



ITP news, patient stories, advice & more...



**'LAST CHANCE
to register for
Convention Tickets'**

The Platelet

JOURNAL OF THE ITP SUPPORT ASSOCIATION

JUNE 2026

The ITP Support Association Team

Charity Registration No. 1064480

THE ITP SUPPORT ASSOCIATION HQ

The Platelet Mission

Kimbolton Road, Bolnhurst,
Beds. MK44 2EL (UK)

Tel: 01234 376559

Web: www.itpsupport.org.uk

E-mail: info@itpsupport.org.uk

Charity Registration No: 1064480

Shirley Watson MBE Founder

TRUSTEES (and other ITPSA Board Members)

Professor Adrian Newland CBE (Chair, Trustee)

Professor Nichola Cooper (Trustee)

Richard Blake (Trustee)

Agne Zice (Trustee)

Dr Quentin Hill (ITP Forum Representative)

Rhonda Anderson (Patient Observer)

Ella Sophia Ellis (Young Patient Observer)

Rhona Bowie (Young Patient Observer)

Tom O'Neil (Young Patient Observer)

ITP CNS Louise Taylor

OFFICE (also Board Members)

Management Team

Mervyn Morgan

VOLUNTEERS

Social Media

Iris Web Media

Mervyn Morgan

Patient Mentors

Rhonda Anderson

Karen Smith

Website

Mervyn Morgan

MEDICAL ADVISORS (Adult ITP)

Prof. Adrian C. Newland CBE

MA FRCP FRCPath

Dr. Drew Provan

MD FRCP PRCPPath

Dr. Jecko Thachil

MRCP FRCPath

Dr. Will Lester

MBChB(hons), BSc, MRCP, FRCPath, PhD

Dr. Nichola Cooper

MA, MBBS, MD, FRCP, FRCPath

Dr. Gerard Crotty

MB BCh BAO, FRCPath, FRCPI

Dr. Catherine Bagot MBBS

Dr Vickie McDonald

Prof. David Kuter

Louise Taylor ITP Nurse Consultant

MEDICAL ADVISORS (Childhood ITP)

Dr. John Grainger

MBChB MD MRCP FRCPath

Dr. Mike Richards

MA BM BCh DM MRCP FRCPath

Dr. Cindy Neunert MD MSCS

AMERICAN PERSPECTIVE (Contributors)

Dr. Cindy Neunert MD MSCS

Prof. Spero R. Cataland MD FAAP (USA)

Dr. Adam Cuker MD MS

Dr. Rachael Grace MD MMSc

GRIFOLS

The ITP Support Association acknowledges its gratitude to GRIFOLS for grants to assist with the printing and distribution costs of The Platelet.

The Platelet is the quarterly journal of The ITP Support Association. The Platelet is copyright and may not be copied, quoted or reproduced without written permission of the ITP Support Association (copyright holder). Articles in The Platelet represent the opinion of the writer, or writers, and not necessarily those of The ITP Support Association. Whilst every effort is made to ensure the accuracy of information, responsibility for omissions or errors cannot be accepted by The ITP Support Association, its personnel or medical advisors since circumstances and particulars vary from person to person. The Platelet is available free of charge to all to members of The ITP Support Association. It may not be sold.

The ITP Support Association is a registered charity which promotes and supports the general welfare of patients, and the families of patients, with Immune Thrombocytopenia. The Association aims to assist in funding approved ITP research projects, advancing the understanding and treatment of ITP in co-operation with the medical profession.

The ITP Support Association is non profit-making and relies upon subscriptions, donations, bequests and fundraising by friends of the Association to enable its operation and to fund vital research into ITP. All donations are gratefully received and acknowledged.

From ITP HQ

Building Momentum: Research, Advocacy and Engagement Ahead of the 2026 Annual Patient Convention

As the ITP Support Association prepares to welcome patients, clinicians and partners to the Annual Patient Convention at the Royal College of Pathologists on **27 June 2026**, a significant programme of work is already underway. This activity reflects a coordinated effort to strengthen patient voice, expand research insight, and deepen engagement with the clinical and trial landscape in immune thrombocytopenia (ITP).

This year's Convention represents the culmination of months of patient engagement, data collection, and advocacy initiatives designed to ensure that discussions on the day are grounded in real-world patient experience and forward-looking opportunity.

You can still book your place at the 2026 ITPSA Annual Patient convention, go to www.itpsupport.org.uk.

Listening to Patients: Survey Work Shaping the Agenda

A central pillar of the Association's work in the lead-up to the Convention has been the analysis of recent patient survey data. These surveys, conducted across a broad patient cohort, provide critical insight into the lived experience of ITP and the evolving challenges faced by patients.

Key emerging themes include:

- **Treatment burden and tolerability:** Patients continue to report variability in response to therapies, with side effects—such as fatigue, headaches, and cognitive impact—remaining a significant concern.
- **Quality of life considerations:** Beyond platelet counts, patients emphasise the importance of energy levels, mental wellbeing, and the ability to maintain normal daily activities.
- **Healthcare interaction and support:** Variability in access to specialist care and consistency of information remains evident across regions.
- **Decision-making and information gaps:** Patients report a need for clearer, accessible information when navigating treatment choices and clinical trial opportunities.

These findings have or will be published within these pages, but will directly inform session topics, panel discussions, and speaker contributions at the Convention. Importantly, they also provide a

robust evidence base to support ongoing advocacy with healthcare providers, regulators, and industry partners.

Enabling Participation: The Clinical Trial Ambassador Initiative

Alongside survey work, the Mervyn Morgan from the ITPSA and our good friend and colleague Barbara Lovrencic from the ITP Italy recently undertook several weeks of training to become Clinical Trial Ambassadors, this is a European wide initiative.



Becoming a Clinical Trial Ambassador involves:

- Developing a clear understanding of **clinical trial design**, including phases, endpoints, and safety monitoring
- Supporting patients in **navigating**

trial opportunities, including how to identify appropriate studies and ask informed questions

Contents

3	From ITP HQ
5	ITP Patient Mentors
5	ITP Young Adults Group
6	ITP Annual Patient Convention 2026
10	Research and ITP by Prof Adrian Newland
12	Clinical Trials currently in the UK and Ireland
13	Facebook Members Private Group
14	ITP Study – Fortrea
15	ITP Study – Takeda
16	Year in review – Adam Metcalf
17	What brings you joy? By Rhonda Anderson
19	International ITP Alliance – 10 Years
21	Survey results -Drug Treatment Availability
23	Survey results – Patient reported side effects with TPO-RAs
26	Shared Decision-Making Document
28	Patient Explainer – ITP Discussion Guide
31	ITP Discussion Guide
33	New Medical Emergency Card
34	Share your patient story
34	Try out the ITPSA Red Bubble shop
35	Fundraising Report
36	Sky Diving for ITP
37	Plasma Donation
38	Leaving a Legacy
39	Order a free ICH alert card
40	Ways to Donate
41	Visit our YouTube Channel
42	Publications List
44	Membership Form

From ITP HQ Cont...

- Acting as a bridge between patients, clinicians, and researchers—helping to **demystify clinical trials** and address common concerns
- Promoting awareness of the importance of participation in advancing future ITP treatments

Looking Ahead to June 2026

The Annual Patient Convention at the Royal College of Pathologists will bring these strands together offering a unique opportunity to translate months of preparatory work into meaningful dialogue and shared learning.

Attendees can expect:

- Expert-led sessions informed by real patient data
- Open discussion on treatment challenges and emerging therapies
- Practical insights into clinical trials and participation
- Opportunities to connect with others living with ITP

Above all, the event will reinforce the Association's core mission:

bringing patients and specialists together for support, education and research.

The work underway in advance of the 2026 Convention demonstrates a clear strategic direction for the ITP Support Association—one that places patient insight, research engagement, and collaborative dialogue at its centre.

Through robust survey programmes and initiatives such as the Clinical Trial Ambassador scheme, the Association is not only preparing for a successful event but actively shaping the future landscape of ITP care and research in the UK and beyond.

Young Adults Group

We are delighted to introduce the ITP Young Adults Group – a dedicated sub-group of the ITP Support Association UK, created specifically for young adults aged 18–30 living with Immune Thrombocytopenia (ITP).

The ITP Young Adults Group has been created to offer something simple, yet powerful: connection.

This is a space designed exclusively for young adults with ITP, whether you are newly diagnosed, living with chronic ITP, or somewhere in between. It offers the opportunity to connect with others who truly understand the lived experience, while also providing

ways to engage more closely with the wider ITP Support Association community.

Most importantly, this group belongs to its members. It will grow and evolve based on what young adults with ITP want and need from a supportive, understanding community.

If you are aged 18–30 and living with ITP, we would love to welcome you. Details of how to join can be found within these pages.

Celebrating Our Fundraisers

We are continually inspired by the dedication and creativity of our fundraisers, whose efforts make a real difference to the support we can offer. From community events to personal challenges, their commitment strengthens our work and helps raise awareness of ITP across the country. This edition includes more details about some of the wonderful individuals and groups who have been fundraising on our behalf, and we extend our heartfelt thanks to each and every one of them.

'Silver Standard' for Excellence in Industry Award



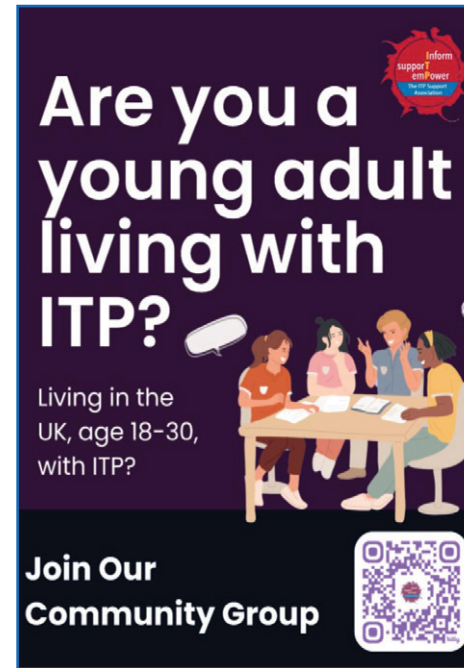
ITP Support Associations Platinum Sponsor for 2026



Mervyn Morgan CEO ITPSA



ITP Young Adults Group



Welcome to the ITP Young Adults Group

We are delighted to introduce the ITP Young Adults Group – a dedicated sub-group of the ITP Support Association UK, created specifically for young adults aged 18–30 living with Immune Thrombocytopenia (ITP).

The ITP Young Adults Group has been created to offer something simple, yet powerful: connection.

This is a space designed exclusively for young adults with ITP, whether you are newly diagnosed, living with chronic ITP, or somewhere in between. It offers the opportunity to connect with others who truly understand the lived experience, while also providing ways to engage more closely with the wider ITP Support Association community.

Most importantly, this group belongs to its members. It will grow and evolve based on what young adults with ITP want and need from a supportive, understanding community.

If you are aged 18–30 and living with ITP, we would love to welcome you. Complete the form below to join and become part of the community.

PATIENT MENTORS

If you need to talk to someone about your ITP we have a small team of Patient Mentors who will be happy to help.

If you would like to speak to one of our ITP Patient Mentors email info@itpsupport.org.uk with your details and we will put you in touch

Rhonda Anderson – ITP Patient in long term remission
Rhonda is based in the Southeast.

Karen Smith – ITP Patient
Karen is based in the Southwest.

We are looking for additional Patient Mentors, if you feel this could be you, please email us at info@itpsupport.org.uk with your details and we will contact you.

support

ITP Annual Patient Convention 2026



ITP Support Association Annual Patient Convention 2026: London (27 June 2026)

The ITP Support Association's Annual Patient Convention returns on Saturday 27 June 2026, hosted at the Royal College of Pathologists, 6 Alie Street, London E1 8QT.

This is our flagship UK event—**bringing patients, families, carers, and healthcare professionals together** in one room to focus on what matters most: practical support, up-to-date education, and progress in ITP care. The Convention is designed to be accessible whether you're newly diagnosed, have lived with ITP for years, or support someone who does.

To register and book at the early bird ticket price go to: <https://bit.ly/49AINZJ>

What the day is about

The Convention provides a structured opportunity to:

- **Hear directly from leading ITP clinicians and researchers** on current practice and emerging

developments in diagnosis and treatment.

- **Ask questions openly in a supportive environment**—covering everyday realities as well as complex treatment decisions.
- **Connect with the community**—meeting others who understand ITP first-hand, and sharing experience, tips, and reassurance.

The Royal College of Pathologists listing for the event describes it as the ITP Support Association's annual patient convention, focused on the latest developments in ITP treatment and diagnosis, with "many of the world's top ITP experts" presenting.

Speakers: Leading Voices in ITP Research and Care

We are honoured to welcome a distinguished lineup of international ITP experts presenting at the Convention. Confirmed speakers include:

- **Professor Adrian Newland** – internationally recognised haematologist
- **Professor Nichola Cooper** – expert clinician and researcher
- **Professor David Kuter** – leading authority on ITP pathophysiology and treatment
- **Professor Cindy Neunert** – specialist in ITP research and clinical practice
- **Dr Fred Chen** – renowned ITP clinician
- **Dr Catherine Bagot** – expert in clinical haematology
- **Dr Drew Provan** – world renowned haematologist
- **Professor John Semple** – specialist in platelet immunobiology
- **Dr Alice Hart** – expert in ITP care and patient support
- **Dr John Grainger** – experienced ITP clinician and educator

Together, this group represents some of the most recognised names in the field, spanning adult and paediatric ITP, emerging therapies, and patient-centred care.

A venue built for learning and conversation

This year's Convention takes place at the Royal College of Pathologists' home at **6 Alie Street**, a modern conference venue in the Aldgate area

(often referred to as "Events @ No 6").

It's well connected for attendees travelling across London and from outside the capital.

Getting there: travel pointers

If you're planning your journey, the Royal College of Pathologists' directions page highlights several convenient options:

- **Underground:** Aldgate, Aldgate East, Tower Hill
- **DLR:** Tower Gateway
- **National Rail:** Liverpool Street and Fenchurch Street (around a 10-minute walk)

What to Expect at the Convention

The 2026 Convention offers a blend of expert talks, Q&A sessions, and breakout discussions tailored to both patients and healthcare professionals. Topics are expected to include:

- **Latest evidence on ITP diagnosis and management**
- **Advances in treatments and understanding long-term outcomes**
- **Understanding and managing side effects of therapies**
- **Support strategies for patients, families, and carers**

Doors open at 09:30 BST with the first presentation commencing at 10:00 BST; the programme runs through the afternoon with scheduled opportunities for networking and community support.

For healthcare professionals: CPD

The Royal College of Pathologists event listing notes the Convention is accredited for **6 CPD credits**.



Our list of Speakers at this year's event.



Professor Adrian Newland is Professor of Haematology at Barts Health National Health Service (NHS) Trust, London, UK. He has a research department within the Medical School, where he is a former Head of the Division

of Haematology. Prof Newland is also the Chair of Trustees of the ITP Support Association and a Medical Advisor.

Chair of Trustees Professor Newland will be chairing the Question-and-Answer session at the Convention.



Professor David Kuter is Director of Clinical Haematology at Massachusetts General Hospital and Professor of Medicine at Harvard Medical School. Professor Kuter is also a ITPSA Medical Advisor.

Professor Kuter will share the details of the latest developments in ITP during his talk.



Professor Nichola Cooper trained at Cambridge University and Barts and the London School of Medicine and Dentistry. She completed her haematology training at University College Hospital and subsequently gained research experience at Cornell Medical College, New York and the Institute of Child Health, University College London. Professor Cooper is also a ITPSA Trustee and Medical Advisor.

ITPSA Trustee Prof Cooper's talk will cover the I-WISH study, some interesting findings from patients and healthcare professionals.



Dr Drew Provan is currently Emeritus Reader in Autoimmune Haematology at Barts and the London School of Medicine and Dentistry. Dr Provan, along with international colleagues published the consensus guidelines for the diagnosis and management of ITP in children and adults published in Blood. Dr Provan is also a ITPSA Medical Advisor.

A really interesting topic, 'Can AI help in ITP', and who better to discuss that expert Dr Drew Provan.

**Dr. Guillaume Moulis -**

Introducing Dr Moulis who will be talking about Epidemiology of ITP



Dr John Grainger is Chair of British Society of Haematology Paediatric Haematology committee, national lead for paediatric ITP, national lead for IVIg in haematology and national lead for paediatric haematology training. He is

also the medical advisor for the ITP Support Association. Dr Grainger is also a ITPSA Medical Advisor.

Paediatric ITP expert Dr John Grainger will be one of the experts in the Women and Children Breakout group session



Dr Cindy Neunert is an Associate Professor of Paediatrics at Columbia University at CUMC, New York and an Attending Physician Paediatrics at New York Presbyterian Morgan Stanley Children's Hospital, New York. She joined our medical

advisers in 2016 and has enjoyed a long-standing relationship with Professor James George of Oklahoma and George Buchanan from Dallas, Texas. Dr Neunert is also a ITPSA Medical Advisor and regular contributor to our Platelet Journal.

Dr Neunert will be discussing 'Treatment of newly presenting ITP.



Dr Catherine Bagot BSc, MBBS, MD, FRCPath is a Consultant Haematologist at Glasgow Royal Infirmary, UK, where she specialises in Haemostasis and Thrombosis and is the co-director of the West of Scotland

Haemophilia and Thrombosis centre. Her clinical interests include venous thrombosis treatment and prevention, the management of inherited bleeding disorders, obstetric haematology and immune thrombocytopenia (ITP). Dr Bagot is also an ITPSA medical advisor.

Dr Bagot will be sharing the results and findings from the ITPSA TPO Survey.



Dr Fred Chen is a Consultant Haematologist at Barts Health NHS Trust. He also manages the ITP Adult Registry. He promotes collaboration across specialities to bring together the best care for the patient. He has extensive experience in diverse areas of

haematology and leads several disease-specific multidisciplinary team meetings (MDT).

Dr Chen will update the Convention on the work of the ITP Adult Registry.



Dr Alice Hart MRCP FRCPath(Haem) is an NIHR Doctoral Clinical Research Fellow in non-malignant haematology at Imperial College London and Imperial College Healthcare NHS Trust, where she also trained in

medicine. With a specialist research interest in paediatric ITP, she has completed a study in children with ITP to investigate cerebral microbleeds and changes in cognitive function, quality of life or fatigue. Dr Hart will be talking about Adolescence – coping with ITP.



Mervyn Morgan is the CEO of the ITP Support Association and has organised various conferences, including ITPSA Patient Conventions since 2016. Mervyn is also a board member of the ITP International Alliance. In addition, Mervyn is also a

co-author, along with other members of the

ITP International Alliance of various ITP related abstracts and ITP resource materials.

Mervyn will open the event and share the introductions with Prof Newland.

AGENDA

ITP Support Association Annual Patients' Convention 2026 - 27th June 2026

The Royal College of Pathologists, 6 Alie Street, London, E1 8QT

9.30 – 10.00 **Registration and Coffee**

10.00-10.10 **Welcome and Introduction - Mervyn Morgan**

10.10-10.35 **New Developments in ITP - David Kuter, Massachusetts General Hospital**

10.35-11.30 **Breakout sessions**

• **Adult & Adolescents - David Kuter, Catherine Bagot, Alice Hart**

• **Women & Children - Cindy Neunert, Nikki Cooper, John Grainger**

11.30-11.55 **Break and Exhibition**

11.40-12.00 **Can AI help in ITP - Drew Provan, Barts and the London School of Medicine, Barts NHS Trust**

12.00-12.25 **Adolescence: coping with ITP - Alice Hart**

12.25-13.30 **Lunch and Exhibition**

13.30-13.55 **Treatment of Newly Presenting ITP - Cindy Neunert, Columbia University Medical Center, USA**

13.55-14.20 **Thrombopoietin's - side effects and new developments - Catherine Bagot**

14.20-14.45 **Health related Quality of Life - the I-WISH study - Nikki Cooper**

14.45-15.10 **Break and Exhibition**

15.10-15.35 **Developments in ITP - From the Adult Registry - Fred Chen, Barts NHS Trust**

15.35-15.55 **Epidemiology of ITP - Guillaume Moulis**

15.55-16.55 **Q&A - Professor Adrian Newland, Barts and the London School of Medicine, Barts NHS Trust, Chair - ITPSA**

Topics and speakers may be subject to change
All sponsors have provided sponsorship towards

this independent programme. Please note that sponsors have had no input into the content of the programme or the choice of speakers.

Sponsors will have the opportunity to exhibit with a company stand during the meeting.

Platinum**Gold****Bronze**

Research and the ITP

The ITP Support Association is a registered charity dedicated to promoting and improving the welfare of patients and families affected by Immune Thrombocytopenia (ITP). Central to our mission is the provision of clear, reliable information and meaningful support to those living with this condition. We offer written resources, online support, expert advice, mentoring, and opportunities for patients to meet and share experiences at conventions and smaller meetings.

Beyond direct patient support, the Association plays a vital role in raising awareness of ITP at regional, national, and international levels. This is achieved through close collaboration with professional societies and specialist groups, the organisation of medical seminars, and ongoing engagement with regulators, commissioners, and NHS bodies. We also work actively with other patient organisations and maintain strong links with international partners, including the Platelet Disorder Support Association (PDSA) in the United States and several European patient groups. Through these collaborations, and particularly via our links with the European Hematology Association (EHA), we have contributed to broader recognition of ITP as a bleeding disorder.

Supporting and Enabling Research

A core objective of the Association is to encourage and support high-quality research into ITP for the direct benefit of patients. We have been particularly successful in working with pharmaceutical companies to support clinical trials, helping to ensure that patient perspectives are represented and that research addresses real clinical needs. In addition, we collect and disseminate information on all available clinical trials in the UK, enabling patients to make informed decisions about participation. We also engage directly with trial sponsors to provide structured patient feedback. While the Association is keen to fund research directly, we recognise that, as a relatively small organisation, our resources must be used strategically. We therefore avoid competing with major funding bodies where substantial external funding is already available. Instead, our approach

has focused on two complementary strategies: supporting carefully selected individual research projects and funding national patient registries.

The ITP Registries

One of the Association's most significant contributions to research has been the funding and development of the Adult and Paediatric ITP Registries, as well as more recent registries in Pregnancy and Secondary ITP. These registries have proved to be exceptionally good value for money and have generated data with a substantial impact on clinical practice.

Research arising from the Paediatric Registry contributed to both romiplostim and eltrombopag becoming available for children with ITP. Data from the Adult Registry demonstrated an increased incidence of thrombosis in ITP, highlighted the significant burden of fatigue experienced by patients, and documented changes in treatment patterns over time. Importantly, the Registry showed sustained long-term responses following cessation of thrombopoietin receptor agonists in adults.

More recent analyses involving over 300 patients treated with rituximab, using either low- or high-dose regimens, demonstrated that the lower-dose option is both effective and more economical. This finding has enabled wider use of the treatment. Registry data on spleen scanning and platelet survival have also had a major influence on clinical decision-making, leading to a marked reduction in unnecessary surgery and sparing many patients from inappropriate splenectomy.

Individual Research Projects and Pilot Studies

In addition to registry funding, the Association has provided more than £250,000 to support individual research projects over the years. All applications are rigorously assessed, and while not all projects lead to positive results, this reflects the inherent nature of research. Importantly, negative findings are often just as valuable in guiding clinical practice.

Notable projects include a study conducted at Addenbrooke's Hospital examining the relationship between food, allergy, and ITP. This research found no association, demonstrating that while rare individual reactions may occur, diet is not a major factor in ITP. This has helped dispel common misconceptions among patients.

The Association also supported a pilot study on ITP in pregnancy led by Dr Angharad Care in Liverpool. The findings, published in the journal *Platelets*, led directly to the establishment of the Pregnancy Registry, which has now collected data on over 100 pregnancies. Early results have confirmed the increased risk of severe postdelivery haemorrhage and highlighted the importance of specialist care for pregnant women with ITP.

Another important study, led by Professor Nikki Cooper at Imperial College, investigated the presence of microbleeds—tiny, clinically silent bleeds—in the brains of children with persistently low platelet counts. Although these bleeds do not cause immediate symptoms, they may have implications for long-term neurological outcomes. This work, presented at the Association's Convention and published in *Platelets*, led to a much larger NIHR-funded PhD study, worth over £400,000, undertaken by Dr Alice Hart.

Patient-reported outcome data from this research also identified an unmet need for education among young people with ITP. This directly informed the development of the ITP and Me book, which has since been translated into multiple languages and is widely used internationally.

More recently, Professor Cooper has led a study examining the gut microbiome in patients with ITP. Early findings have been sufficiently promising to attract further external funding from the NIHR (approximately £330,000) and will support a larger investigation into the role of the microbiome in ITP and the potential for targeted interventions.

The Trustees consider these smaller pilot studies—typically funded at levels of up to £20,000—to be an effective use of the Association's resources. By supporting early-stage research, we help generate the preliminary data needed to attract larger grants from major funding bodies. This approach has already proven successful, including in the initial

genetics study of ITP using DNA obtained through the Adult Registry, which subsequently received £75,000 from Barts Charity. In addition, the Medical Research Council has funded a PhD Fellowship to explore ITP genetics at Imperial College and Hammersmith Hospital, with partial support from the National Institute for Health and Care Research. The Association is also a noncommercial partner of the NIHR, providing further support for research applications.

Future Directions

Looking ahead, the Association intends to continue supporting high-quality pilot studies and is actively seeking ideas from members about priority areas for future research. We will also invite proposals from researchers working in ITP-related fields. All grant applications will continue to be reviewed by external assessors alongside our own expert advisers, and all funded projects will be closely monitored to ensure responsible use of funds.

Acknowledgements

The Association is deeply grateful to its members for their enthusiastic and imaginative fundraising, and for the extraordinary generosity of all who support our work. We are committed to ensuring that all funds are used carefully and effectively, both to support patients and families living with ITP and to advance understanding of the disease and its treatment. In doing so, we aim to fulfil the broader objectives set out in our charitable charter.

Professor Adrian Newland CBE

Chair of Trustees

The ITP Support Association



Current ITP Clinical Trials in the UK and Ireland



Clinical trials are structured research studies in which participants volunteer to evaluate new treatments, interventions, or diagnostic approaches aimed at preventing, detecting, treating, or managing diseases and medical conditions. Some studies assess how individuals respond to a new intervention and monitor potential side effects, while others are designed to determine the most effective and appropriate dosing of a particular treatment.

A number of clinical trials are currently available in the United Kingdom and Ireland for the treatment of Immune Thrombocytopenia (ITP), with further details provided below. In addition, international trials are ongoing. A comprehensive and regularly updated listing can be accessed via ClinicalTrials.gov.

Study of lanalumab in Adults

With Primary Immune Thrombocytopenia (ITP) and Warm-antibody Autoimmune Hemolytic Anemia (wAIHA) Who Have Previously Benefited From lanalumab (VAY RE-HIT).

Sponsor: Novartis Pharmaceuticals

Locations:

Imperial College, London W12 OHS - [Recruiting](#)

A Study of Efgartigimod IV in Participants From 12 Years to Less Than 18 Years of Age With Chronic Immune Thrombocytopenia (ITP).

Sponsor: Argenx

Locations:

Cardiff, CF14 4XW - [Recruiting](#)

A Follow-up Study of Mezagitamab in Adults With Chronic Primary Immune Thrombocytopenia.

Sponsor: Takeda

Locations:

Barts Health NHS Trust, London, E1 1BB - [Recruiting](#)

University College London Hospitals, London, NW1 2PG

Imperial College NHS Trust, London,

W12 OHS - [Recruiting](#)

University Hospitals of Leicester NHS

Trust, LE1 5WW - [Recruiting](#)

Southampton General Hospital, SO16 6YD

Guys Hospital NHS Trust, SE1 9RT

Royal Liverpool and Broadgreen University Hospitals NHS Trust, L7 8XP

Greater Glasgow Health Board, G31 2ER

University Hospitals of North Midlands NHS Trust,

Royal Stoke University Hospital, ST4 6QG

Leeds Teaching Hospitals NHS Trust, LS9 TF

A Study of Mezagitamab in Adults With Chronic Primary Immune Thrombocytopenia.

Sponsor: Takeda

Locations:

Barts Health NHS Trust, London, E1 1BB - [Recruiting](#)

University College London Hospitals,

London, NW1 2PG

Imperial College NHS Trust, London,

W12 OHS - [Recruiting](#)

University Hospitals of Leicester NHS

Trust, LE1 5WW - [Recruiting](#)

Southampton General Hospital,

SO16 6YD - [Recruiting](#)

Guys Hospital NHS Trust, SE1 9RT - [Recruiting](#)

Royal Liverpool and Broadgreen University

Hospitals NHS Trust, L7 8XP - [Recruiting](#)

Greater Glasgow Health Board, G31 2ER - [Recruiting](#)

University Hospitals of North Midlands NHS Trust,

Royal Stoke University Hospital, ST4 6QG - [Recruiting](#)

Leeds Teaching Hospitals NHS

Trust, LS9 TF - [Recruiting](#)

A Study to Assess the Efficacy and Safety of Efgartigimod IV in Adult Participants With Primary Immune Thrombocytopenia (advance NEXT).

Sponsor: argenx

Locations:

Mater Misericordiae University Hospital,

Dublin, Ireland, DO7 R2WY - [Recruiting](#)

St James's Hospital - Cancer Clinical Trials Office,

Dublin, Ireland, DO8 NHY1 - [Recruiting](#)

Queen Elizabeth Hospital Birmingham,

B15 2GW - [Recruiting](#)

Bradford Teaching Hospitals NHS

Foundation, BD9 6RJ - [Recruiting](#)

University Hospitals Coventry and Warwickshire

NHS Trust, CV2 2DX - [Recruiting](#)

Glasgow Royal Infirmary - North Glasgow

University Hospital Division, G4 0ET - [Recruiting](#)

University Hospitals of Leicester NHS

Trust, LE1 5WW - [Recruiting](#)

Barts Health NHS Trust, London, E1 1BB - [Recruiting](#)

Imperial College NHS Trust, London,

W12 OHS - [Recruiting](#)

Royal Cornwall Hospital (RCH),

Truro, TR1 3LJ - [Recruiting](#)

A Study of Pirtobrutinib in Participants With Immune Thrombocytopenia.

Sponsor: Eli Lilly and Company

Bristol Haematology and Oncology

Centre, BS2 8ED - [Recruiting](#)

St James's University Hospital,

Leeds, LS9 7TF - [Recruiting](#)

Leicester Royal Infirmary, LE1 5WW - [Recruiting](#)

Royal London Hospital, , E1 1FR

Imperial College, London, W12 OHS

Facebook Members Private Group



Join our new ITPSA Facebook Group

We now have an ITP Support Association private group, you can share your experiences or ask other ITP patients questions. Almost 500 ITP Patients have already joined and are sharing their knowledge and experiences with ITP,

It's a friendly bunch of people who have or know someone who has ITP (Immune thrombocytopenia).

The group is a private place where we can share experiences and help people get a better idea of what you may face during a difficult time.

This group is respectful and will never judge you or your situation. A place to also make new friends.

We hope you find any information given very useful to you as an individual. Join it now, scan the QR Code above to join.

Or <https://www.facebook.com/groups/235978790548730/>



ITP Study - Fortrea

Fortrea | **ELIKNIK**

YOU'LL RECEIVE
£7675
PLUS TRAVEL
PAYMENTS

Do You Have Immune Thrombocytopenia?
You May Be Eligible for a Clinical Study

We are recruiting males & females, age 18-80,
with a BMI between 17.5-35

1 6-Night Stay **11** Out-Patient Visits **1** Follow Up Call

Find out if you are eligible for Study 780567:
Call Us: 0113 394 5200
Visit FortreaClinicalTrials.com

ITP Study - Takeda



Join Us on a Journey of New ITP Research

If you have chronic primary immune thrombocytopenia (ITP) that has not responded well or has stopped responding to treatments, consider the Meza ITP Study. This study is researching once-weekly investigational injections given in two eight-week dosing intervention periods, separated by a non-dosing period. To learn more, scan the QR code or visit MezaITP.com/pag.

Meza ITP
S T U D Y

Year in Review by Adam Metcalfe



Over the past year, I turned 30. Still young in the grand scheme of things, but it's the first landmark birthday where you begin to feel like time is moving on and you're growing a little older. It's also been the time to pause and reflect on the key moments which have shaped my three decades on the planet. One of those moments being the time where I came closest to death. Whilst approaching my 4th birthday, I contracted ITP, and not just any strain of ITP, I got the short, sharp extreme condition which almost took my life within an instant. It aggressively attacked my platelets and caused a huge amount of blood loss. Needing an emergency platelet blood transfusion to save my life, if it hadn't been for the quick thinking of my Mum and hospital staff, I wouldn't be sat writing this piece today.

So in the first year of my thirties, I wanted to acknowledge this landmark moment and contribute in some small way to spreading the word about this little-known disease. I wanted to give back in whatever way that I could, because if we don't speak up, no one will be aware of the condition. Over the course of the past year, I have had the pleasure of fundraising for ITP Support Association by completing the Great Manchester Run.

Alongside this I have also gave blood in honour of the emergency transfusion which I received that night

whilst also speaking about my condition on various panel talks. I have loved every moment, and it has been liberating to speak up and raise awareness.

Whilst doing all of these things, the main question I get is "what is ITP, I've never heard of it?!" This highlights why we must keep discussing the condition at every chance that we get. This is certainly something which I intend to do beyond my 30th year as I still live with many of the side-effects today. On a daily basis, I get fatigued, suffer from a weakened immune system, develop easy bruising and those pesky purple dots appearing for no good reason! I now look at all of these things as a blessing, a badge of honour, as I know that it could have been a lot worse! I've experienced many highs and lows which everybody does in life, but none of them would have been possible had I not been a survivor of ITP.

ITP effects people in many different ways. With multiple variations of the condition, some people live with far more impacting daily symptoms than me. However, going forward, I intend to continue running, continue donating and continue talking about all things ITP. I encourage you all to do the same, because discussion equals awareness which then equals understanding.

I'd love to hear your stories too, so if ever you want to connect, please let me know and let's support each other.



By Adam Metcalfe
ITP Survivor

What Brings You Joy?

This may not be an easy question to answer.

How do we find Joy? I don't suppose that many of us can remember when we were literally jumping for joy. Maybe when we were a child anticipating a great event such as a birthday or Christmas or a holiday, especially from school!

Our everyday lives are not necessarily joyful and we may regret that, but we can substitute pure joy with satisfaction and positive feelings, and heart-warming events that many things bring us. We just need to look for them, and celebrate them, and hopefully gain warm feelings and satisfaction from them. Counting little things that make us happy can be a useful tool.

To be honest, I have not felt very joyful this year, so my thoughts turn to how to remedy this state of affairs. A lot of things have impacted on us all, that have robbed us of our joy in life. I will not list them here, you will know your own 'kill joy' triggers and worries. It is easy enough to fall prey to negativity, worry and stress, and there are plenty of every day reasons not to be joyful.

Recently I took some pictures of the spring flowers in my son's garden and sent them around on WhatsApp. I was not expecting the wonderful, positive reactions I got from friends. I asked permission for this poetic reply to be part of this article, from a friend who has had many challenges in her life:

"It is refreshing to connect with nature; I take my shoes off and walk on the grass. It is important to me to connect with the earth from whence we came. It is "grounding" and self-affirming when everywhere around is turmoil and hurt. The soil reminds me that I am a child of the earth and deeply loved.

So when you find yourself fretting, my dear friend, step back into nature and take in the beauty around you.

The warm sunshine on your face, the unique smells of the different blossoms, the pastel colours of the flowering buds against the verdant shades of new shoots on branches and the colours returning to the grass.

If you are still, you can hear the birds twittering amongst themselves, happy to see another day, but they don't even know where their next meal is coming from...not that that fact steals their joy! Why don't we stop often enough to enjoy all these free pleasures?'

That is an excellent question. When I did take time out to admire the beautiful Spring flowers, it made a great deal of difference to my mood and I felt uplifted. I sat outside with the sunshine on my face and breathed deeply and relaxed, it made a big difference to me. Then I felt refreshed to do something else that had been challenging me. In fact I decided to have a break from it and returned to it the next day. A good decision as I came back to it refreshed.

Following the nature theme, the latest David Attenborough series on Secret Gardens is wonderful to watch. In fact I haven't seen it all yet, but plan to. In the first episode I really loved the Mallard mother duck who made her nest in a tree to protect her babies. Even though the eggs were laid on different days they all hatched at the same time by communicating with each other in their eggs – how amazing is that! The ducklings then had to jump out of the tree to get to the water and their food. It was nail biting to watch them making that huge leap, but they all made it, to a sigh of relief from me, I had been feeling quite tense on their behalf. Again the wonders of nature. Do mother ducks worry about their ducklings, I wonder? They certainly defend them with vigour.

My dear friend of 96 who lived down the road, sadly died in January. I miss her as we used to have great conversations and lots of laughs as we let down our barriers and said exactly what we felt, which brought

What Brings You Joy? Cont...

on mirth, and we laughed until we cried. Some people subscribe to laughter therapy. Some even claim to be cured by watching comedy in a big way.

Helping others is another way to feel satisfaction. A little gift of your own making, or a bunch of flowers, or a little personal offering, such as the lavender bags I make every year, are always acceptable and very small, but have a big impact on people. You see their faces light up as they smell the lavender fragrance and tell you where they are going to place them, under their pillow or in a drawer or wardrobe.

A walk I went on recently to get out of the house and post our local election votes, turned out to be very satisfying. By chance I met 3 people with whom I had some conversations and that was really interesting and productive. One of them has some icons in her house and it just so happens I am researching icons at the moment for myself and a friend who has another icon in her house. Finding out interesting things can bring satisfaction and excitement.

How can I make myself better?

Rest and sleep are very important.

Music, reading, a real book or online, relaxation, playing games, shopping, cooking, gardening, meeting friends, talking to someone, even cleaning and taking time out in any way that pleases you, are all ways to feel better. They do not have to be amazing. Look for the joy in everyday things.

Even very slow progress is still progress.

Making a list of the things that please you, such as making things, and then having a plan to achieve the things that that you enjoy, alone or with others, is a positive step in the right direction of guiding your own life and activities to give you joy, even if it is of the low key variety.

So...you may not be jumping for joy, like the Spring

lambs gambolling, (frolicking, jumping, sprouting) in the sunny fields, but you can live with positivity, satisfaction, and heart-warming events in your life. Even watching the lambs can be enjoyable and joyful... The cuteness of baby animals, even human ones, can be joyful.

'Joy is created by the positive things today that you repeat tomorrow.'

From my U3A local Newsletter.

'All in the Mind' BBC Radio 4 programme website, has hints on how to stop worrying and is an excellent, accessible programme on mental health issues. They are into their 81st series!

I hope this article will help to lighten your mood, and that will be all that I aim to do, sitting here at my computer first thing in the morning. If you experience Joy, that will be a bonus.

Please share your Joy with the editor, and I will make your ideas and suggestions the subject of another article in the Platelet.

Many thanks, and may Joy be with you!

Rhonda Anderson
April 2026



The International ITP Alliance



The International ITP Alliance
A Decade of Achievement
A Global Voice for People Living with ITP

Building a Global Voice for ITP

The Alliance was established to create a unified global network of patient organisations supporting individuals and families affected by immune thrombocytopenia (ITP).

By the mid-2010s, national ITP charities and support groups had developed strong local foundations. However, leaders recognised that many of the challenges facing patients — access to treatment, research engagement, awareness, and advocacy — were shared internationally. A coordinated global approach was needed.

When patient organisations work together across borders, the impact extends far beyond any single country.

The Foundational Years (2015–2016)

Following ideas some time earlier from our friends in the Netherlands the vision of an 'ITP Alliance' was formalised during the European Haematology Association Congress in Copenhagen. Representatives from leading patient organisations agreed to create a structured international partnership.

The vision was clear:

To connect patient support groups worldwide in order to strengthen education, advocacy, and research collaboration across borders.

In September 2016, the first official Alliance meeting was held in Melksham, United Kingdom. Hosted by the ITP Support Association, the meeting welcomed representatives from Denmark, the Netherlands, Sweden, Finland, Italy, India, the United States and the UK. This meeting marked the formal launch of the International ITP Alliance as a collaborative global entity.



The first ITP International Alliance Meeting 2016
Image taken by Mervyn Morgan

Expansion and International Reach

Following its establishment, the Alliance expanded steadily. Over subsequent years, additional national and regional organisations joined, creating a truly global network spanning Europe, North America, Asia and Australasia.

By the early 2020s, more than 30 ITP patient support organisations from nearly 30 countries were participating in the Alliance. This growth reflected both the demand for collaboration and the strength of shared purpose among member groups.

This expansion has seen Alliance meetings in the USA, UK and Australia.

Purpose and Core Activities

The International ITP Alliance operates around five central pillars:

The International ITP Alliance

1. Education - Providing reliable, accessible information about ITP for patients, families and healthcare professionals.

2. Awareness - Coordinating international campaigns, including Global ITP Awareness Week each September, to improve recognition and understanding of ITP worldwide.

3. Advocacy - Amplifying the patient voice in policy discussions, regulatory engagement and global healthcare dialogue.

4. Collaboration - Sharing best practice between member organisations, supporting the development of new national groups, and strengthening governance standards.

5. Global Information Hub - Supporting the development of a central online resource, GlobalITP.org, which connects patients to information and national support organisations.

Regular meetings — often aligned with major international haematology congresses — allow Alliance members to coordinate messaging, share strategic priorities and strengthen global advocacy.

A Platform for the Patient Voice

One of the most significant achievements of the Alliance has been elevating patient experience into international clinical and research conversations. By working collectively, member organisations have strengthened engagement with researchers, clinicians and industry partners.

The Alliance demonstrates how patient-led organisations, when connected internationally, can:

- Improve consistency of information
- Share advocacy tools and resources
- Support emerging organisations in developing countries
- Increase the visibility of ITP as a rare autoimmune condition

Continuing the Mission

Today, the International ITP Alliance stands as the primary global collaboration of ITP patient organisations. Its continued growth reflects a shared commitment to education, research engagement and international solidarity.

Mervyn Morgan
UK and Ireland ITP Support Association
One of the founding members of the ITP International Alliance



Survey Results – Drug Treatment Availability

Drug Treatment Availability and Satisfaction Survey Publication Report

Executive Summary

This report presents findings from a UK-wide survey exploring patient experiences with TPO-RA therapies and perspectives on switching to generic eltrombopag.

Towards the end of 2025 Eltrombopag (one of a class of drugs for ITP known as TPO-RAs) came off patent and a generic version was made available at a greatly reduced cost to the NHS.

A joint statement on the use of generic eltrombopag was prepared by the ITP Clinical Forum, The ITP Support Association after discussion with NHS Pharmacy.

The survey, organised by the ITP Support Association, was open for just over 2 weeks, with 92 individuals completing the survey. The survey closed on 14th April 2026.

While overall satisfaction with current treatments is relatively high, significant concerns emerge regarding switching practices, particularly around effectiveness, platelet stability, and lack of patient consultation. These findings highlight the need for improved communication, shared decision-making, and patient-centred care pathways.

Treatment Landscape

Eltrombopag is the most commonly prescribed TPO-RA, followed by romiplostim and avatrombopag. Patients often transition between therapies due to efficacy, tolerability, or lifestyle considerations. The data reinforces that treatment pathways are highly individualised.

Which TPO-RA drug are you currently being prescribed?

Patient Satisfaction

Most respondents report being satisfied or very satisfied with their current therapy. However, satisfaction is nuanced, with many patients reporting fluctuations in platelet counts, dose optimisation challenges, and ongoing uncertainty about long-term outcomes.

How satisfied are you with the effectiveness of your current TPO-RA medication?

Generic Switching: Key Findings

A substantial proportion of patients report either being switched or informed of a potential switch to generic eltrombopag. Sentiment towards switching is predominantly negative or cautious. Concerns centre on reduced effectiveness, increased side effects, and loss of platelet stability.

Has your NHS Trust indicated a switch to the Generic Eltrombopag?

Core Patient Concerns

- Effectiveness: Fear of reduced response following switching
- Side Effects: Reports of headaches, fatigue, and new symptoms
- Platelet Stability: Concerns about fluctuations and instability
- Communication: Lack of prior consultation or warning
- Cost Perception: Belief that switching is driven by cost-saving measures.

How do you feel about the potential switch to Generic Eltrombopag?

Patient Voice Highlights

“No warning, advice or discussion before switching medication.”

“My platelet count dropped at the same time as the switch.”

“I am worried about losing stability – it has taken years to get right.”

“The change felt driven by cost, not by what is best

Survey Results – Drug Treatment Availability *Cont...*

for me.”

“I have more headaches since switching.”

“I wasn’t consulted – the medication was just changed.”

“This treatment keeps me stable – I don’t want to risk that.”

“There needs to be more discussion with patients before changes are made.”

What concerns, if any, do you have about switching to Generic Eltrombopag?

Confidence in Healthcare Providers

Confidence levels are mixed. While some patients express strong trust in their clinicians, many report reduced confidence linked to poor communication around treatment changes rather than clinical care itself.

How confident are you in your healthcare provider’s decision regarding your medication?

Communication and Shared Decision-Making

A consistent finding is the absence of meaningful patient engagement prior to treatment changes. Many respondents report being switched without discussion, contributing to anxiety and reduced trust.

Have you discussed the potential switch with your healthcare provider?

Treatment Complexity

Patients describe complex treatment journeys involving multiple therapies, dose adjustments, and balancing efficacy with side effects. This complexity reinforces the risks associated with non-medical switching.

Key Themes

Clinical: Stability is prioritised over absolute platelet count.

System: Variation across NHS trusts and perceived cost pressures.

Patient Experience: Strong preference for continuity and involvement.

Strategic Implications

1. Introduce mandatory patient consultation prior to switching.
2. Strengthen guidance on non-medical switching.
3. Develop patient education resources.
4. Generate real-world evidence to inform policy and practice.

Key Findings

Switching to generic eltrombopag is widespread and often poorly communicated. Effectiveness and stability are the dominant patient concerns, with many reporting anxiety and reduced confidence in decision-making processes.

Conclusion

This survey provides clear evidence that while TPO-RA therapies are effective for many patients, the process of switching—particularly to generic alternatives—introduces significant concern. Addressing communication gaps and ensuring patient involvement will be critical to maintaining trust and optimising outcomes.

Mervyn Morgan
CEO

ITP Support Association (Immune Thrombocytopenia)

Office: 01234376559

Mobile: 07751569137

Email: mervyn.morgan@itpsupport.org.uk

Web: www.itpsupport.org.uk

Report prepared 17th April 2026

Copyright © 2026 The ITP Support Association

Survey Results – Patient Reported Side Effects

Patient-Reported Side Effects of Thrombopoietin Receptor Agonists (TPO-RAs) in ITP

1. Executive Summary

This survey captures real-world patient experiences of thrombopoietin receptor agonists (TPO-RAs)—primarily **eltrombopag, romiplostim, and avatrombopag**—used in the management of immune thrombocytopenia (ITP). The survey was carried out in 2025, and we had 153 Responses from IYP patients.

Key findings indicate:

- **High variability in patient experience**, ranging from no side effects to significant multi-system burden
- **Common symptom clusters**: neurological (headache, brain fog), gastrointestinal (nausea, diarrhoea), musculoskeletal (pain), and dermatological (itching, rashes)
- **Notable psychosocial burden**, including sleep disturbance, anxiety, and low mood
- **Heterogeneity between drugs**, with some patients reporting better tolerability or effectiveness depending on agent
- **Clinically significant adverse events** reported, including suspected thrombosis and severe pain episodes

Importantly, a proportion of patients report **no side effects and meaningful therapeutic benefit**, underscoring the variability in response.

2. Methodology Overview

- **Data source**: Patient-reported survey responses (n ≈ multi-page dataset; qualitative + structured responses)
- **Population**: Individuals diagnosed with ITP and treated with ≥1 TPO-RA
- **Drugs assessed**:

- Eltrombopag
- Romiplostim
- Avatrombopag
- **Data types**:
 - Structured symptom checklists
 - Free-text qualitative comments
 - Medication history and comorbid treatments

3. Treatment Exposure

Patients reported use of:

- **Single-agent therapy**
- **Sequential or multiple TPO-RA exposure** (switching due to efficacy, tolerability, or logistics)

Examples include:

- Patients trialling all three agents over time
- Treatment discontinuation due to adverse events or logistical burden (e.g., travel for romiplostim injections)

4. Side Effect Profile

4.1 Most Frequently Reported Symptoms (Thematic Clusters)

Neurological / Cognitive

- Headaches
- Brain fog
- Dizziness
- Abnormal dreams

Widely reported across all three agents

Gastrointestinal

- Nausea
- Diarrhoea
- Acid reflux
- Decreased appetite

Some patients reported severe or persistent diarrhoea affecting quality of life

Survey Results - Patient Reported Side Effects *Cont...*

Musculoskeletal

- Shoulder pain
- Back or pelvic pain
- Joint pain

Pain syndromes were occasionally severe and disabling

Dermatological

- Itching
 - Skin rashes
 - Skin flushing
- Sleep and Fatigue
- Trouble sleeping
 - Fatigue

Sleep disturbance emerged as a recurring and impactful issue

Psychological

- Anxiety
- Depression / low mood

These symptoms appear across multiple drugs and may overlap with disease burden.

4.2 Less Common but Notable Effects

- Hair loss (variable onset from weeks to >1 year)
- Pins and needles / neuropathic symptoms
- Hearing deterioration
- Sinusitis / infection susceptibility
- Dehydration / increased thirst

4.3 Serious or Clinically Significant Events

Although infrequent, several responses highlight high-risk safety signals:

- Suspected or confirmed thrombotic events
- Severe pain leading to hospital admission
- Rapid platelet increases associated with

complications

- Transaminitis leading to discontinuation (eltrombopag)

These findings reinforce the importance of monitoring and risk stratification.

5. Drug-Specific Observations

Eltrombopag

- Broadest range of reported symptoms
- Frequently associated with:
 - Headaches
 - Gastrointestinal disturbance
 - Liver-related concerns (transaminitis)
- Some patients report excellent efficacy with minimal side effects

Romiplostim

- Mixed tolerability profile:
- Some report no side effects
- Others report multi-system symptoms including cognitive and mood effects
- Practical burden (injections, travel) noted

Avatrombopag

- Often perceived as:
 - Better tolerated in some patients
 - Associated with pain syndromes and neurological symptoms in others
 - Cases of rapid platelet response with complications reported

6. Patient Voice – Key Themes

6.1 Symptom Attribution Uncertainty

"I didn't realise some of the symptoms... were potentially linked to TPOs before conducting this survey."

- Patients often struggle to distinguish:
- Drug effects vs disease symptoms

- Drug effects vs comorbidities or age

6.2 Trade-Off Between Efficacy and Tolerability

"Eltrombopag... no adverse effects... lifesaver."
"Bad diarrhoea... did not improve count much."

Patients weigh:

- Platelet response
- Side effect burden
- Quality of life

6.3 Impact on Daily Living

- Sleep disruption
- Reduced ability to work or socialise
- Limitations on outdoor activity (e.g., sun sensitivity)

6.4 Treatment Journey Complexity

- Frequent switching between therapies
- Polypharmacy (steroids, immunosuppressants, etc.)
- Difficulty isolating causality

7. Vaccine Attribution

- Mixed responses:
 - Some patients believe ITP onset was vaccine-related
 - Others explicitly reject this link

This reflects perception variability rather than causal evidence within the dataset.

8. Key Insights for Stakeholders

For Clinicians

- High inter-patient variability → personalised treatment selection essential
- Monitor:
 - Neurological symptoms
 - Gastrointestinal tolerance
 - Thrombotic risk
- Address psychological burden proactively

For Patients

- Symptom tracking may improve attribution and

management

- Awareness of potential side effects is currently incomplete

For Industry / Research

- Need for:
 - Better patient-reported outcome (PRO) integration
 - Comparative tolerability studies across TPO-RAs
 - Real-world safety registries

9. Limitations

- Self-reported data → subject to recall and attribution bias
- Incomplete responses (skipped questions common)
- No standardised severity grading
- No denominator for precise incidence calculation

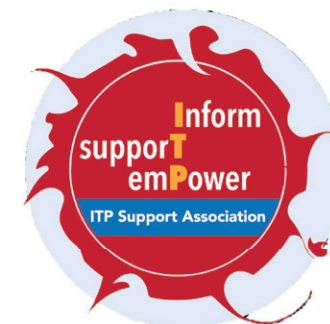
10. Conclusion

This survey highlights that while TPO-RAs are highly effective therapies for ITP, their side effect burden is heterogeneous and often under-recognised.

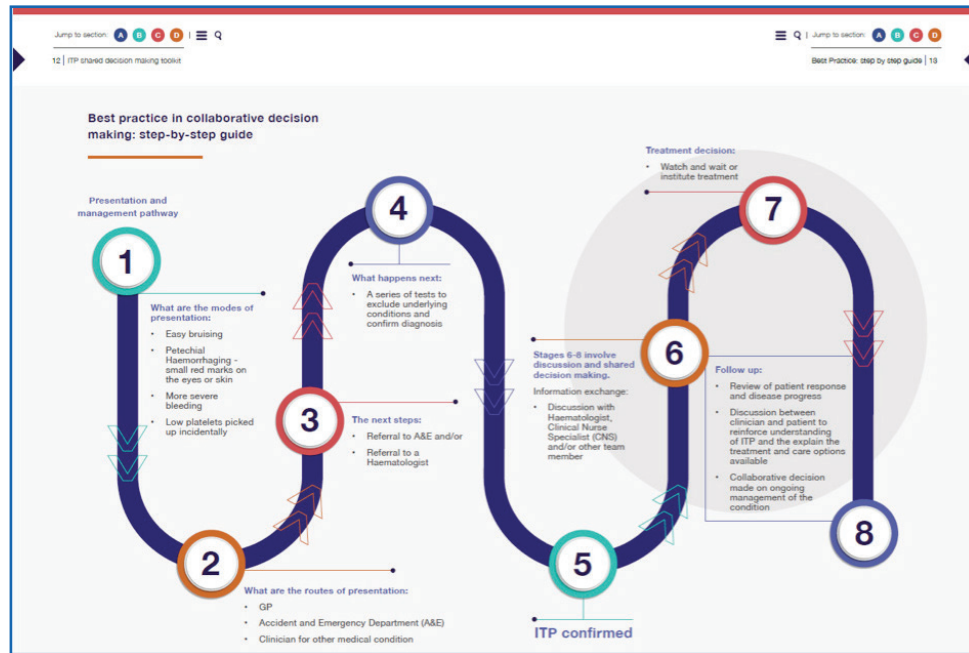
The findings reinforce a central principle: TPO-RA treatment is not one-size-fits-all—optimisation requires continuous patient engagement, monitoring, and shared decision-making.

Mervyn Morgan

UK and Ireland ITP Support Association



Shared Decision Making Document available in Six Languages



'Making the right choices in ITP management and care' – A shared decision-making toolkit for patients.

To download the English Language version click this link: Making the right choices in ITP management and care.

The toolkit is now available to download in French, German, Italian, Spanish and Portuguese please visit our website at www.itpsupport.org.uk.

Ground-breaking new toolkit launched to support patients with rare blood condition to take ownership of their care.

Shared decision-making toolkit developed for people with Immune Thrombocytopenia (ITP) – a rare autoimmune blood disorder that causes a

shortage of platelets and bruising.

Toolkit developed via a multi-stakeholder ITP Expert Working Group led by the ITP Support Association and the UK ITP Clinical Forum.

The toolkit will facilitate improved treatment and care by empowering and educating patients – and reminding healthcare professionals – about the importance of ongoing collaborative decision making in the management of ITP.

As part of Global ITP Awareness Week (20-25 September), the ITP Support Association and the UK ITP Forum are pleased to launch Making the right choices in ITP management and care – A shared decision-making toolkit for patients.

The toolkit is a response to the results of a patient

survey made by the ITP Support Association in 2020. The survey highlighted inconsistencies in the diagnosis and management of ITP – which can negatively impact patients.

It defines what best practice collaborative decision making in ITP management and care looks like and provides a practical guide to help patients, carers and healthcare professionals achieve this.

This material allows the patient to develop knowledge, skills, and the confidence needed to make managed and informed decisions about personalised health and care. It will ensure that more ITP patients are on care plans that appropriately suit their lifestyle and individual circumstances, improving their quality of life – which can be severely impacted if an individual is placed on a suboptimal care plan.

This toolkit is ground breaking in that it is one of the first haematological conditions to develop specific guidance in response to National Institute for Health and Care Excellence (NICE) recommendations for shared decision-making practices to be implemented across all conditions. The toolkit is endorsed by the Royal College of Pathologists, Royal College of Physicians, The British Society for Haematology, and the Genetic Alliance UK.

The ITP Expert Working Group and partners are calling for this best practice guidance to be adopted across all healthcare settings in the UK. Professor Adrian Newland, Chair of the ITP Support Association, said:

"Following our recent patient survey, the ITP Support Association identified significant disparities between patient experiences of care and whether individual preferences were considered in care management plans. We decided that we should bring together a group of

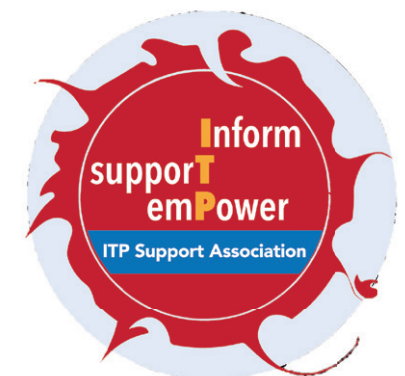
haematologists with a particular expertise in ITP to develop this toolkit that, we hope, will empower patients to hold collaborative and honest discussions with their clinician which in turn will result in better outcomes and quality of life."

Dr Quentin Hill, Chair of the UK ITP Forum, said:

"The ITP toolkit is an excellent introduction and companion document to support and empower patients. It guides them step by step through the journey of diagnosis and medical care. A collaborative approach is more rewarding for patients and clinicians, and I have no hesitation in recommending that the ITP Toolkit is given to all patients at presentation."

Dr Sue Pavord, Consultant Haematologist, Oxford University Hospitals and ITP Expert Working Group member said:

"It has been a real pleasure working with patients and the ITP Support Association in preparing this Toolkit. Mutual understanding and joint decision-making is crucial when planning management which is suitable and acceptable to the individual patient. I encourage all NHS trusts and haematological teams to review the Toolkit and refer to the guidance when deciding on treatment and care with an ITP patient."



ITP Patient Explainer

Make the most of your appointment with your care team, using the **ITP Discussion Guide**

For people living with ITP



NP-23508 | Date of preparation: September 2022

ITP Patient Explainer Cont...

What is the ITP Discussion Guide?

The ITP Discussion Guide is a tool that can help support focused discussions with your care team about your ITP care goals, needs and preferences.

Highlight what matters most to you and discuss it with your care team to make a joint decision about your care plan.

How do I use the ITP Discussion Guide?

- 1 **Complete your personal ITP Discussion Guide** by answering questions about your last month managing ITP
- 2 **Highlight your top care priorities** based on your answers, so that you can remember what you want to discuss at your next ITP appointment
- 3 **Bring your completed guide** to your ITP appointment
- 4 **Use the guide to help structure a discussion with you care team** about what's most important to you in your daily life with ITP

Scan the QR code to complete your own ITP Discussion Guide

You don't need to register to use the ITP Discussion Guide. None of your data is stored, tracked, shared, processed or saved.



NP-23508 | Date of preparation: September 2022

ITP Patient Explainer Cont...

Why highlighting what matters most to you with your care team is important

While controlling your bleeding is essential, maintaining your health is also about your ability to enjoy and get on with life.

When you and your clinician understand what's important to each other, you can make decisions about your care together. Your clinician can then design your care plan with your personal needs, preferences, and goals in mind.

Top tips for using the ITP Discussion Guide for your next consultation

- Usually, our first reaction is the most accurate, so don't spend too much time thinking about your answers, just go with your gut
- Remember that each response will be individual to you, so there is no right or wrong answer
- Use the guide ahead of each appointment to track any changes over time, and let your care team know if your priorities have changed since your last appointment
- Ask for an explanation of anything you don't understand or feel unsure about
- Refer to the guide if you feel like your care priorities aren't being heard
- Don't be afraid to say if you feel like your goals, needs and preferences are not being taken seriously

ITP Discussion Guide



Your ITP Discussion Guide

This guide is designed to help you have more focused discussions about your ITP care needs and preferences with your carer / care team

- 1 **Reflect on your last month managing ITP** and note down what matters most to you. You do not need to complete everything: focus on the elements that are most important to you.
- 2 Once completed, **tick the stars next to the questions that are most important to you.**
- 3 **Bring your completed guide to your next appointment** and discuss it with a member of your care team:
 - Use the guide to outline your top care priorities and go through your other issues in turn
 - Help your care team to understand your goals and what's most important to you in your daily life.
- 4 **Make a joint decision** on your future care plan.

Today's date:

Note down today's date so you can look back and track how you're feeling over time.

____/____/____

My goals

First, write down your short-term goals; the things that are most important to you right now (this week / month).

For example, having a nice walk with the dog this week.

Then, write down your longer-term goals; the things that are most important to you in the future (next 6 months).

For example, going on a cycling holiday in three months.

Living with ITP

Living with ITP can affect your wellbeing and how you cope with everyday activities. **Use the scales below to rate how ITP affects your day-to-day life. Circle the score that best reflects how you feel.**

Coping with ITP symptoms

How have ITP symptoms impacted your daily life in the last month (including fatigue, bleeding, bruising, etc.)?

☹️ 1 2 3 4 5 😊 ★

Feeling on top of things

Do you feel able to carry out everyday tasks like washing yourself, dressing up, cooking, DIY, doing household chores and shopping?

☹️ 1 2 3 4 5 😊 ★

Having emotional wellbeing

Do you feel positive (in control of your thoughts and feelings), or more negative (anxious, upset or depressed)?

☹️ 1 2 3 4 5 😊 ★

Pursuing hobbies

Do you feel you can pursue the activities you enjoy the most?

☹️ 1 2 3 4 5 😊 ★

Spending time with friends and family

Do you feel you can spend time with or care for family and friends in the way you want to?

☹️ 1 2 3 4 5 😊 ★

Performing well at work or school

Do you feel you can excel in your work and/or studies?

☹️ 1 2 3 4 5 😊 ★

Taking part in sports and exercise

Do you feel you can reach your sport and exercise goals?

☹️ 1 2 3 4 5 😊 ★

Use this space to write down further details about how ITP affects your day-to-day life.

ITP Discussion Guide Cont...

Managing ITP effectively

To enable you to live your life the way you want to, it's important to work with your care team to find a treatment that works well for you. **Use the scales below to rate how you feel about your ITP treatment. Circle the score that best reflects how you feel.**

How well does your ITP treatment help you to manage / prevent your symptoms (including fatigue, bleeding, bruising etc.)?

☹️ 1 2 3 4 5 😊 ★

How satisfied are you that your treatment maintains or increases platelet production?

☹️ 1 2 3 4 5 😊 ★

How satisfied are you with how often you take your treatment?

☹️ 1 2 3 4 5 😊 ★

How satisfied are you with the number of blood tests needed to check your platelet count due to treatment?

☹️ 1 2 3 4 5 😊 ★

How satisfied are you with the way your treatment is administered?

☹️ 1 2 3 4 5 😊 ★

How easy is it for you to fit your treatment intake into your usual daily routine? (For example, commuting, working, eating, sleeping)

☹️ 1 2 3 4 5 😊 ★

How easy is it for you to take treatment when your routine changes? For example, when on holiday?

☹️ 1 2 3 4 5 😊 ★

Overall, how satisfied do you feel with your treatment and/or care?

☹️ 1 2 3 4 5 😊 ★

Notes:

Use this space to write down further details about how your treatment and care impacts your daily life, or any wishes you would like to share with your care team.

ITP treatment and your goals

Does ITP or ITP treatment currently affect your ability to pursue your personal goals?

YES NO

Use this space to write down how ITP affects your personal goals.

Priority discussion points for your next consultation

Look back over the questions and tick the stars highlighting the elements that are most important to you.

Use this space to write down the 1-3 most important topics you would like to discuss at your next ITP appointment.

And finally...

- ★ Don't be afraid to say if you feel that you're not being heard, or your issues aren't being taken seriously
- ★ Ask for an explanation of anything you don't understand

The ITP Discussion Guide has been co-created by the UK ITP Support Association, Sobi AB and Health Unlimited and funded by Sobi AB | NP-23507 | Date of preparation August 2022

NEW - Medical Emergency Card



NEW - ITP Medical Emergency Card – credit card size, the patient can add their own medical details, including GP Details, Emergency Contact details and medication information.

The ITP Emergency Card is a small card that individuals carry with them to provide important medical information about their ITP in case of emergencies. It typically includes details such as the person's name, emergency contact information, known allergies, chronic conditions, medications being taken, and any specific medical directives or instructions.

Having an ITP Emergency Card can be helpful in situations where the person is unable to communicate their medical history or conditions, such as during accidents or emergencies. It allows medical professionals or first responders to quickly access vital information, ensuring appropriate and timely care.



Emergency Cards are often recommended for individuals with chronic illnesses, allergies, or other medical conditions that may require specific treatment or precautions.

It's important to keep the ITP Emergency Card with you at all times, ideally in a place easily accessible to others, like your wallet or purse.

It's also a good idea to inform your emergency contacts about the existence and location of your ITP Emergency Card, so they can provide the necessary information if you're unable to do so.



Remember, the ITP Emergency Card is just one tool to help ensure your safety and proper medical care. It's still important to communicate your medical history and conditions to your healthcare providers during regular visits, and to carry any additional identification or documentation that may be required in your specific situation.

New Members receive their own ITP Emergency Alert Card when they join the ITPSA as part of the New Members Pack, not a member, then send a SAE to: The ITP Support Association, The Platelet Mission, Kimbolton Rd, Bolnhurst, Beds, MK44 2EL. The cards are free but donations are appreciated.

Please note this card replaces our old ITP Emergency Card advertised in previous issues of the Platelet.



Share Your Patient Story



Living with a rare disease in the UK and Ireland and anywhere in the world can be extremely isolating for many patients and caregivers.

While each of our patient stories are as individual as we are, patients can still pick out similarities in other peoples ITP journeys which helps them to connect, even when you feel isolated and alone.

<<<< Share your patient story by sending it to >>>> info@itpsupport.org.uk

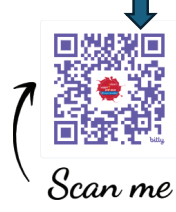
Try out the new ITPSA REDBUBBLE Store

Try out the ITPSA new branded gift items from our REDBUBBLEstore.

They include a design by ITPSA Medical Advisor Dr Drew Provan. By shopping with us you are helping to support the work of the ITPSA in raising awareness for Immune Thrombocytopenia with the profits from each sale going directly to our cause.



Read more patient stories here



Fundraising News

Montague

What a great achievement by a remarkable young man in walking all from the North Sea Coast to the dip his toes in the Irish Sea and along the way raising over £6,000 for the ITP Support Association. Well, done young Montague, What a Superstar.



Andy Parsons

Andy completed the London Marathon in a time of 5 hours, 15 minutes and 7 seconds, supporting the ITP Support Association.

Andy's daughter, Jasmin, was diagnosed with ITP in 2021 when she was hospitalised for a week following a blood test showing a dangerously low platelet count.

Still now, this requires close and regular monitoring.

Andy said after the run, that was the hardest £1.7k I have ever earned in my life.

From everyone at the ITP Support Association, thank you and well done, great work.



Thomas Hoof

Thomas Hoof is raising money for ITP Support Association, starting on 12th April, I'll be taking on a challenge to walk 150 km in 30 days to raise money for the ITP Support Association.

This cause is very personal to our family. When my eldest son Charles was just four years old, he was diagnosed with ITP (Immune Thrombocytopenia). During the acute phase of his illness, he was injured and because his platelet levels were so low, he had to undergo treatment in the hospital. Thankfully, his case was short-lived, and he recovered within six months and was out of the hospital after a week, but it was still a frightening and uncertain time for us as parents.

Skydiving for ITP


Do you fancy doing something different to support the ITP Support Association?

Now you can!

For more information use the link or scan the QR code
<https://bit.ly/3qJ5Lsc>



HOW SKYDIVING WORKS CHARITY GUIDE



SKYLINE SKYDIVING


How It works is the individuals agree to raise a minimum sponsorship of £395 for a tandem skydive. This covers their deposit, jump costs and average sponsorship of \$125 to the charity. Anything raised above the minimum amount means a larger donation towards yourselves.

- \$70 Deposit paid to Skyline at the time of booking.
- \$200 approx. jump cost (varies between airfields) will be invoiced to you a week of the jump.
- \$125 approx. charity sponsorship money.

We will send you email alerts when you receive enquiries and bookings. As well as on the week of your supporter's jump so you can let us know if they have sent any sponsorship directly to you, as this will ultimately affect the amount the airfield asks for on the day.

NO COSTS & NO COMMITMENTS!
That's right. It's as good as it sounds.

HOW SKYDIVING WORKS CHARITY GUIDE



SKYLINE SKYDIVING

What Skyline Provides:

- We add you to www.skylineparachuting.co.uk and that gets 17,000+ visitors per month.
- We have a dedicated email address where participants can contact us directly with any skydiving questions.
- We and our airfields manage the event for you and your supporters so you can concentrate on your inhouse events and/or other major donor gifts.
- We send all confirmation details from here bespoke to each airfield.

You will receive a bespoke booking link provided by Skyline to use on your website/social media to get people signed up to skydiving.

We cover all administration of the event including rescheduling if bad weather or cancellations.

NO COSTS & NO COMMITMENTS!
That's right. It's as good as it sounds.

Plasma Donation



All types can save lives

Your plasma can treat 50 diseases

Join us at blood.co.uk/plasma



The NHS needs more plasma donors but many people don't realise they could donate.

The amazing donors come from all walks of life and plasma is used to treat more than 50 diseases including ITP (Immune thrombocytopenia).

Book an appointment at www.blood.co.uk/plasma

Leaving a Legacy



Thank you for considering leaving a gift to the ITP Support Association in your will and helping to fund the work of the ITP Support Association and research into Immune thrombocytopenia.

There are 3 main types of gift you can make:

- residuary – a share in, or all of, what's left of the value of your estate after family and friends have been taken care of
- pecuniary – a specific sum of money
- specific – an item such as jewellery or a piece of art

The advantage of leaving a share (also known as a residuary gift) is that it stays the same over time and you won't need to change your will to keep up with inflation.

This planning form guides you through the steps you need to consider when you write your will and it helps you gather your thoughts and plans in one place.

Visit www.itpsupport.org.uk and download our Making a Will Planner Form

If you already have a will and you want to include a gift to the ITP Support Association (sometimes called a legacy), there may not be any need to rewrite it.

You can ask a qualified professional such as a solicitor to add an amendment (called a codicil). As a general rule, if the change you wish to make is quite small or simple, you can use a codicil, and if the change is more significant or complex you should

make a new will.

Visit www.itpsupport.org.uk and download the Codicil Form for the ITP Support Association.

Suggested wording for making your gift to the ITP Support Association

This suggested legal wording will assist your solicitor in drawing up or amending your will to include your gift to help our vital work.

Wording for a residuary gift

I give the residue of my estate to The ITP Support Association, The Platelet Mission, Kimbolton Road, Bolnhurst, Beds, MK44 2EL Registered Charity Number 1064480 * for its general charitable purposes (which includes research). I further direct that the receipt of the Chief Executive (CEO) or other proper officer of the said charity for the time being shall be a full and sufficient discharge for the said gift.

Wording for a gift of money or an item

I give the sum of £_____ (or the item specified) to The ITP Support Association, The Platelet Mission, Kimbolton Road, Bolnhurst, Beds, MK44 2EL Registered Charity Number 1064480 for its general charitable purposes (which includes research). I further direct that the receipt of the Chief Executive (CEO) or other proper officer of the said charity for the time being shall be a full and sufficient discharge for the said gift.

Note

We can not recommend a particular solicitor to make your will but we suggest you contact the Law Society who can provide details of solicitors in your area, including those who specialise in wills. We always recommend that your will is drafted by a qualified professional such as a solicitor as their businesses are regulated by law.

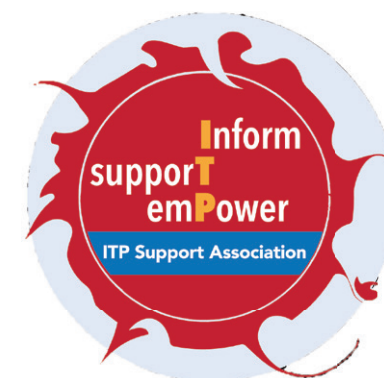
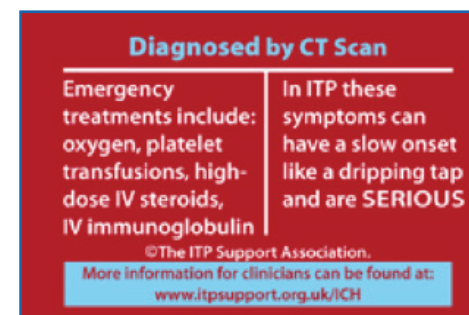
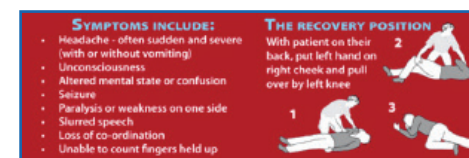
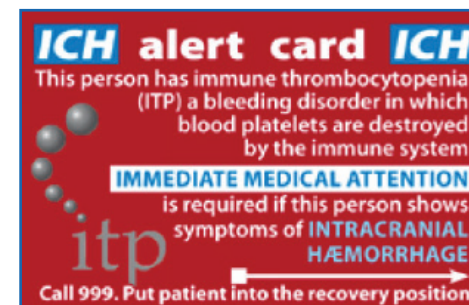
Order a free ICH alert card

Having an ICH alert card is rather like taking out travel insurance. You hope you'll not have to ever use it but it is there to give you peace of mind in case the worst happens.

It is very rare for anyone with ITP to have a brain haemorrhage (ICH), but if it should happen to you, fast action by you or those around you, plus prompt scans and specific treatment by emergency doctors can help prevent a serious situation becoming a disaster. The ITP Support Association's ICH alert card was developed in 2012 with assistance from Professor Adrian Newland, who said 'ICH is very rare in patients with counts over 10, and even in those under 10 is only usually seen if there are other complicating factors.'

The card's purpose is to make patients aware of the early warning signs of ICH and to alert paramedics or A&E staff that these signs in ITP patients must be taken seriously. We have sent batches of ICH alert cards for distribution at ITP Clinical Centres and other interested hospitals. Our medical advisors strongly suggest that ITP patients should carry one just as people on steroids carry steroid information cards, and people with epilepsy carry alert cards to help in the event of a seizure.

If you or your child have ITP and don't already have one of these folded red plastic alert cards, you can order yours now by sending your request with an SAE to: The ITP Support Association, The Platelet Mission, Kimbolton Rd, Bolnhurst, Beds, MK44 2EL. The cards are free but donations are appreciated.



Ways To Donate

The ITP Support Association is on JustGiving
Please visit our page at <https://www.justgiving.com/itpsupportassociation> and make a donation.



Facebook



Since the end of 2018 many friends of the ITP Support Association have used Facebook as a platform to help raise donations for the Association. It has raised over £20,000 in support of the ITP Support Association. Facebook has 'no fees' which means 100% of the contributions are donated to the ITP Support Association. Visit our Facebook page for details.

RAISE MONEY FOR ITP WHEN YOU SHOP ON LINE at no extra cost to you!



You shop directly with the retailer, same goods, same prices, but by signing up (for free) on Easy Fundraising.

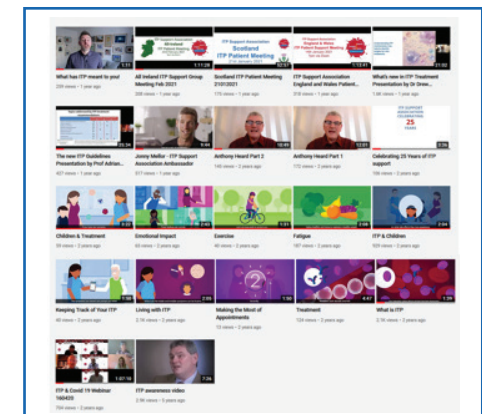
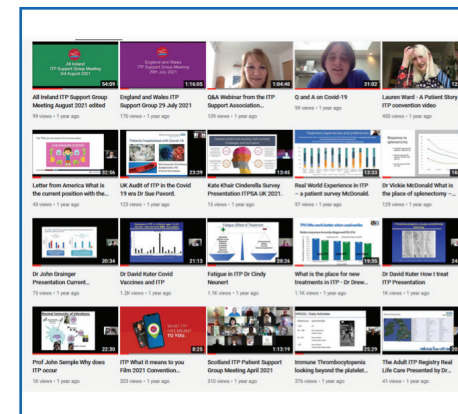
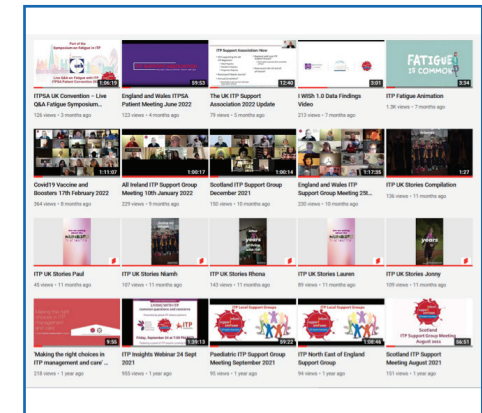
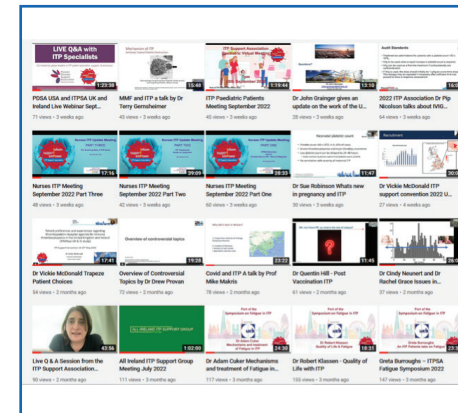
Go to www.easyfundraising.org.uk/causes/itpsupportassociation and use the links on the easyfundraising site to take you to your chosen retailer. You'll get access to hundreds of exclusive discounts and voucher codes. Join the increasing number of supporters who have raised hundreds of pounds for the Association.

Visit our YouTube Channel



The ITP Support Association YouTube Channel has almost 140 videos covering ITP. Plus, with now over 1,000 YouTube subscribers, thank you to everyone for helping to reach this milestone.

Go to our YouTube Channel and press subscribe <https://www.youtube.com/@ITPSAUK/videos>



Publications List

BOOKLETS

Please note these booklets and articles are now available, free to download from our website, visit www.itpsupport.org.uk and click on the Membership tab, then Membership resources.

Shared Decision Making 'Making the right choices in ITP management and care' – A ground-breaking booklet mapping the process from diagnosis to treatment. This document has been endorsed by a number of Royal Colleges and the BSH.

ITP Discussion Guide – produced in conjunction with Sobi, this is a questionnaire type guide that you complete prior to your clinical appointment, helps you ask the right questions during your appointment.

ITP Discussion Guide patient explainer – helps you understand the ITP discussion guide.

ITP Discussion Guide Clinician explainer – take a copy with you for your Doctor or Consultant.

Know about ITP – core information booklet.

Fatigue in ITP – about this hidden symptom of ITP with suggestions on how to cope.

What did you call it? – question & answers about adult ITP.

What did you call it? – question & answers about childhood ITP.

ITP 'n stuff – question & answers about ITP for teenagers.

ITP and pregnancy – what to expect with a low platelet count in pregnancy.

Drugs that cause or aggravate thrombocytopenia – drugs to avoid with ITP.

Splenectomy – About open and keyhole surgery, indium labelled spleen scan, and aftercare.

Holiday insurance & travel guide – advice on travelling, flying, vaccinations & insurance.

Protocol for dentists treating patients with ITP – to give to your dentist.

Guidelines for schools, clubs, and playgroups – to give to a child's school.

Choosing your sport – which sports are safe with ITP?

James/Jessica tells his/her story – a book about ITP for newly diagnosed children.

'I have chronic ITP' – a follow-on booklet for children whose ITP doesn't remit.

FACTSHEETS

Treatment table – a list of drugs used to treat ITP and their possible side effects (download from website)

Holiday factsheet – ITP information and patient emergency details with English translation: available in Dutch, French, German, Greek, Italian, Russian, Spanish, Turkish or Romanian.

Pupil's factsheet – ITP information with space for child's emergency details and photo (download from website)

Employer's factsheet – ITP information with space for employee's emergency details.

ARTICLES PUBLISHED IN PREVIOUS ISSUES OF THE PLATELET

1. Colds and 'flu
2. ITP and skin irritation
3. MMR vaccine and ITP
4. Needlephobia in children
5. Hayfever and ITP
6. ITP & school attendance
7. ITP investigation & treatment procedures
8. Insurance issues
9. Accessing drug information
10. Is drug treatment a risk worth taking?
11. → e ITP pupil moving to senior school
12. Alert medical cards and jewellery
13. Healthy eating with ITP
14. H-pylori (stomach bacteria) & ITP
15. Causes of excess infections in ITP
16. A summary of low platelet disorders
17. Night calls – when to call the doctor
18. Service recruitment & ITP
19. Dentistry and ITP (questions & answers)
20. Women & ITP (questions & answers)
21. New insights on what causes ITP
22. Neonatal → thrombocytopenia
23. Post Transfusion Purpura
24. Must I mention my ITP at a job interview?
25. → e versatility of platelets

Publications List cont...

26. How is ITP diagnosed?
27. ITP – in dogs!
28. Complications of ITP
29. Flying & ITP
30. Who needs Vitamin D supplements
31. Why don't we see an immunologist
32. What does the ITP Support Association do?
33. Sustained responses with TPO drugs
34. Is splenectomy still a valid treatment today?
35. Where are we with ITP today?
36. Are young platelets better?

AMERICAN PERSPECTIVES

1. A history of ITP
2. ITP in pregnancy
3. What is a platelet?
4. How is ITP diagnosed?
5. Non-intervention in childhood ITP
6. Activity restrictions in ITP children
7. How many platelets are enough?
8. Splenectomy and ITP
9. Can I die from ITP
10. → The child newly diagnosed with ITP
11. Surgery in the patient with ITP
12. Are alternative & herbal remedies safe?
13. Use of steroids – a boon and a bane
14. Immunoglobulin – good and bad news
15. Intravenous Anti-D – another treatment
16. Chronic ITP – disease or risk factor?
17. Platelet counts – how useful are they?
18. ITP, sports, and sports injuries
19. After failure of splenectomy & steroids
20. ITP in the elderly
21. Rituximab for ITP
22. ITP and tiredness
23. Viruses and childhood ITP
24. Increasing platelet production
25. What happens to adults with ITP
26. ITP and 'cure'
27. What is a clinical trial?
28. → The relationship between ITP and lupus
29. ITP in adolescents
30. → The development of new ITP drugs
31. Menstrual periods in women with ITP
32. Coping with prednisolone – book review
33. Assessment of bleeding severity in ITP
34. Steroid side effects
35. Splenectomy for children with ITP?
36. What happens after a child recovers?
37. Prevention of infections in asplenic
38. Who cares for patients with ITP
39. Who needs the new TPO drugs for ITP
40. TPO drugs in children & adolescents
41. Platelets & walnuts (food intolerance case)
42. Let's let ITP kids be normal

43. Silent haemorrhage in ITP
44. When bad bleeding happens
45. How often does ITP occur
46. How do haematologists treat ITP patients
47. Low platelets in children- is it always ITP?
48. Low platelets in adults- is it always ITP?
49. ITP: It's not only about bleeding
50. Vitamins, alcohol & ITP
51. Familial (hereditary) thrombocytopenia
52. → The full blood count – what does it tell us?
53. Abnormal blood clots in ITP
54. Treatment of ITP children, Who and when
55. Immuno suppressive therapy
56. Platelet counts during pregnancy
57. Vaccinations – An ounce of prevention
58. Spinal anaesthesia, and childbirth
59. ITP and Depression
60. Adherence to ITP therapy
61. Bone marrow biopsy and ITP
62. Don't forget splenectomy (in adults)
63. Splenectomy for children with ITP
64. I have ITP. Should I be taking this blood thinner?
65. ITP, Platelet Counts, and Pregnancy
66. ITP and New Treatments: The view from your side of the pond
67. New Drugs for ITP- Why wait?
68. How do ITP patients know what's the right thing to do?
69. Understanding the Immune System
70. New Drugs for an "Old" Disease
71. Different Bleeding Symptoms Despite Similar Platelet Counts
72. COVID-19 and ITP
73. Teaching a New Dog a New Trick
74. COVID-19 Vaccination: What you Need to Know
75. Participating in Research in ITP
76. What is vaccine-induced immune thrombotic thrombocytopenia (VITT) and is there a connection with ITP?
77. Are people with ITP immunocompromised?
78. Revisiting Splenectomy for Treating ITP
79. Fatigue

To order any of these items (free to members), send a stamped addressed envelope to: **The ITP Support Association, The Platelet Mission, Kimbolton Road, Bohnhurst, Beds, MK44 2EL.**

MEMBERSHIP SUBSCRIPTION FORM:

PLEASE USE THIS FORM TO PAY BY CHEQUE, POSTAL ORDER OR STANDING ORDER

YOU CAN PAY ONLINE AT WWW.ITPSUPPORT.ORG.UK

SECTION 1: MEMBERSHIP DATABASE CONTACT INFORMATION *Please complete this section*

TITLE	<input type="checkbox"/> Mr	<input type="checkbox"/> Mrs	<input type="checkbox"/> Miss	<input type="checkbox"/> Ms	<input type="checkbox"/> Dr	<input type="checkbox"/> Other
NAME						
ADDRESS						
ADDRESS						
POSTCODE				TELEPHONE		
EMAIL						
Let us keep in touch	Opt in <input type="checkbox"/>	<i>Please tick the box</i>		<input type="checkbox"/> Email	<input type="checkbox"/> Post	<input type="checkbox"/> Phone

SECTION 2: PLEASE INDICATE YOUR ITP STATUS *Please tick the appropriate box*

This assists us if we need to produce statistics about our membership for health organisations or pharma companies

- Person with ITP (ongoing or in episodes) In remission from ITP Parent of ITP child
- Family member of someone with ITP Friend or other Health Professional

SECTION 3: PAYMENT *Please tick the appropriate box(es)*

- Please Gift Aid my payment (Please complete the gift aid form if you haven't sent us one before)
- I wish to pay by standing order (Please complete the standing order form)
- I wish to pay by cheque (Please complete the section below. We are grateful for added donations)

MEMBERSHIP	<small>*After 31st January 2020</small> *£15 UK *£20 Overseas	FOR OFFICE USE
GENERAL DONATION		
RESEARCH DONATION		
TOTAL ENCLOSED		

Please return this form with your cheque or standing order form to:-

The ITP Support Association, The Platelet Mission, Kimbolton Road, Bolnhurst, Beds MK44 2EL

The associations privacy policy is available at: www.itpsupport.org.uk

To join or renew your membership of the ITP Support Association, you can complete the form above, visit <https://bit.ly/ITPSAJoin> and scan the QR Code and click join. Please note that if you are renewing membership please still click join as the CRM system will automatically add to your existing membership.



Send this form to: The ITP Support Association,
The Platelet Mission, Kimbolton Rd, Bolnhurst, Beds, MK44 2EL

