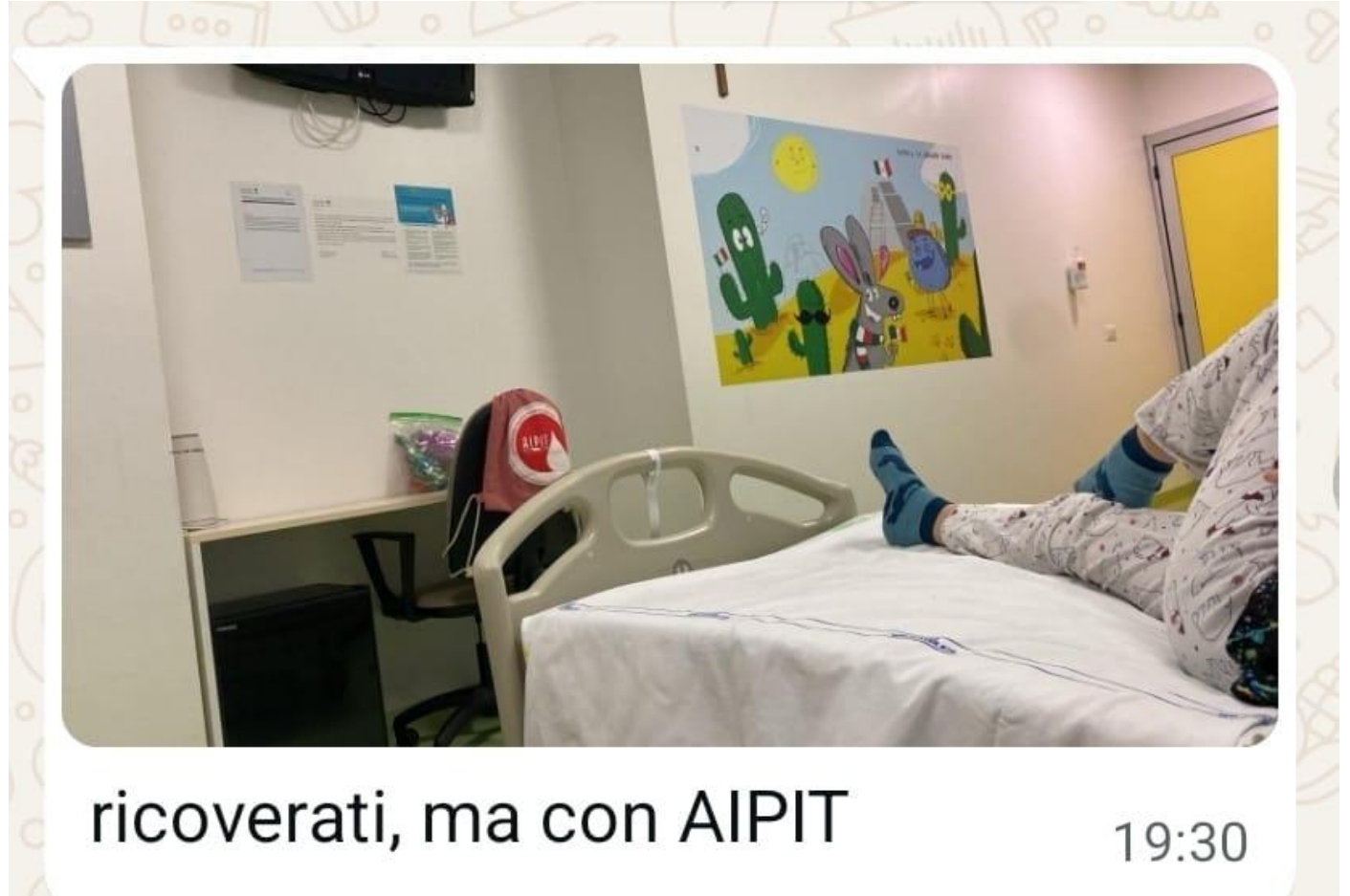
Teamwork is the only way to create meaningful and sustainable solutions that will have a positive impact on patients' quality of life.



PATIENT ORGANISATIONS AS PARTNERS

PAG key activities:

- Advocacy
- Information
- Education
- Support
- Multi stakeholder collaboration
- Scientific research promotion



Barbara Lovrencic

Hospitalised, but with AIPIT

E.M.



"Be the change that you wish to see in the world."

Mahatma Ghandhi



International
ITP Alliance

A global voice for immune
thrombocytopenia

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