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ITP Support Association

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


# 'What a Convention.'

# The Platelet

JOURNAL OF THE ITP SUPPORT ASSOCIATION

**SEPTEMBER** 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**



GRIFOLS

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# From ITP HQ

I am writing this early (July) as I will be taking some time off for a visit to Hospital so by the time you read this edition summer will be all but over, we'd like to take a moment to thank everyone who has supported the ITP Support Association over the past few months.

Whether you've attended one of our events, shared your experiences, volunteered your time or simply continued your membership, your support makes a real difference to our work and to the ITP community.

It was a real pleasure to welcome so many of you to this year's Annual Patient Convention. Seeing patients, families, carers and healthcare professionals come together to learn, ask questions and share experiences is always a reminder of how important our community is. We hope those who attended left feeling better informed, encouraged and reassured, and we'd like to offer our heartfelt thanks to all of our speakers, exhibitors and volunteers who helped make the day such a success.

As this is also the tenth anniversary of the International ITP Alliance I have also included a report covering the ITP Patient Conference in Australia from the wonderful CEO of ITP AUSNZ Danielle Boyle, those of you who attended our Convention may have seen Danielle she was supporting us with the organisation for our event.

We at the ITP Support Association (UK and Ireland) are proud to be the original ITP Patient Organisation and it makes us so proud that so many others have followed our road.

## ITP Awareness Week

At the end of September we have ITP Awareness Week, one of the most important dates in our calendar. It gives us all the opportunity to shine a spotlight on a condition that is still not widely understood and to help more people recognise the challenges faced by those living with ITP. Whether you share one of our social media posts, wear our awareness colours, talk to friends and colleagues about ITP or simply start a conversation, every action helps raise awareness and strengthens our voice

## New Publications

We're also delighted to introduce two new publications at our convention that we hope will be valuable additions to our range of patient information. Living with ITP has been written to provide practical advice and encouragement for people managing the day-to-day realities of living with ITP, while our new booklet on Pregnancy in ITP offers clear, up-to-date information for women with ITP who are planning a pregnancy, expecting

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# From ITP HQ Cont...

a baby or navigating the months that follow. We know that reliable information can make a real difference, and we hope these resources will help patients feel more confident and supported. If you'd like a copy, see the details within this edition.

Also in this edition is a wonderful article from ITP Mentor Rhonda Anderson on the subject of 'Overcoming Anxiety'.

Whilst we are on the subject of mentors we would like to welcome new ITP Mentor Lauren Roden to the role. Lauren, an ITP patient, originally from the USA but now lives in Cumbria.

**Thank you**

Finally, thank you once again for being part of the ITP Support Association. We are proud of what we achieve together, and none of it would be possible without the kindness, generosity and continued encouragement of our members and supporters. We look forward to keeping in touch over the coming months and hope you'll continue to join us as we work to improve the lives of everyone affected by ITP.




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**Mervyn Morgan CEO ITPSA**

**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.

Lauren Roden – ITP Patient
Lauren is based in the Northwest

support





# ITP Annual Patient Convention 2026 - That's a wrap

**ITP Support Association Annual Patient Convention 2026**
**Royal College of Pathologists, London – Saturday 27 June 2026**
**Bringing Patients and Specialists Together**

For more than three decades, the ITP Support Association has been committed to ensuring that everyone affected by Immune Thrombocytopenia (ITP) has access to reliable information, expert advice and the support of a community that truly understands the condition. Our Annual Patient Convention has become the flagship event in the Association's calendar, bringing together leading international clinicians, researchers, patients, families and industry partners for a day dedicated to education, collaboration and hope.

This year's Convention, held at the **Royal College of Pathologists** in London, proved to be one of our strongest programmes to date. With over a dozen internationally respected speakers from the UK, Europe and the United States, delegates were treated to a comprehensive overview of the latest developments in ITP research, treatment and patient care. The programme also included interactive breakout sessions, opportunities to meet specialists face-to-face, an extensive exhibition and the ever-popular question-and-answer panel.

**A Warm Welcome**

Opening the Convention, **Mervyn Morgan**, Chief Executive of the ITP Support Association, welcomed delegates from across the United Kingdom and overseas.

In his introduction, he reflected on another remarkable year for the Association. From expanding patient education and supporting groundbreaking research to representing the patient voice within international collaborations and clinical trials, the charity continues to ensure that patients remain central to advances in ITP care.

He also thanked the Medical Advisory Panel, trustees, volunteers, sponsors and exhibitors whose continued support enables the Association to deliver independent, high-quality educational events year after year.

**International Expertise Opens the Day**


The scientific programme began with an outstanding presentation from **Professor David Kuter** of Massachusetts General Hospital, USA, one of the world's leading authorities on ITP.

His lecture, "**New Developments in ITP,**" provided delegates with an overview of how the understanding and management of ITP continues to evolve. He discussed advances in disease biology, emerging therapies and how ongoing research is improving outcomes for patients. His presentation reinforced the exciting pace of innovation currently taking place within the field of ITP and highlighted the importance of continued clinical research.

**Smaller Groups, Bigger Conversations**

One of the most popular parts of this year's Convention was the introduction of dedicated breakout sessions, allowing delegates to discuss issues most relevant to them in a more informal environment.

# ITP Annual Patient Convention 2026 - That's a wrap

Adults and adolescents met with **Professor David Kuter, Prof Catherine Bagot** and **Dr Alice Hart**, while families of children and young people joined **Dr Cindy Neunert, Professor Nichola Cooper** and **Professor John Grainger.**

These sessions encouraged open discussion, allowing patients and families to ask detailed questions that may not have been possible during the main presentations. Delegates particularly appreciated the opportunity to speak directly with internationally recognised experts about their own experiences of living with ITP.

## Can Artificial Intelligence Help Patients?

One of the most thought-provoking presentations of the day came from Professor **Drew Provan**, who explored whether Artificial Intelligence can help in ITP.

As AI rapidly becomes part of everyday healthcare, Professor Provan explained how these technologies could support clinicians through improved data analysis, assist researchers in identifying treatment patterns and potentially enhance decision-making in the future. He also discussed the importance of maintaining the human relationship between clinician and patient, ensuring that technology supports rather than replaces clinical judgement.

The session generated considerable discussion, highlighting both the exciting opportunities and the careful consideration required as AI becomes increasingly integrated into modern medicine.

## Supporting Young People Through Adolescence

Living with ITP during adolescence presents unique challenges, and **Dr Alice Hart** delivered an insightful presentation examining the physical, emotional and social aspects of growing up with the condition.

She discussed the impact that ITP can have on education, friendships, sport, independence and mental wellbeing. Importantly, she emphasised strategies that healthcare professionals, parents and young people can use to help adolescents successfully navigate this important stage of life.

For many families attending the Convention, this practical and compassionate session provided valuable reassurance.

## Managing Newly Diagnosed ITP

Following lunch, delegates heard from **Prof Cindy Neunert** from Columbia University Medical Center, USA, who presented an excellent overview of the treatment of newly presenting ITP.



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Her presentation examined current international approaches to diagnosis, first-line treatment options and how clinicians balance treatment decisions with the needs and preferences of individual patients. She highlighted the importance of shared decision-making and ensuring that treatment plans consider not only platelet counts but also bleeding symptoms, lifestyle and quality of life.

Her evidence-based review was particularly valuable for newly diagnosed patients and their families.

## Understanding Thrombopoietin Receptor Agonists

One of the afternoon's most practical clinical sessions was delivered by **Prof Catherine Bagot**, who reviewed the use of thrombopoietin receptor agonists (TPO-RAs).

She discussed their role in modern ITP management, common side effects, recent developments and the growing clinical experience with these important treatments.

Prof Bagot also included the results of the TPO/Ra patient survey and the Survey covering the use of Generic Eltrombopag carried out by the ITPSA.

Delegates appreciated the balanced discussion, which acknowledged both the benefits and practical considerations associated with long-term therapy.

## Quality of Life Matters

Medical success cannot be measured by platelet counts alone, and **Professor Nichola Cooper** reminded delegates of this during her presentation on Health-Related Quality of Life and the I-WISh Study.


Drawing on findings from the international I-WISh programme, she demonstrated how fatigue, anxiety, uncertainty and the day-to-day impact of living with ITP often affect patients as much as bleeding symptoms themselves.

Her presentation reinforced an increasingly important message within modern healthcare—that understanding the patient's experience is essential to delivering truly effective care. Quality of life continues to be recognised as a critical outcome alongside clinical measures.

## Learning from the UK Adult Registry

Research remains at the heart of improving patient care, and **Dr Fred Chen** provided delegates with an update on the Adult ITP Registry.


The registry continues to generate valuable real-world evidence that helps clinicians better understand treatment pathways, patient outcomes and long-term disease management. Such information complements clinical trial data and supports improvements in everyday practice across the NHS.

The presentation highlighted the enormous value of collecting high-quality patient data to guide future research and healthcare planning.

## Understanding the Bigger Picture

The final scientific presentation came from **Professor Guillaume Moulis**, who explored the epidemiology of ITP.

His talk examined how frequently ITP occurs, who is affected and how population-based studies are helping researchers better understand the condition. Epidemiological research continues to provide essential information that shapes healthcare policy, resource planning and future scientific investigation.

**Questions That Matter Most**

The Convention concluded with the ever-popular Question and Answer Panel, chaired by **Professor Adrian Newland**, Chair of the ITP Support Association.


For many delegates, this remains the highlight of the day. Patients asked thoughtful and practical questions covering treatment choices, vaccinations, pregnancy, fatigue, clinical trials, long-term remission, surgery and future therapies.

The willingness of the expert panel to provide honest, evidence-based and patient-centred answers demonstrated exactly why these meetings remain so highly valued by the ITP community.

**More Than a Conference**

Beyond the lecture theatre, the Convention offered countless opportunities for conversation.

Patients who may never previously have met another person living with ITP found reassurance in sharing experiences. Families exchanged practical advice, clinicians met with patient advocates, and industry partners showcased ongoing research and educational initiatives through an exhibition held throughout the day.

These informal conversations are often just as valuable as the formal presentations, reminding everyone that no one should face ITP alone.

**Feedback from those attending**

*• It was interesting and everyone was so friendly and hearing other's experiences makes you realise you're not on your own. Definitely in my calendar for next year.*
*• It was so lovely to connect with everyone. Feels very isolating at times with ITP, nice to know there is an amazing Network of support and help.*
*• It was a great way to meet and speak to other patients and expert doctors in the field.*
*• The haematologist struck exactly the right balance when translating complex clinical topics into language that was easy for patients to understand. They adapted their presentation well throughout, ensuring the content remained relevant, engaging, and appropriate for the audience. It was clear they had considered the patient perspective, which made the session both accessible and informative.*
*• It was lovely and uplifting and so needed - ITP can feel very isolating.*
*• The Q&A forum at the end as it is totally patient orientated.*
*• Can AI help in ITP. An interesting, thought provoking presentation explaining how AI could be used to analyse results much faster, maybe ID biological sub types of ITP , speed up diagnosis, predict bleeding risk etc. A world away from when I received treatment 50 years ago.*
*• Just want to say thank you for arranging such a wonderful informative event*
*• it was good to hear about other areas of the UK and the world how they treat patients with ITP.*
*• Thank you to everyone who has organised this very important event for patients and their families. The support it gives is very valuable and helpful and an annual boost to everyone in the ITP community. Very well done for an excellent Convention.*
*• Well done to all the team, an amazing event, loved the book have given it to my parents to Read as they still call it ITU.*
*• Congratulations on a fantastic event. Thank-you for all the work done by Mervyn and the ITP Support Association UK.*

**Looking to the Future**

The 2026 Annual Patient Convention once again demonstrated the unique role played by the ITP Support Association in bringing together patients and the world's leading experts in immune thrombocytopenia.

The breadth of the programme reflected the rapidly evolving nature of ITP research—from artificial intelligence and quality-of-life studies to new treatments, registry data and international collaboration. Throughout the day, one message remained constant: progress is being driven not only by scientific discovery but also by the voices of patients who continue to shape the future of ITP care.
The ITP Support Association extends its sincere thanks to every speaker, delegate, volunteer, exhibitor and sponsor for helping to make the





Convention such a memorable success. Together, we continue to build a stronger, more informed and more connected ITP community.

**Who's Who from this years 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 Cornel 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 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

**Professor 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.

**Professor 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 thrombocytopaenia (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 Guillaume Moulis** – Introducing Dr Moulis who will be talking about Epidemiology of ITP

**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.

# International ITP Alliance News

This is the 10th Anniversary of the International ITP Alliance, so to help celebrate, we are including the report from the recent Patient conference organised by our friends at ITP Australia and New Zealand (ITPANZ). This was held in Melbourne Victoria, Australia.

**S2026 ITP Patient Conference: The Moments That Mattered**
**Melbourne Town Hall · Knowledge · Connection · Confidence**

The 2026 ITP Patient Conference brought together patients, families, clinicians, researchers, nurses, and supporters from across Australia and New Zealand — and if you weren't in the room, you missed a day filled with breakthroughs, clarity, laughter, and the kind of connection that can only happen when people truly understand one another.
Held at Melbourne Town Hall, this year's theme — Knowledge, Connection, Confidence — came to life in every session. Below are the moments that shaped the day and left the community buzzing long after the final applause.

**Platelet Function: Why the Number Isn't the Whole Story**

Professor Elizabeth Gardiner opened the conference with a session that changed how many patients think about their condition. Her message was simple but powerful:

• "It's not just about the count… it's also about the function."
• "Platelets are not just little sacs of membrane… they are full of granules and mitochondria."
• "Two people with a platelet count of 50 — one may bleed, the other may not."

Elizabeth walked the audience through stunning new imaging of megakaryocytes — the "parent cells" that produce platelets — and explained why platelet behaviour varies so dramatically between individuals.

She also shared emerging research showing that platelet function testing may soon help clinicians identify who is actually at risk of bleeding, even when counts look "safe."

For many patients, this was the first time their lived experience finally aligned with the science.

**Side Effects & Risk: Making Sense of the Why Behind the What**

Dr Danny Hsu delivered one of the most practical and reassuring sessions of the day. Using analogies that had the whole room nodding, he explained why side effects happen and how to interpret risk without fear.

Highlights included:
• "If you imagine the body as a house with many locks… ideally we want one key for one door."
• "Some keys open other doors — that's what side effects are."
• "Every symptom in a clinical trial must be documented… whether the drug caused it or not."
• "When we say something is rare, patients often interpret that very differently to the actual statistics."

Danny also broke down the difference between risk on paper and risk in real life, giving patients tools to understand medication leaflets, ask better questions, and feel more confident in their treatment decisions.

**ITP in Adolescents: A Critical Stage of Life**

Paediatric haematologist Dr Melanie Jackson brought compassion and clarity to the unique challenges faced by young people with ITP.



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Key insights:
•"Navigating ITP in adolescence… it's a complex interplay between the illness and development."
• 25–30% of young people go on to develop chronic ITP.
• Identity, independence, emotional regulation, and peer relationships are all affected.
• "Having an adolescent with a chronic illness poses stress to the whole family."
•"Connecting with others who have ITP really helps."
Mel reminded the audience that adolescence is already a time of enormous change — and chronic illness can amplify every challenge. Her message was clear: young people need support, validation, and a team around them.

**Women's Health & Menopause: Understanding the Overlap**

Dr Sara Ng delivered a session that resonated deeply with women in the room. She connected the dots between hormones, ageing, and platelet-related symptoms in a way that felt both validating and empowering.

Standout quotes:
"Women with ITP don't just manage platelets — they manage them alongside hormonal shifts."
"Menopause can account for 43% of a woman's life."
"As oestrogen depletes, the skin thins and capillaries become more fragile."
"Having ITP does not ban you from HRT."
Sara emphasised that bruising, bleeding, brain fog, and fatigue can have multiple causes — and that women deserve care that considers both their haematology and hormonal health.

**Shared Decision Making: Your Voice Matters**

Nurse Practitioner Rebecca Dring reminded everyone that healthcare works best when patients and clinicians work together.

Key messages:
• "It's a collaborative approach… you bring your life, we bring the science."
• "You actually have to be engaged in your healthcare."
• "If you don't understand something, please ask for clarification."

Her session empowered patients to ask questions, express their goals, and take an active role in their care.

**Myth Busting ITP: Facts Over Fear**

Associate Professor Dr Phil Choi delivered clarity with compassion, tackling the biggest misconceptions in ITP.

Highlights:
• "The platelet count itself doesn't predict bleeding very well."
• "Fatigue is the number one most dominant side effect."
• "People with single-digit platelets can fly safely."
• "Vaccinations don't make the disease worse."

Phil's session gave patients permission to stop fearing the myths and start trusting the facts.

**A Community That Shows Up**

The conference closed with one of the day's most meaningful parts — hearing directly from people living with ITP. Danielle shared her own experience, from diagnosis and clinical trials to the emotional toll of uncertainty and the moment she finally met others with ITP and realised she wasn't alone. Her message resonated across the room:

"ITP changed my life, but it gave me more than it took away. It connected me to a community I never knew I needed."

This led to the first public look at the early findings from the latest Australia–New Zealand Patient Survey. The results highlighted what many in the audience had experienced themselves: delays in diagnosis, the sharp drop in mental well-being after diagnosis, the invisible burden of fatigue and anxiety, and the reality that many patients still feel unheard in treatment decisions. Women also shared the additional challenges they face around menstruation and feeling dismissed when discussing symptoms.

These insights weren't just statistics — they reflected the lived experiences of the people sitting in the room. Danielle reminded everyone that this data will guide ITPANZ's work over the next 12–24 months, shaping new tools, education, advocacy, and support.

The session ended with a reminder of what makes this community so powerful:

"Being able to speak to somebody who understands what you're going through is the best thing in the world."

**Article by Danielle Boyle**

**Editor's note: Huge congratulations to ITPANZ CEO Danielle Boyle for another outstanding conference.**

# 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 Ianalumab in Adults With Primary Immune Thrombocytopenia (ITP) and Warm-antibody Autoimmune Hemolytic Anemia (wAIHA) Who Have Previously Benefited From Ianalumab (VAY RE-HIT).**
**Sponsor: Novartis Pharmaceuticals**
**Locations:**
**Imperial College, London W12 0HS - Recruiting**

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**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 - Recruiting**
**Imperial College NHS Trust, London, W12 0HS - 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**

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**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 0HS - 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 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 0HS – Recruiting**
**Royal Cornwall Hospital (RCH), Truro, TR1 3LJ - Recruiting**

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**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 0HS**

# 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,

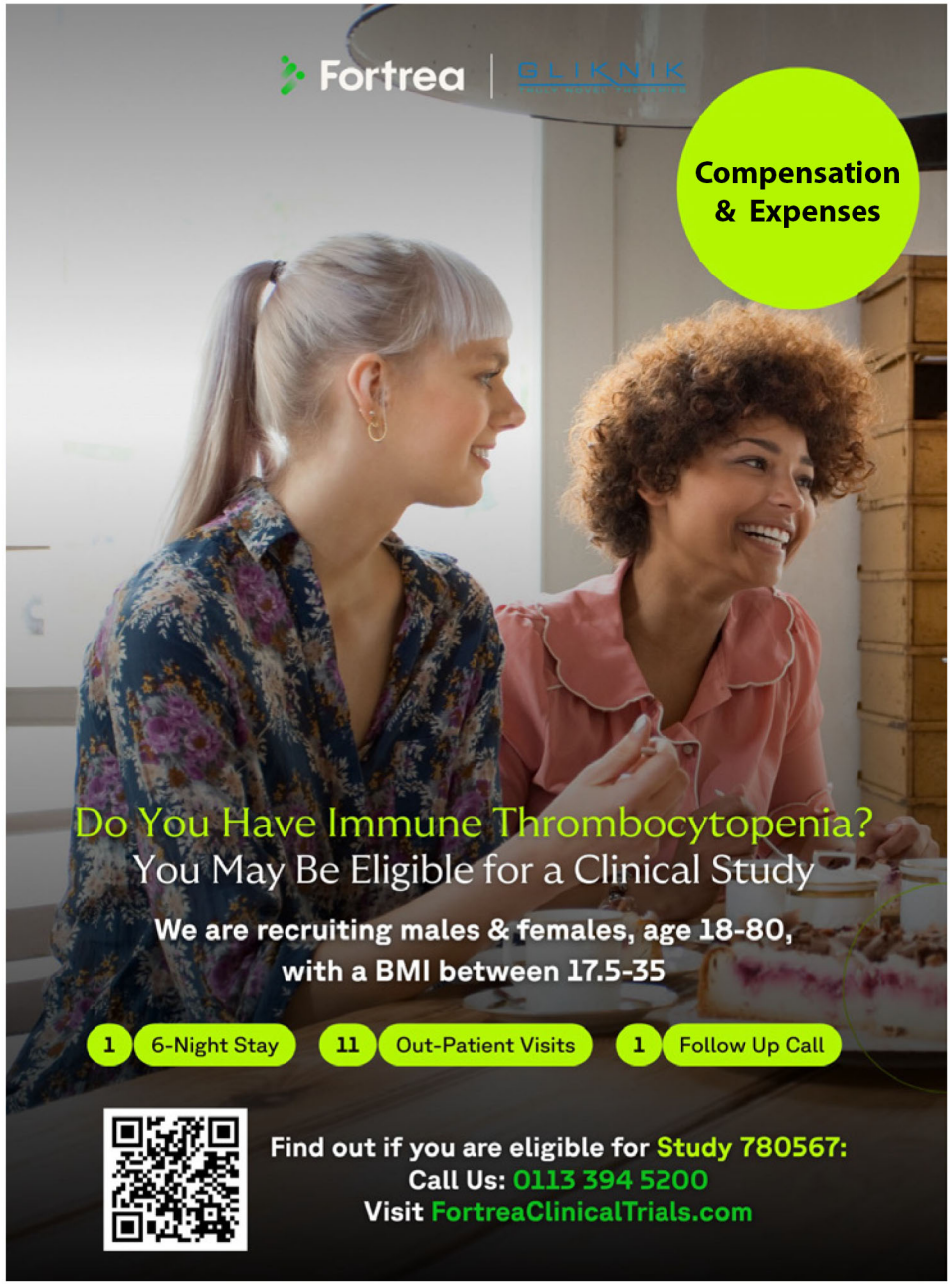
Its a friendly bunch of people who have or know someone who has ITP (Immune thrombocytopenia).

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

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## 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 STUDY

# ITP: A Whole Person Health Model of Care

**ITP: A Whole Person Health Model of Care – Prof Cindy Neunert**

Whole person health is a concept rooted in integrative health and medicine. Many people think about integrative medicine as being used in place of conventional medicine, however when applied correctly integrative medicine works alongside conventional treatments. Whole-person health is an integrated, patient-centered care model that considers the full experiences of your life, and the close tie between your mind, body, spirit, and the environment. The goal is to shift the focus from merely treating an isolated disease such as ITP to proactively promoting overall resilience, preventing illness, and restoring well-being and health. It looks to connect to the innate healing capacity of the human body—an amazing source of health that is within each of us.

There are a few cornerstones to this care approach. The first is that care is always patient- centered. The patient is an active participant in their care, and their goals and health journey are important to medical care. Second, there is strong appreciation for the link between the mind and body with regards to overall wellbeing and impact on health. Because of this, methods that work to strengthen the mind will in turn work to bring health to the body. Third, health and wellness are complex concepts that are made up by many things including: sleep, nutrition, movement, resilience, environment, relationships, and spirituality. Each of these can have an impact on chronic disease. Fourth, non-conventional or integrative health methods can address many of these health aspects. These can include things like aromatherapy, herbal medicine, mindfulness, yoga, massage, reiki. The selection of these different methods is based on the on the individual needs and symptoms of the patient. Lastly, we should ensure that the patient is an surrounded by an environment that promotes health.

The Platelet Disorder Support Association ITP Natural History Study collected information on integrative medicine use among patients with ITP. More the half of the participants (53%) reported using both conventional therapies as well as integrative health treatments. These included dietary modifications, such as gluten-free and anti-inflammatory. In addition, participants also reported using supplements to treat their disease, including melatonin, folic acid, papaya leaf extract, coenzyme Q10, chlorophyll, and vitamins C, D, K, and B12. The inclusive of integrative health approaches seems to increase with ITP disease duration with only 10% reported within the first year of their ITP diagnosis; 30% within the first 5 years, and 53% within the first 9 years. Despite the frequent use of these modalities, discussions about use between patients and healthcare providers were infrequent (23%).

Why is whole person health important in ITP? We know that for many patients ITP is a chronic condition that over time leads to changes beyond just the physical disease manifestations. It impacts energy, daily living, and relationships. We know that our medical therapies do little to nothing to address these aspects of ITP. We also know that many patients are already seeking out integrative health approaches to their care. Therefore, we can do better in addressing the needs of patients by looking at a whole person care model and encouraging dialogue between physicians and patient about ways to reduce the burden of living with ITP and restore optimal health and wellbeing..





# Overcoming Anxiety

Before the 2026 annual ITP Convention in June, I had decided to write this article. During the various discussions and talks, mental health issues and anxiety about ITP, a long term condition, and the unpredictability of it, came up several times.

If you are experiencing severe Worry, Stress and Anxiety, that impacts your life so you cannot function, it is time to seek professional help as soon as possible, especially if you are thinking of harming yourself or someone else.

Anxiety can be caused by trauma, and panic attacks can be caused by Anxiety. If any of these things are affecting you, please contact your GP or go to hospital where you can get treatment.

This article is about manageable, everyday anxiety that we can do something about ourselves.

Following on from Finding Joy, I asked a few people what gave them Joy. Most replied with simple things such as being with family, especially grandchildren, helping people, their garden, a favourite hobby, seeing friends, their Faith, holidays and many other every day pass times. No one said a lot of money, a flash car or other material things, although I am sure these things bring Joy to many people. (My car brings me Joy, especially when someone else has cleaned it for me, and it is polished and shiny!) I was pleasantly surprised by the replies, although I was expecting similar answers. Ask yourself, 'What gives me Joy?' Your answer may surprise you.

Anxiety seems to be all around us and it is hard to avoid and overcome when it settles in our being and churns us up.

Humans are not wired with a tranquil brain. A laid back attitude would not save your life and let you survive, back in the bad old days! We are wired with the Fight or Flight adrenaline response so that we can survive the woolly mammoth, the sabre-toothed tiger and the neighbouring tribe waging war on us.

These days we may be lucky enough not to have to worry too much about these things, (although we must acknowledge the sadly war torn areas of the world, and wonder how those people cope with the anxiety that must bring.)

Even in our society the brain still has the Fight or Flight response to other everyday stresses.

Anxiety is not your own fault, self-blame can be very destructive to your confidence.

Constant Anxiety is like the fire alarm that has got stuck on, and is ringing all the time.

The body and mind go into a high state of alert and find it very hard to calm down once highly stimulated.

There is no shortage of things to stress us, family and relationship worries, technological stress, financial concerns and general life anxiety, including fear of the future and the unknown. You will be able to add your own set of stressors. On top of all that, you have your ITP diagnosis, a long term condition that is unpredictable, and can stop you from doing what you want to do.

The Doctors who spoke at the Convention, said how helpful they had found a talk by Doctor Andrew Morgan, who is an Acceptance and Commitment Therapist, among other things. You can find helpful resources here: **https://drandrewmorgan.co.uk/FAQ**

In addition he has done some Zoom sessions with us, and they can be found on the ITP YouTube channel with many other resources. **https://www.youtube.com/@ITPSAUK/videos**

There are many self-help books on stress management and anxiety and your local library is sure to have a selection that could be useful. One I listened to on Audio from Borrowbox, my library App, was Hardwiring Happiness, The New Brain Science of Contentment, Calm and Confidence, by Rick Hanson. A lot to learn and it was so good I would listen to it again.

# What Brings You Joy? Cont...

Mindfulness and Meditation together with Relaxation can be learnt, and again there are free resources and Apps to be found. These changes in your routine take time to develop, so be patient with yourself and give each thing at least 2 weeks of a trial, before you decide to carry on or not.

Always search for NHS and trusted sources online, and beware of anything that requires payment. There is plenty of good quality information freely available.

Our speakers discussed how stretched NHS resources are and the need for themselves to be informed and able to help and guide patients. If you have mild symptoms, but they are bothering you, be your own therapist. Talk to your GP and ask for what is available to you immediately, such as joining a group. Your Consultant may be able to guide you to their hospital services.

You are already in a group, called the ITP Support Association, welcome and congratulations for finding us and joining us! I know many of you are very long standing members, we value and appreciate your continued support.

We have a lot of resources on the website for you, so please use them for information to learn about and share with family members, so they understand as well.

Remember, Knowledge is Power, and can bring peace of mind. Being well informed about your condition, no matter what it is, is always a good idea and reassuring, for you and your family and friends, although it may not feel like that at initial diagnosis.

One of the best measures to counter Anxiety, Worry and Stress is Distraction. These activities can also be used for mild pain.

You will not be surprised to find that they are the sorts of things I have mentioned in a lot of other articles I have written in the Health and Wellbeing columns of The Platelet over the years.

Always helpful is a sensible lifestyle with exercise, a healthy diet and adequate hydration, good sleep routines and organisation in your life. These strategies will help daily routines and duties, which all have to be fitted in.

Find the things that appeal to you. It may be listening to music or going to a disco, there are some in the day now, I am told! Meeting a friend, chatting on the phone, going for a walk, communing with nature, planning a holiday or day out. Going to a film or play, reading a book, or visiting a place of interest or visiting a museum or art gallery. Pampering yourself with a massage, beauty treatment or Spa Day may do the trick. Men can do this too...very fashionable now! A soak in the bath is very relaxing. Going to your football team's game or meeting the boys in the pub, with social interaction opportunities, can all be helpful distractions and can ward off loneliness. Some people find singing in a choir very helpful for health and wellbeing. Joining organisations such as U3A, Arts Society, Coast Guards, Ramblers and other outdoors organisations, and many other voluntary organisations, benefits you, and the people you are helping. Food Banks, Baby Equipment Banks, Salvation Army, Charity Shops and many others would be appreciative of your help.

Volunteering is an excellent way to meet people, do something positive for others, and best of all, it is good for your own health and wellbeing too! Helping others is very rewarding.

Plan ahead, so you are not rushing and stressing over what you are due to do. Allow enough time to get to places, have spare money ready for an emergency. Rushing about leads to mistakes and accidents, that cause more stress and anxiety.

It is very important to practise any techniques you adopt. Mindfulness practise every day is optimum, even twice a day, as a habit and when you need it. Some of these things will not come easily to you, but with practise they do become more familiar and helpful and can form part of your calmness routine.





All the things you decide to take on to help with your anxiety will untrip the brain for a bit. They will give you more sense of control and tranquillity and a calmer and more enjoyable life.

Breathing and grounding exercises are short-term solutions, but can be very helpful if you begin to feel overwhelmed and need a quick fix to settle down. Look online for information.

Some people enjoy drawing for relaxation, shopping or even housework. At the end you can feel a sense of achievement that is a mood raiser, and feeds back positive feelings. Although I am not a lover of housework, when I have finished, I do feel a sense of achievement, until someone trails in a muddy mess, just where I have cleaned!

It can be helpful to share your anxious feelings with a trusted friend or family member. Discussing how you feel and why, is often enough to lessen the feelings, and ease the pain they cause.

Writing down how you feel and your plan to help yourself is also a good tool. Journaling is often used to help get your thoughts in order and formulate your plan.

See if your own Health Authority runs the Expert Patient Programme, a free self-management course for people with long-term conditions.

Here is the information from NELFT: ***https://www.nelft.nhs.uk/epp/***

In conclusion, Worry, Stress and Anxiety are common and normal.

At any time you can use strategies to help yourself feel calmer.

Distraction is a pleasant and useful tool.

Choose the things that are easy for you and that you want to do.

There are plenty of free resources available to help.

Sharing your feelings and activities with trusted others can be helpful.

Writing down your feelings, the reasons for them and your plan for self-help can be very positive and calming.

Give a trial of at least 2 weeks for every new thing you try.

Adopt the ones that work well for you and keep in regular practise.

Find out what other people do to keep calm. Share and work together.

Going for a walk in nature is free and can be very restorative.

Work out strategies to keep calm so you can carry on doing the things you want to do.

Find out what brings you Joy and make sure you do your Joyful activities regularly.

There is much more on Anxiety and how to overcome it elsewhere, for you to find.

I saw this notice in a friend's house, it read:

'During my life I have worried about a lot of things that never happened!'

Worth thinking about...

Good luck with your quest for calmness and tranquillity, but remember that it is not necessarily our natural state of mind. We have to work to achieve peace of mind and restfulness. In the end it is always the same, we have to do the work ourselves, no one else can do it for us...

My action plan is to use deep breathing techniques for calmness. Lots of information online to research.

Please let me know how you get on.

**Rhonda Anderson**
**June 2026**

# ITPSA Young Adults Group


**Young Adults Group Update**

The ITP Young Adults Group recently held its first virtual meeting in May, bringing together a great group of young people from across the ITP community.

The session provided an opportunity for new members to introduce themselves, learn more about the aims of the group, and share their experiences of living with ITP. Discussions covered a range of topics relevant to the group, including education, early careers, and the challenges of transitioning between paediatric and adult care - as an ITP Patient. Given the mix of experiences within the group, there was also valuable discussion around the concerns and questions often faced by those who are newly diagnosed with ITP.

The engagement throughout the meeting was excellent. Members openly sharing their experiences and supporting one another. It highlighted the real value of creating a space where ITP patient can connect with each other.

Following the success of this first meeting, the group plans to continue with monthly virtual sessions, alongside an in-person meeting at the upcoming ITP Annual Conference, followed by an informal social gathering afterwards.

We're all really excited about the future of the group and the opportunity it presents to support, connect, and empower young people living with ITP.

**Update by Ella-Sophia Ellis**

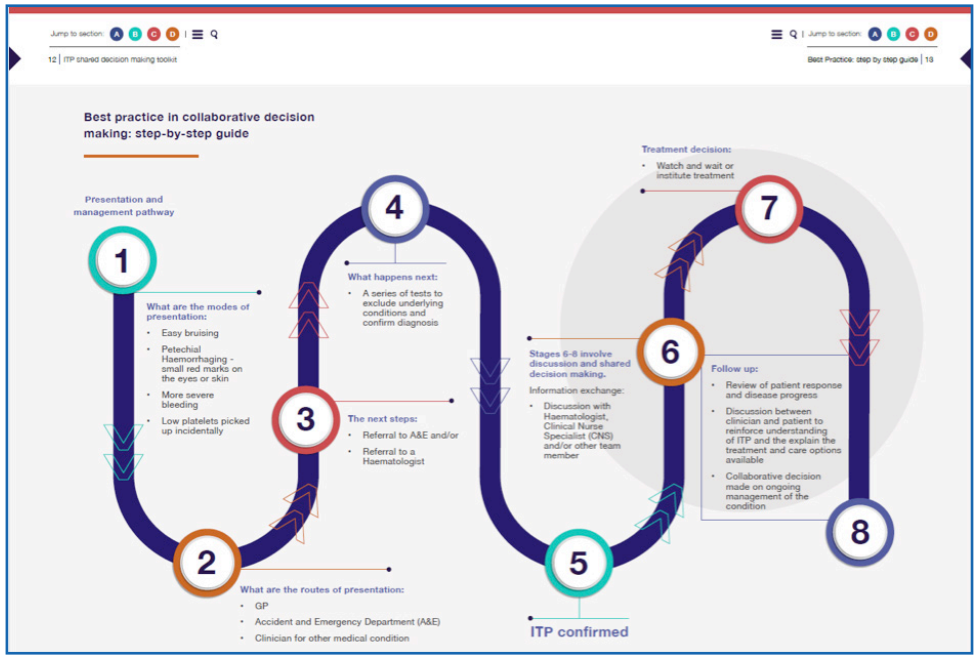




# NEW Christmas Cards for 2026

**With the Christmas greeting in English and Welsh. Cards can be ordered via our website at www.itpsupport.org.uk A big thankyou for our friends at the Cardiff ITP Patient meeting for requesting cards with duel greetings.**

# 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 though 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.

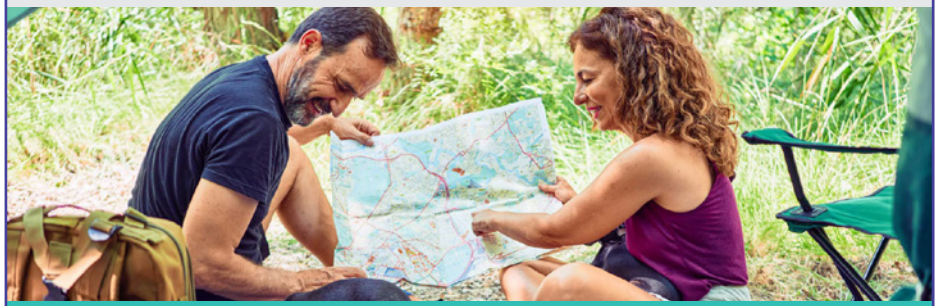
Highlight what matters most to you and discuss it with your care team to make a joint decision about your care plan.

### 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

NP-23508 | Date of preparation: September 2022





# 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.)?*

**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?*

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

**Pursuing hobbies**
*Do you feel you can pursue the activities you enjoy the most?*

**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?*

**Performing well at work or school**
*Do you feel you can excel in your work and/or studies?*

**Taking part in sports and exercise**
*Do you feel you can reach your sport and exercise goals?*


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

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

# 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.***

Inform supporT emPower
ITP Support Association

# Share Your Patient Story

Read more patient stories here

Scan me

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.**

REDBUBBLE

**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.**

Scan me





# Fundraising Report

## FUNDRAISING HEROS

Thank you to Maesteg Park FC and Maesteg Netball Club. Freddie was admitted to hospital in September 2025 with so many unknowns, and after months of worry and uncertainty, we finally received answers in March 2026.

When Maesteg Park FC asked if they could support the ITP Support Association as one of the charities for their annual fundraiser, we were incredibly touched and grateful.

As a family, we cannot thank everyone enough for the love, kindness, and support shown to us throughout this emotional rollercoaster of a journey. The support we have received has meant more to us than words can say.

Thanks to the amazing efforts of Maesteg Park FC, Maesteg Netball Club, and our wonderful community, an incredible £750 was raised for the ITP Support Association — a charity that is incredibly close to our hearts.

## IN LOVING Memory

This has been a sad period for the ITP family, we sadly lost more good friends of the Association:

**Chris Davidson**

**Janet Clements**

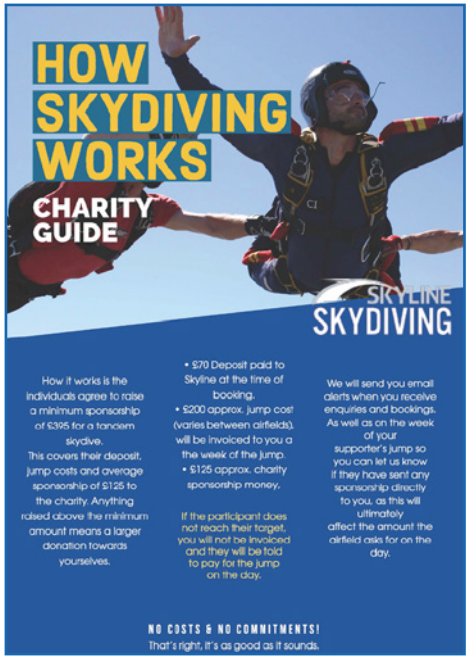
**Margaret G Rock**

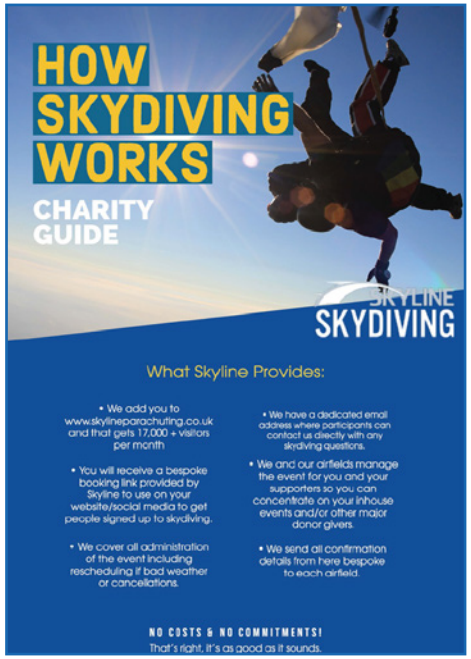
# Skydiving for ITP

**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**








# 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.

# 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 is 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.



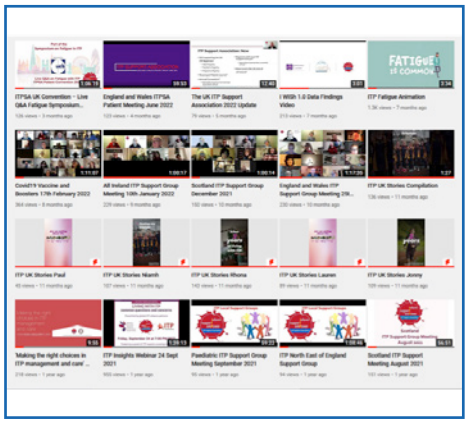


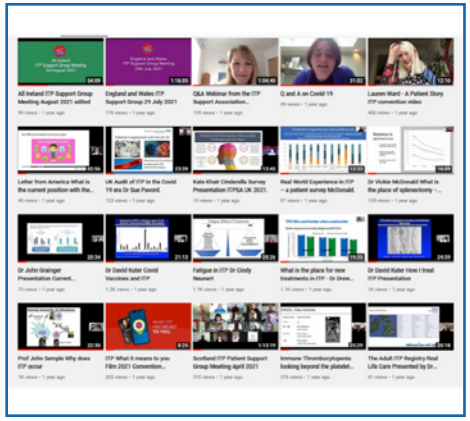
# Visit our YouTube Channel

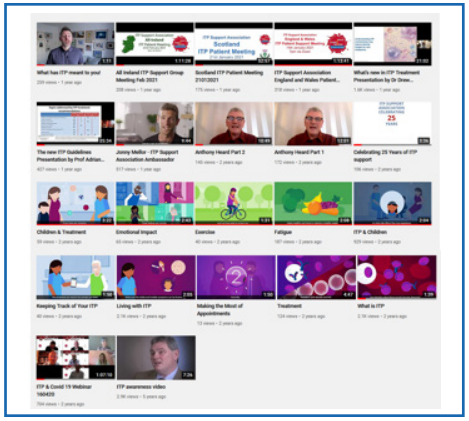
Subscribe to our YouTube Channel

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







# New ITP Books

**Living with ITP Book**


**SO, I HAVE ITP – WHAT NOW?**

Our new Patient Resource – Living with ITP, now available as a digital download.

Discovering that you have been diagnosed with ITP may be a shock. You may feel anxious about having a disease with a complicated name that you have never heard of before and you are sure to be wondering what the future will hold.

The information in this book will help you understand more about ITP. You will find out how it might affect your everyday life and how to deal with any challenges it may bring.

To try and understand how you are feeling right now, we have talked to adults of all ages who have been diagnosed with ITP at some point in their lives. As you read through the book you will hear their thoughts and experiences, which we hope will reassure you.

As you will find out, being diagnosed with ITP is NOT a life sentence and with the right support and information you should be able to look forward to the future with confidence.

To download the digital version click this link: **https://bit.ly/49LzlRc**

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

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

**ITP in Pregnancy**

Another welcome new patient resource from the ITP Support Association, now available in print and as a digital download.

Being told you have low platelets in pregnancy can feel worrying. You may have been diagnosed with ITP before becoming pregnant or it might be considered as a reason for low platelet counts during pregnancy.

This leaflet explains what ITP is, how it is treated during pregnancy, what to expect during birth






and how your baby will be checked. Please remember that most women with ITP have healthy pregnancies and healthy babies. Your midwife, obstetric team and haematology team will look after you together.

To download the digital version click this link **https://bit.ly/4wOYhBq**

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

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

**ITP and Me – An ITP Book for Young Adults and Teenagers**


Are you a young person who has been diagnosed with ITP?

Then this book is for YOU!

ITP and Me – An ITP Book for Young Adults and Teenagers

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

48 pages of information that will help guide you along your ITP journey.

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

SCAN ME

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

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

# 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.**

***You can order Books marked with a * by emailing info@itpsupport.org.uk with your postal address details, all we ask if that you make a donation via our JustGiving page to cover the postage.***

### AVAILABLE AS PRINTED COPIES AND DOWNLOAD

**Living with ITP – new for 2026, over 70 pages of ITP info to support the patient.***

**Pregnancy and ITP – new for 2026 a fantastic resource for ITP patients who are pregnant or thinking about having a baby.***

**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.***

### AVAILABLE AS A DOWNLOAD

**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**

**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





# Publications List cont...

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
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 asplenics
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

**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.**

# MEMBERSHIP SUBSCRIPTION FORM:

**PLEASE USE THIS FORM TO PAY BE 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 | ☐ Mr ☐ Mrs ☐ Miss ☐ Ms ☐ Dr ☐ Other | | |
| NAME | | | |
| ADDRESS | | | |
| ADDRESS | | | |
| POSTCODE | | TELEPHONE | |
| EMAIL | | | |
| Let us keep in touch | Opt in ☐ *Please tick the box* | ☐ Email ☐ Post ☐ 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

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**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 or 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,
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