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ITP Support Association

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

The Platelet

JOURNAL OF THE ITP SUPPORT ASSOCIATION

SEPTEMBER 2025

The ITP Support Association Team

Charity Registration No. 1064480

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GRIFOLS

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

From ITP HQ

Welcome to the September 2025 edition of The Platelet.

It's been a tremendously busy and rewarding summer, following on from our very successful ITP Patient Convention at the beautiful Bridgewater Hall in Manchester this May. My heartfelt thanks go to all the patients who attended, as well as to the medical advisors and international experts who generously gave their time and expertise to support the event.

Over the summer, we were delighted to take part in the European Haematology Association (EHA) Congress in Milan. I was also fortunate to join the EHA Advocates Training Programme, completing the course and receiving certification — a benefit not just for our Association, but for ITP patients across the UK. In addition, we continue to play an active role in the EHA ITP Guidelines Committee, and I am now a member of the Guidelines Steering Group. Several important meetings are planned for September, with more updates to follow later in the year.

July also saw one of the true highlights of 2025 — our 30th Anniversary Celebration at the House of Commons in London. We are deeply grateful to our local MP, Richard Fuller, for sponsoring this special event. The celebration brought together 44 attendees, including our founder Shirley Watson MBE and her husband Frank, some of the Association's very first trustees, and many long-standing supporters. A special thank you to the patients who have raised vital funds for us over the past year — many of whose stories you'll have read about in recent editions of The Platelet.

One of the most heart-warming moments of the evening was a speech by young patient advocate Ella Sophia Ellis. Many will remember that at our 15th Anniversary event—also held at the House of Commons—Ella, then just 11 years old, delivered an inspiring speech. At our 30th Anniversary celebration, she recreated that moment, this time with both of her parents present. It was a touching reminder of how these two milestone receptions are beautifully connected.

That same evening, we were proud to launch our new team book, ITP and Me—a collaboration between Professor Nicky Cooper and Dr. Alice Hart's team at Imperial and the ITP Support Association. All the key contributors to the book attended the House of Commons reception, including Amanda, the writer, whose work on the project has been outstanding.

As we go to press with The Platelet, we are delighted to share that in the first month alone we have sent out 700 copies of the book—an incredible response. You can find more details in this edition, but if you would like your own copy, simply make a donation to the ITP Support

Contents

From ITP HQ

Association to cover the cost of postage, and we will send you a copy of ITP and me free of charge. Trustees, we say goodbye but also say thank you to Anthony Heard for his help and support over many years. However as one chapter ends another opens and we welcome two new Trustees, please welcome Agne Zice and Richard Blake, both ITP patients who will bring some added expertise to the Trustees. We will publish more information about the new trustees in the December edition of the Platelet.

In this edition, you'll also find a full list of our forthcoming meetings—both virtual and in-person. More in-person events will be announced as the year progresses, so do keep an eye out.

If you'd like to take part in one of our virtual sessions, we encourage you to register. One particularly popular event has been the meeting with clinical psychologist Dr. Andrew Morgan. His first session, held last month, was very well attended, and the second is scheduled in the coming weeks.

If you haven't already signed up, we'd be delighted to welcome you.

And with all this going on we also have ITP Awareness Week coming up at the end of September, don't forget to #Lightup4ITP.

Thank you for your continued support.

Mervyn Morgan CEO ITPSA

'Silver Standard' for Excellence in Industry Award ITP Support Associations Platinum Sponsor for 2024

patient partnership index
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rare strength

ITP Support Association — 30th Anniversary Reception

House of Commons, Westminster, London - Sponsor / Host MP: Richard Fuller MP

On Tuesday 8th July 2025 the ITP Support Association celebrated its 30th anniversary with a reception in the House of Commons, kindly sponsored by Bedfordshire Member of Parliament Richard Fuller MP.

This journey started earlier in the year at a meeting between Richard Fuller MP and the ITPSA CEO Mervyn Morgan. The result of which was support for a reception at the House of Commons.

The reception brought together patients, carers, medical advisors, healthcare professionals, charity supporters, trustees (past and present, industry partners and parliamentary guests to mark three decades of patient advocacy, peer support and awareness-raising for immune thrombocytopenia (ITP).

In total we had 44 guests in attendance, which included the Charities founder Shirley Watson MBE and husband Frank Watson plus one of the organisations first trustees Keith Lewis, the current Chair of Trustees Prof Adrian Newland CBE and CEO Mervyn Morgan.

Several Parlamentarians attended including Richard Fuller MP, Alistair Strathern MP and Lord Lindsey.

A highlight of the event was a speech from Ella-Sophia Ellis who is now a patient observer on the charities board, Ella also spoke at the Association last House of commons reception for its 15th year anniversary and now she was back to speak once more with her proud parents looking on.

There were also short speeches from the ITPSA CEO Mervyn Morgan and the Chair of Trustees Prof Adrian Newland, both highlighted the significance of the work and the vision started by the Charities founder

ITP Support Association — 30th Anniversary Reception

Shirley Watson MBE back in 1995.

They also spoke about the organisations current work and the support it is providing for those with the condition that is immune thrombocytopenia (ITP).

- Celebrate 30 years of the ITP Support Association and acknowledge founders, volunteers and supporters.
- Raise awareness of ITP among parliamentarians and policy makers.
- Strengthen relationships with clinicians, patient advocates, and industry partners.
- Showcase current priorities (patient support services, research funding, access issues).

We were also honored to have several ITP patients and friends who are also fundraising heroes from the world of distance running and ironman events.

L/R Mervyn Morgan, Shirley Watson MBE, Frank Watson, Rhonda Anderson and Howard Anderson

The event not only celebrated the charity's achievements, raised the profile of patient issues in Parliament, and strengthened relationships with clinical and policy partners but it also so the official launch of its latest publication 'ITP and me' an essential guide to ITP for Teenagers and Young Adults.

Some of the team behind the Teen Book 'ITP and Me'

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ITP Awareness Week 2025

ITP Awareness Week 2025

In 2024, hundreds of locations around the world turned **PURPLE** during September to help raise awareness for those living with Immune Thrombocytopenia.

This is the 10th year of our community celebrating **Global ITP Awareness Week (22–28 September 2025)** and as part of the **#LightUp4ITP** campaign, we invite landmarks across the United Kingdom and Ireland to light up **Purple or any colour** to support those living with ITP.

We are reaching out to request that landmarks in your town (Town Halls, Public Buildings etc) be illuminated in **purple (or any colour) on Friday, 26 September 2025**, for 'I sporT purPle for Platelets Day.' This global event raises awareness for ITP and symbolises the bravery and hope of patients. Last year, hundreds of locations around the World participated, lets get the UK and Ireland lighting on this year – helping to shine a light on this rare disease.

Download the template letter (Word Format) using the QR Code below and start contacting your local Hospital Trusts, Councils and organisations for support. If you're successful, don't forget to email Mervyn at info@itpsupport.org.uk so we can include them into the list!

And don't forget to share it across social media using:

#ITPSA

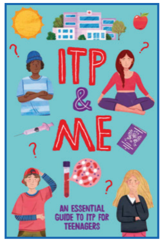
#ITPAwarenessWeek

#Global4ITP

#LightUp4ITP

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 £3 donation to cover the cost of postage and packing, email us your postal address to **info@itpsupport.org.uk** and make the donation via our JustGiving page at Donate – Donation amount – JustGiving

Acknowledgements

We would like to give a big thank you to all the young people who took part in the ITP discussion groups for this book:

Ariana Silva
Charlie Henderson
Ella Ellis
Ellie Keegan
Georgina Guterman
Maia Ramasamy
Muhamed Shahsivari
Orla Farren
Monty Savarino

Professor Nichola Cooper and Dr Alice Hart, Haematology Consultants at Imperial London, spearheaded this project. They would like to thank Mervyn Morgan at the ITP Support Association, Dr John Grainger and Chloe Goodall (who wrote the original ITP'n'Stuff leaflet on which this book is based), and Rhonda Bowie (Patient Advocate).

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.

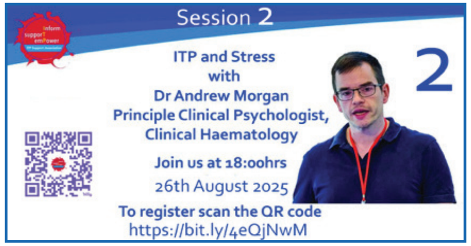
We are looking for additional Patient Mentors, if you feel this could be you, please email us at info@itpsupport.org.uk with your details and we will contact you.

Save The Date

Dates for your Diaries.

The following meetings will be taking place or are planned for the months ahead.

Dr Andrew Morgan - Clinical Psychologist - ITP and Stress Session 2
Tuesday, August 26 at 6pm.


Session 2
ITP and Stress
with
Dr Andrew Morgan
Principle Clinical Psychologist,
Clinical Haematology
Join us at 18:00hrs
26th August 2025
To register scan the QR code
https://bit.ly/4eQjNwM

Bloomfield Hospital ITP Patient Meeting
12th September


Scan me
https://bit.ly/4lu3hoo
Scotland
ITP Virtual Meeting
7pm Tuesday
16th September 2025
With
Dr Catherine Bagot

Scotland ITP Support Association Virtual Patient Meeting
Tuesday, 16 September at 7pm

All Ireland ITPSA Patient Meeting Wednesday, October 29 at 7pm - Details coming soon

Kings College Hospital NHS Trust ITP Patient Meeting
Nottingham NHS Trust ITP Patient Meeting


Session 3
ITP and Stress
with
Dr Andrew Morgan
Principle Clinical Psychologist,
Clinical Haematology
Join us at 18:00hrs
25th Sept 2025
To register scan the QR code
https://bit.ly/411ETTd

Dr Andrew Morgan - Clinical Psychologist - ITP and Stress - Session 3
Thursday, September 25 t 6:30pm


ITP Patient Support Day
29th September 2025
5pm to 7pm
St. Bartholomew's Church
Brinklow Rd, Binley, Coventry CV3 2DT
Free parking
To register
Scan me
University Hospitals Coventry and Warwickshire NHS Trust
ITP Support Association 1995 - 2025

ITP Support Meeting - Coventry and Warwickshire NHS Trust
Monday, September 29 at 5pm


All-Ireland
ITP Patient Meeting
with
Dr Gerard Crotty
7pm on Weds
29th October 2025
Scan the QR Code
to register
https://bit.ly/ITPIreOct2025
www.itpsupport.org.uk
ITP Support Association 1995 - 2025

EHA 2025 Report - Mervyn Morgan

The EHA Haematology Patient Advocates Training Program is an initiative developed by the European Haematology Association (EHA) in partnership with the European Patient Advocacy Institute, to empower patient advocates with knowledge, skills, and connections to effectively represent and support patients with haematological conditions.

In 2024 the ITPSA UK and Ireland Nominated Ella-Sophia Ellis and Rhona Bowie, two young ITP patient, to take part in the training program.

In 2025 the program was looking for older candidates to take part in the program, so both Mervyn Morgan and Dianne White from the ITPSA UK and Ireland were put forward and accepted.

This year's training program was in two parts, an intensive programme of lectures and tasks in Munich back in the early part of 2025 and then an equally intense schedule at the EHA Congress in Milan in June 2025. Delegates from the class of 2024 joined our group in Milan, including Ella-Sophia Ellis. Unfortunately.

Background and Purpose

The program was established to:

- Bridge the gap between patients and professionals in the field of haematology.
- Educate patient advocates about key medical, scientific, and regulatory aspects of haematological care and research.
- Foster collaboration between patient groups and haematology professionals.
- Strengthen patient involvement in research, policy-making, and clinical trials.

It aligns with EHA's broader commitment to patient-centred care and engagement.

Key Features of the Program

Educational Modules
Participants receive in-depth training on:

- Hematologic diseases
- Clinical research and trial design
- Drug development and regulatory processes
- Health policy and advocacy strategies
- Scientific communication and ethics

Workshops and Networking
The program included:

- Interactive workshops
- Mentorship by EHA experts
- Opportunities to attend EHA Congresses
- Networking with clinicians, researchers, and other patient advocates

Patient Advocate Involvement in EHA Activities
Graduates of the program are often involved in:

- EHA Scientific Working Groups
- Congress planning
- Educational initiatives and public awareness campaigns

Impact

- Enhanced patient representation in haematology.
- Improved patient-researcher collaboration in clinical and policy decisions.
- Created a growing network of informed patient leaders across Europe.

Our thanks must go to the members of the European Patient Advocacy Institute who organised a wonderful course, equal thanks must also go to the other patient advocates on the course from many rare disease areas including one of our friends from ITP Norway Katherine Peckel Lundervoid.

Jan Geissler presents Mervyn Morgan with his EHA Advocates Training certificate.

Mervyn Morgan

Why Patient Advocates Matter by Ella Sophia Ellis

Part 1: Reflections on EHA2025 - A Young Advocate's Experience

Attending the European Haematology Association (EHA) Conference 2025 in Milan as a young patient advocate (AYA) for the ITP Support Association was an unforgettable experience.

The Conference itself was dynamic and wide-ranging. Each day was filled with clinical lectures, panel discussions, and poster sessions covering many different areas; from ground-breaking clinical trials to patient-centred approaches in haematology care. As an AYA representative, I had the opportunity to attend sessions hosted by EHA that were specifically designed for patient involvement.

EHA covers both malignant and non-malignant haematological conditions, bringing together clinicians, researchers, and advocates from across the spectrum of blood disorders. Being part of EHA meant joining a wider community of understanding around rare and complex illnesses and seeing how experiences of different conditions often overlap in meaningful ways.

Over the course of the event, I spoke with clinicians and researchers from across Europe who were genuinely curious about the real-life impact of the conditions they study and treat. I shared my personal experience of living with ITP, focusing particularly on the challenges unique to young adults. These included navigating university/work deadlines alongside hospital visits, dealing with unpredictable fatigue, and the constant, quiet anxiety that a spontaneous bleed could disrupt an otherwise normal week. These stories aren't just anecdotal, they offer critical insight into the day-to-day realities of life with ITP. They're perspectives that don't always make it into clinical trials or scientific papers, but they are central to how we live with the condition.

That's why having patient advocates at EHA matters. It brings forward a perspective that's often overlooked, yet essential for improving care models and truly understanding the patient journey. Participating in EHA was about helping build a bridge between the clinical and the personal; contributing to discussions that can ultimately lead to more responsive, compassionate, and inclusive care.

Part 2: The Importance of AYA Patient Advocates

ITP isn't just a clinical diagnosis, it's something that can shape how you live, plan, and see yourself. For young adults living with ITP, it can be especially complex, as it coincides with a period full of major transitions: beginning higher education, newly entering the professional workforce, forming relationships, and establishing independence, such as living away for the first time.

Balancing all of that while living with a chronic condition can feel exceptionally overwhelming. There are days when fatigue affects your ability to focus, when regular blood tests interfere with university or work schedules, or when the risk of a sudden bleed means cancelling social plans with friends and family. Add to this the emotional toll of dealing with a condition that is largely invisible to others, and it becomes clear why many young adults can feel isolated or misunderstood.

There's also a growing awareness of the link between chronic illnesses and mental health particularly among young adults. The emotional and psychological impacts of living with a rare haematological and often misunderstood condition are significant yet support in these areas remains underdeveloped in many medical settings. It's not enough to look at platelet counts alone. We need healthcare models that recognise the full spectrum of what patient's experience: physically, emotionally, and socially.

This is why AYA advocates are essential. Our lived experiences help shape what support actually needs to look like. Not only in hospitals or clinics, but in everyday life. We bring forward insights that can inform more flexible, empathetic, and age-appropriate care.

At EHA2025, AYA voices contributed meaningfully to important conversations, from improving the transition from paediatric to adult services, to highlighting the need for better education, workplace support, and patient networks. Patient advocacy isn't just about raising awareness. It's about influencing systems, shaping services, and ensuring young people are not left behind in medical decision-making.

Part 3: The Future Ahead as a Patient Advocate...

As EHA2025 concluded, I left with a strong sense of hope. Hope that young adult perspectives will continue to be included in haematology care frameworks and beyond. The lived experiences of AYAs are vital to the evolution of patient-centred care.

ITP is more than a blood disorder. It impacts how we learn, work, connect, and grow. Being part of EHA gave me a deeper appreciation for the shared challenges faced by those living with a range of rare and complex disorders. It reminded me that patient communities can support and learn from one another, helping to drive progress for everyone.

If we are serious about improving outcomes for people living with ITP, we must commit to listening and creating space for patients' voices to be heard - across all age-ranges and demographics. Because better care begins by truly understanding the people behind the condition.

By Ella Sophia Ellis

Facebook Members Private Group

Join our
facebook
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/235978790548730n.

Other Highlights from EHA 2025

What a fantastic few days Prof Nichola Cooper and her team had at the European Haematology Association meeting in Milan from 12-15 June! The team did an outstanding job showcasing their research.

Prof Nichola Cooper was invited to give a Presidential plenary presentation titled 'From biology to targeted therapies in immune thrombocytopenia' – a huge honour that shows how respected her work is around the world. It's wonderful to see our research getting this kind of recognition on such an important stage.

We're also thrilled for Michelle MH Tan, who received the Grifols Research Awards in Immune Thrombocytopenia (GRAIT). We're incredibly grateful for this funding support, which will enable us to advance our work in ITP research.

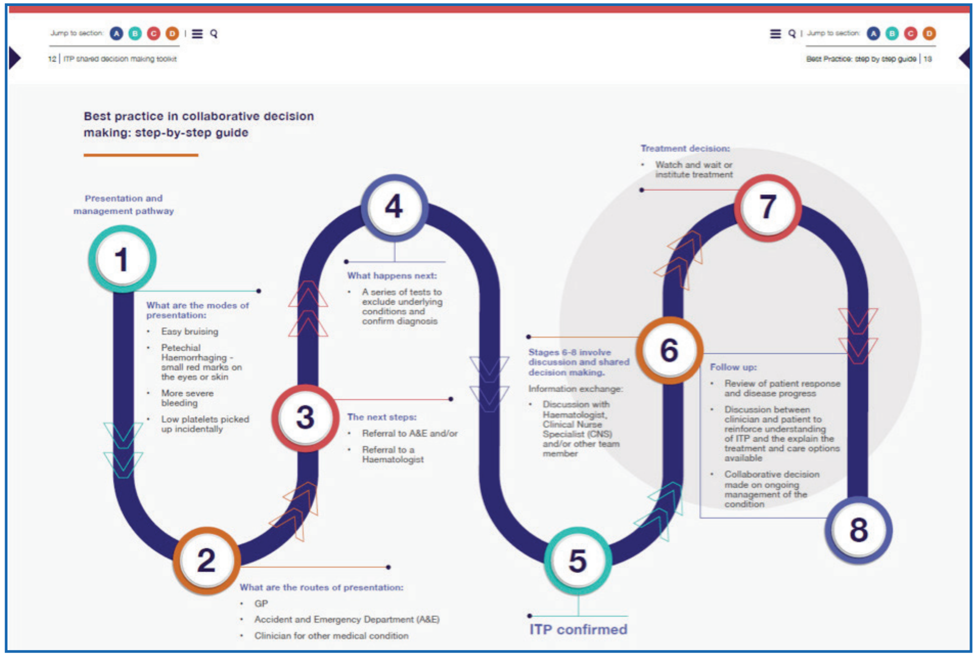
Four other team members – Rocel Saputil, Alicia Au, Lucy Kamuriwo and Nehal Joshi, also presented their research through posters, giving them the chance to share their findings with experts from across the world and build connections for future research collaborations.

Having our team shine so brightly at this major conference makes us all proud. It shows that the important work we're doing here is making a real difference and getting noticed by the international research community.

Congratulations to everyone involved!

Thank you to Barbara Lovrencic – ITP International Alliance Boad Member and President of the AIPIT Italy for this report.

Shared Decision Making Document available in Six Languages



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

Presentation and management pathway

What are the modes of presentation:
- Easy bruising
- Petechial Haemorrhaging - small red marks on the eyes or skin
- More severe bleeding
- Low platelets picked up incidentally

What are the routes of presentation:
- GP
- Accident and Emergency Department (A&E)
- Clinician for other medical condition

The next steps:
- Referral to A&E and/or
- Referral to a Haematologist

What happens next:
- A series of tests to exclude underlying conditions and confirm diagnosis

ITP confirmed

Stages 6-8 involve discussion and shared decision making.

Information exchange:
- Discussion with Haematologist, Clinical Nurse Specialist (CNS) and/or other team member

Treatment decision:
- Watch and wait or institute treatment

Follow up:
- Review of patient response and disease progress
- Discussion between clinician and patient to reinforce understanding of ITP and the explain the treatment and care options available
- Collaborative decision made on ongoing management of the condition

'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.”

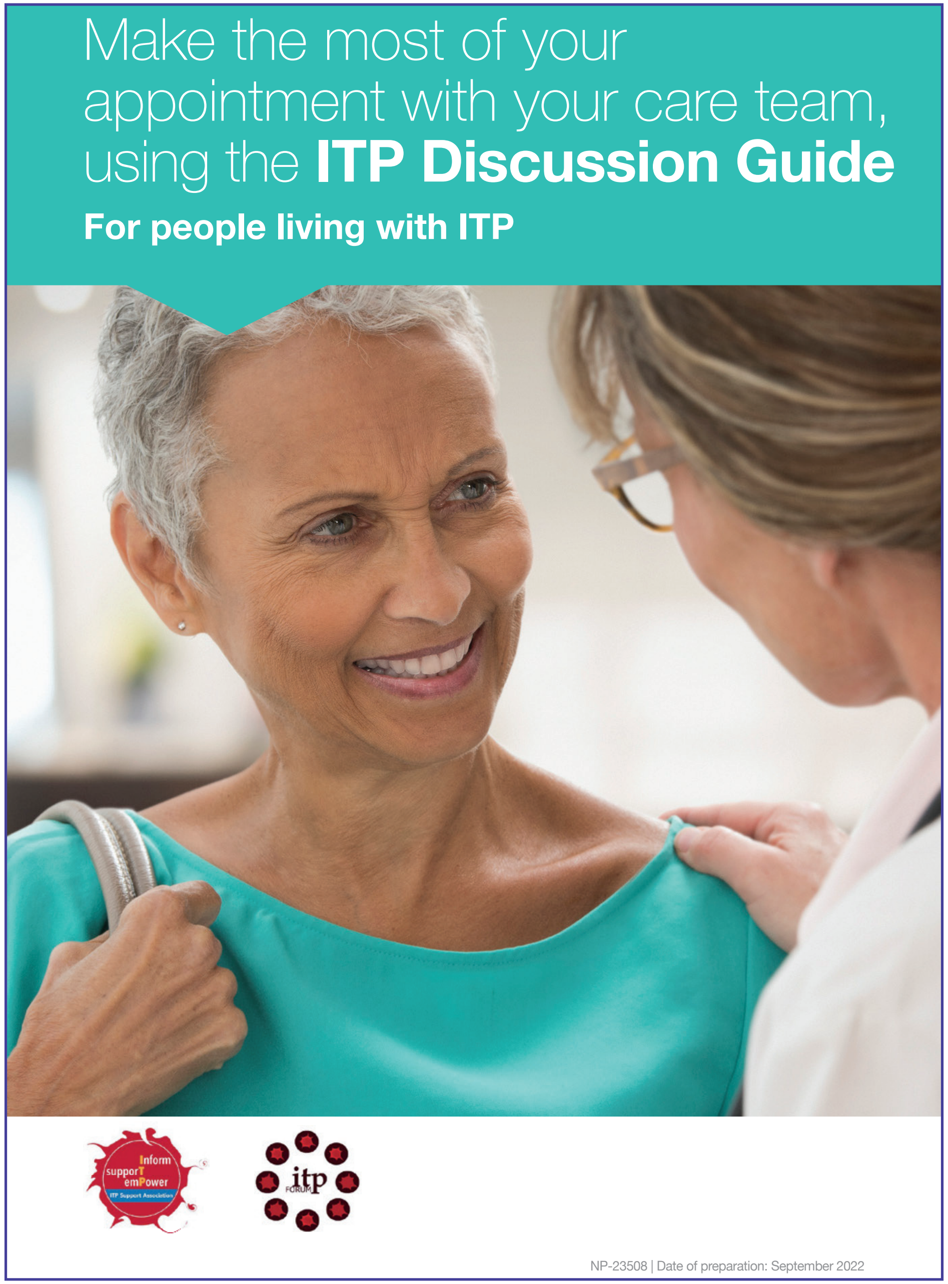
Dr Quentin Hill, Chair of the UK ITP Forum, said:

“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.)?

☹ 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.

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

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

I'm recognising

GLOBAL ITP AWARENESS WEEK

in

Insert location here

SEPTEMBER 22-28

#Global4ITP #LightUp4ITP
#ITPAwarenessWeek
#PaintThePlanetPurple

A global voice for immune thrombocytopenia (ITP) community

GlobalITP.org

Immune Thrombocytopenia - a quick summary

Immune Thrombocytopenia – A quick summary
Professor Adrian Newland

What it is ITP? - A disorder in which the body's immune system destroys platelets in the blood. A normal platelet count is between 150- 400 (UK measurement). The platelet count in people with ITP may fall to levels where they are undetectable. Although this is rare.

Immune thrombocytopenia (formerly known as idiopathic thrombocytopenic purpura) is a medical term for an autoimmune disorder (immune) causing a shortage of platelets (thrombocytopenia) and bruising (purpura).

What causes ITP? - For most people there is no known cause, but for others, particularly children it can follow a simple viral infection such as a cold or sore throat and in this group the condition is often transient. In adults this association is much less strong and often no preceding cause can be found. It may follow a viral infection, vaccination or certain medications and is associated with other haematological conditions, although these are rare. ITP can occur as a secondary condition to certain other autoimmune conditions such as Lupus (SLE) diabetes and thyroid disorders to name a few. There is an association with pregnancy and may arise while pregnant or in long-standing ITP may see worsening of the platelet count. This would need close monitoring.

As an autoimmune disease ITP sees disruption of the immune system in which the body mistakes the platelets as being foreign and destroys them often by the production of an antibody to one of the previously mentioned associated factors. This is a simplistic description and your doctor can explain in more detail or through literature provided by the ITPSA.

ITP that arises suddenly is known as acute ITP, if the platelet count remains low after 3 months it will be called persistent ITP, and if the platelet count has not returned to normal after 12 months it will be called chronic ITP. The severity of the condition is determined by the level of the platelet count and is considered severe if the count is less than 30, mild above this level and moderate between 50 and 100. adding the names severe or mild.

What are the Symptoms? - Some people with ITP, especially those with a count over 50, may have no symptoms at all, and their ITP only noticed during a routine blood test. A third of patients may be picked up in this way. Even people with very low counts, can sometimes have few symptoms and may only notice easy bruising.

Common symptoms are:
petechiae (pinprick rash of blood spots)
bruising
nosebleeds
gum bleeds
black mouth (blood) blisters
fatigue
heavy periods

Rare symptoms are:
blood in the eyes
bleeding from the ears
blood in the urine
bleeding from the gut
bleed into the brain

How is ITP Diagnosed? - ITP is usually diagnosed by a blood test showing that only the platelet count is low, and the platelets, red blood cells and white blood cells all look normal. A bone marrow biopsy may be taken at a later stage if the ITP continues, in which a small sample of bone marrow will be taken under local anaesthetic and examined under the microscope. Although this is now unusual. Additional blood tests may be taken at this time to exclude the known associated conditions and other rare clotting or immune diseases that can mimic ITP. If the bone marrow looks normal, with the usual or higher number of platelet parent cells (megakaryocytes) and other blood tests are normal then the doctor will diagnose ITP.

Treatment options for ITP? - Treatment options for ITP are detailed on the ITP Support Association Website at **www.itpsupport.org.uk**.

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

Scan me

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.

Fundraising News

Final Rider Trophy Event – Tuesday 27th May 2025 at Alresford Golf Club

The final participation in the current Rider Trophy, which started in 2000 and has involved golfers from across the Dever Valley competing in a "Rider Cup" style team competition, was played at Alresford GC on 27 May 2025.

Last year's event was put on hold due to the sad passing of "Mr Rider Trophy", Ron Chamberlain, from ITP an immune disorder condition which targets the bodies blood platelets. This year's event took on a very different look with a four-team competition featuring South Wonston, Tipplers, Waggs and Elephants, societies with which Ron was involved.

Forty-three hardy golfers turned out on the day in heavy rain which was testament to the affection in which Ron was held. The room was charged with emotion at the gala dinner as the assembled paid tribute to Ron and remembered also both Peter Roberts and Bill Driver who were present way back at the start.

There was a range of prizes and an auction to support the Charity ITP Support Association, which raised the magnificent sum of £2807 on the day. This brings the total since 2000 to £93,074. Originally the money was given to Naomi House and other local charities like Wessex Heartbeat have been beneficiaries since that time.

Next year there will be a new trophy named "The Arkwright Memorial Trophy" for which more details will be made available nearer the time. Meanwhile the Rider Trophy has found its last resting place in The Drovers in South Wonston where you can see it proudly displayed if you stop off for a pint.

We will publish a picture of the cheque handover in a future edition of the Platelet.

St Andrew's Prep
EASTBOURNE

We also had a wonderful donation from the Year 7 pupils at St Andrews Prep School in Eastbourne raising an amazing £561 for the ITP Support Association.

The donation was accompanied by a wonderful letter signed by the Year 7 pupils.

St Andrew's Prep
EASTBOURNE

from Tom Gregory BA. Headmaster

23 June 2025

Dear Sirs

This term our pupils took part in our annual Headmaster's Challenge where pupils in Year 7 are given the opportunity to become budding entrepreneurs and take part in a 'Grow your Money' fundraising project.

Each pupil is given an investment of £10.00 and working together in groups of up to six pupils, they think of ideas on how to raise the most money across a six week period. During the finale, at our May Fayre Market Day, our pupils have the opportunity to sell any products they have made, raffle off prizes, or sell wet sponges to throw at their favourite teachers!

Our pupils all choose the charity that they wish for their fundraising to go towards, and present to our Headmaster and Director of Studies describing why this charity means so much to them.

I am pleased to share that The ITP Support Association was chosen by one of our groups who raised a total of £561.13 through their fundraising efforts.

We are extremely proud of our pupils and their efforts this year and I am sure you will agree, this is a fantastic achievement.

Please could you contact with my EA, Helen Pugh, hm@standrewsprep.co.uk to let us know your preferred method of transferring donations.

With best wishes, George.S

Tom Gregory
Headmaster

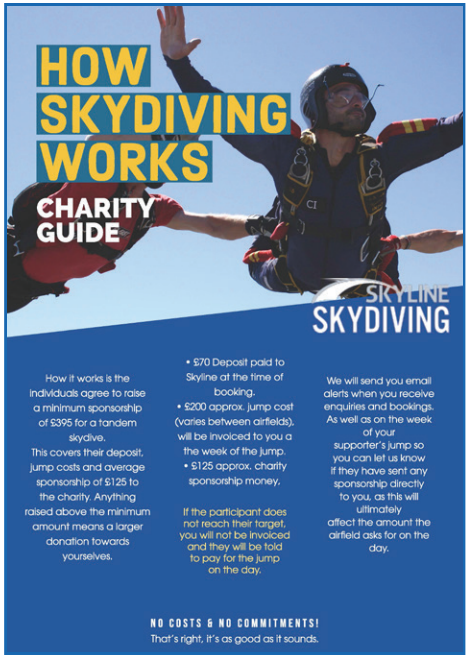
Sebbey.T
Finley M
Tom.P
Zak B
Chollie .W

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

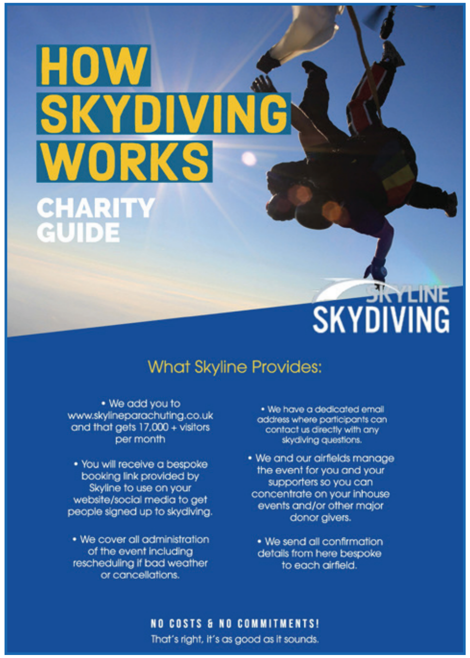
How it works is the individuals agree to raise a minimum sponsorship of £395 for a tandem skydive.
This covers their deposit, jump costs and average sponsorship of £125 to the charity. Anything raised above the minimum amount means a larger donation towards yourselves.

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

If the participant does not reach their target, you will not be invoiced and they will be told to pay for the jump on the day.

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
- 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.
- 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 givers.
- We send all confirmation details from here bespoke to each airfield.

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

Plasma Donation

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.

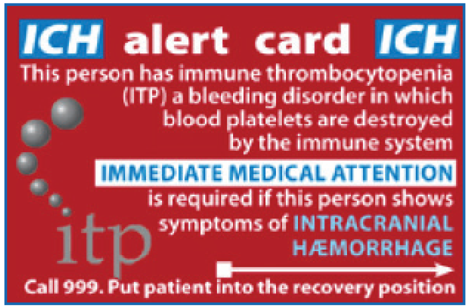
Order a free ICH alert card

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.

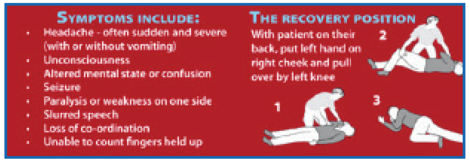


ICH alert card ICH

This person has immune thrombocytopenia (ITP) a bleeding disorder in which blood platelets are destroyed by the immune system

IMMEDIATE MEDICAL ATTENTION is required if this person shows symptoms of INTRACRANIAL HÆMORRHAGE

Call 999. Put patient into the recovery position

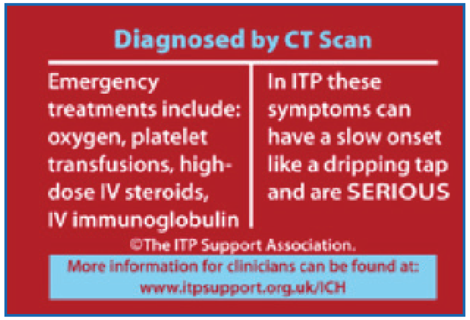


SYMPTOMS INCLUDE:

- Headache - often sudden and severe (with or without vomiting)
- Unconsciousness
- Altered mental state or confusion
- Seizure
- Paralysis or weakness on one side
- Slurred speech
- Loss of co-ordination
- Unable to count fingers held up

THE RECOVERY POSITION

With patient on their back, put left hand on right cheek and pull over by left knee



Diagnosed by CT Scan

Emergency treatments include: oxygen, platelet transfusions, high-dose IV steroids, IV immunoglobulin	In ITP these symptoms can have a slow onset like a dripping tap and are SERIOUS

©The ITP Support Association.

More information for clinicians can be found at: www.itpsupport.org.uk/ICH

Ways To Donate

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

JustGiving™

Facebook

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!

easyfundraising
feel good shopping

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.

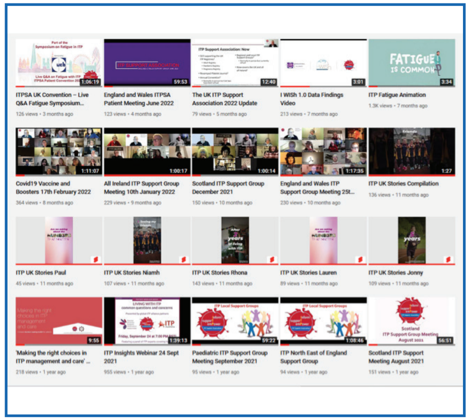
Visit our YouTube Channel

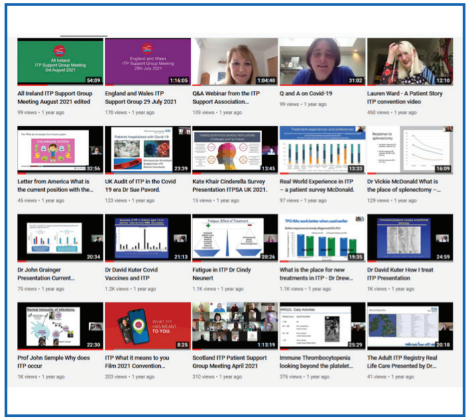
Subscribe to our YouTube Channel

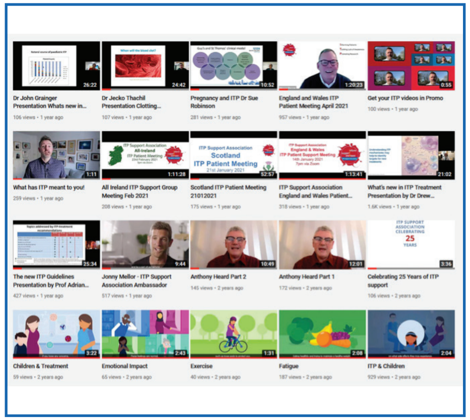
Inform supporT emPower ITP Support Association

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. The 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. The 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 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

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

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**

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	*After 31st January 2020 ***£15 UK *£20 Overseas**
GENERAL DONATION	
RESEARCH DONATION	
TOTAL ENCLOSED	

FOR OFFICE USE

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,
The Platelet Mission, Kimbolton Rd, Bolnhurst, Beds, MK44 2EL

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With support from the ITP Association