



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



The  
**Platelet**

JOURNAL OF THE ITP SUPPORT ASSOCIATION

**MARCH 2024**

# 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](http://www.itpsupport.org.uk)

**E-mail:** [info@itpsupport.org.uk](mailto:info@itpsupport.org.uk)

**Shirley Watson MBE Founder**

## TRUSTEES

Professor Adrian Newland CBE (Chair)

Derek Elston

Xenia Norman

Colin Williams

Anthony Heard (Patient Observer)

## OFFICE

### Chief Executive

Mervyn Morgan

### Deputy Chief Executive

Dianne White

### Office & Fundraising Administrator

Liz Gooch

## VOLUNTEERS

### Social Media

Anthony Heard

Mervyn Morgan

### Group Liaison

Derek Elston

### Patient Mentors

Rhonda Anderson

Derek Elston

Karen Smith

### Website

Mervyn Morgan

## MEDICAL ADVISORS (Adult ITP)

Prof. Adrian C. Newland CBE

MA FRCP FRCPATH

Dr. Drew Provan

MD FRCP PRCPATH

Dr. Jecko Thachil

MRCP FRCPATH

Dr. Will Lester

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

Dr. Nichola Cooper

MA, MBBS, MD, FRCP, FRCPATH

Dr. Gerard Crotty

MB BCh BAO, FRCPATH, FRCP

Dr. Catherine Bagot MBBS

Dr. Vickie McDonald

Prof. David Kuter

Louise Taylor ITP Nurse Consultant

## MEDICAL ADVISORS (Childhood ITP)

Dr. John Grainger

MBChB MD MRCP FRCPATH

Dr. Mike Richards

MA BM BCh DM MRCP FRCPATH

Dr. Cindy Neunert

MD MSCS

## AMERICAN PERSPECTIVE (Contributors)

Dr. Cindy Neunert

MD MSCS

Prof. Spero R. Cataland

MA FAAP (USA)

Dr. Adam Cuker

MD MS

Dr. Rachael Grace

MD MMSc

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

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

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

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

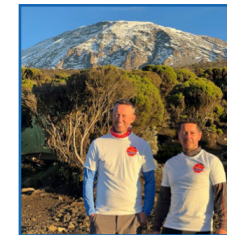
# From ITP HQ

Welcome to the March 2024 edition of the Platelet Journal. At the time of writing, we are preparing for our Ireland Virtual Patient Meeting on the 21st February, which will be followed the week after by our in-person meeting in Liverpool on 1st March. In addition to all of this we are also in full planning and preparation mode for our Annual Patient Convention which is taking place in London in May.

We are pleased to announce that tickets for our Annual Patient Convention are now on sale. The event will take place in London on 11th May at the Cavendish Conference, details on how to obtain tickets and the full meeting agenda are in this edition.

In this issue you will also find details of our latest patient perception survey 2024, please take the time to complete as the information helps to plan our target focus for the year ahead. Details of our 2020 and 2022 surveys are also available on our website.

In addition, some wonderful people are planning a aweinspiring fundraiser for the ITP Support Association, details in this issue, running the Edinburgh Marathon. Details of how to support Eve and Kate are in this edition. If you feel even more adventurous (can you do anything more adventurous than run a Marathon?) why not do a Skydive for ITP, again details are in this issue.



Whilst we are writing about fundraising, two gentlemen, Richard Price and Richard Hoggart climbed Kilimanjaro raising money for 4 charities, (one of which was the ITP Support Association), they raised over £2,000 for our charity, you can see some of the pictures from their adventure in this edition.



Now for some more fantastic news, last month I put forward two names as nominations from the ITP Support Association to the EHA Adolescent and Young Adult (AYA) Patient Advocates Training Program. I can now say congratulations to Rhona Bowie and Ella-Sophia Ellis who have both been successful in being selected as part of this prestigious training programme. The training starts in March with two days in München, Germany. Well done to you both.

We are also pleased to announce that our 2024 UK & Ireland

ITP Support Association Academic Scholarship Programme is now open for nominations, details in this edition plus on our website.

## Annual Patient Convention



Tickets for our Annual Patient Convention are now on sale to book please visit our website at [www.itpsupport.org.uk](http://www.itpsupport.org.uk) or scan the QR Code (above) with your Smart Device.

You will find more about our patient Convention in this issue of the Platelet, including the agenda, listing all the subjects and the names of the top experts who will be attending.



'Silver Standard' for Excellence  
in Industry Award



ITP Support Associations  
Platinum Sponsor for 2024

## Mervyn Morgan CEO ITPSA

# Contents

|    |  |
|----|--|
| 3  | From ITP HQ  |
| 4  | ASH Report by Dr Cindy Neunert                       |
| 5  | ASH Review by Mervyn Morgan                          |
| 6  | Dr James Bussell ASH Award by Danielle Boyle         |
| 8  | Dr Terry Gensheimer ASH Award By Danielle Boyle      |
| 10 | ITP Patient Convention 2024                          |
| 11 | Save the date  |
| 11 | ITPSA Annual Patient Convention 2024                 |
| 12 | New Medical Emergency Card                           |
| 13 | New Patient Perception Survey 2024                   |
| 13 | ITP Patient Mentors                                  |
| 14 | Self Help Information by Rhonda Anderson             |
| 16 | Florio ITP App – Now Available in the UK and Ireland |
| 17 | Visit our YouTube Channel                            |
| 18 | Platform Updates by Anthony Heard                    |
| 19 | Facebook Members Private Group                       |
| 20 | Shared Decision-Making Document                      |
| 22 | Patient Explainer – ITP Discussion Guide             |
| 25 | ITP Discussion Guide                                 |
| 27 | Fundraisers  |
| 28 | Kilimanjaro Challenge                                |
| 29 | Sky Diving for ITP                                   |
| 30 | Leaving a Legacy                                     |
| 31 | Scholarship Programme Nominations                    |
| 32 | Order a free ICH alert card                          |
| 33 | Ways to Donate                                       |
| 34 | Publications List                                    |
| 36 | Membership Form                                      |

# ASH Report by Dr Cindy Neunert



**The 2023 American Society of Hematology Update: Science, collaboration, and advocacy**

The first week of December, when the American Society of Hematology (ASH) holds their annual meeting, is always a busy time for hematologists. This year approximately

30,000 hematologists from over 100 countries came to together to collaborate, advocate for patients, and get all the latest updates on ITP. During this year's meeting there were 3 sessions dedicated to ITP and platelet disorders.

## Session 1: Innovative Treatments for ITP

During this session speakers presented results from clinical trials on novel treatments for ITP. One trial was using the drug rilzabrutinib, a bruton tyrosine kinase inhibitor, to treat adults with ITP. Bruton tyrosine kinase is an important signaler of the immune system that was given to patients for a total of 24 weeks. 35% of the patients were able to have a platelet count  $> 50 \times 10^9/L$  for at least 8 of the last 12 weeks of the study. What is exciting is that patients seem to respond rather quickly to the medication with many patients showing a response as early as two weeks. It is encouraging that this study was open to patients who relapsed after corticosteroids without needing to fail several additional therapies first or have persistent or chronic ITP. This means that now we may have treatments that are approved for patients to get earlier in the course of their disease. It was also shown that this medication was easy for patients to take without a lot of side effects and it improved their health-related quality of life. Results from a study on Efgartigimod were also presented. Efgartigimod is a neonatal Fc receptor blocker. It works to prevent the antibodies that cause ITP from recirculating. This leads to less antibodies available to bind to the platelets and clear them. In the ADVANCE IV study adults with persistent or chronic ITP were treated with either efgartigimod or a placebo (a non-drug infusion) for 24 weeks. The drug was given IV every week for 4 weeks and then either continued every week or switch to every other week depending on the patient's response. The study showed efgartigimod provided a rapid increase in the platelet count, as early as 7 days. This drug may also provide a quick increase in the platelet count for patients who need it. It will be exciting to continue to see the development of these new drugs for patients with ITP.

## Session 2: Clinical Practice, Natural History, and Patient Reported Outcomes

During this session several presentations focused on how ITP affects patients and how we might try to make that better. One presentation addressed the need for

advanced treatments in adult patients with ITP for longer than 3 months. Despite starting a second line treatment, many patients in this group had to switch medication, be treated for bleeding, or be hospitalized. This is an important study showing the need for novel treatments and the impact of ITP on patients. In addition, we learned that patients with ITP may have an increased risk for infection, especially within the first year of treatment. We don't know from this presentation if this is related to the treatment that patients were receiving but it is always important as a patient to ask if any medication you are starting will increase your risk of infection and what you can do to try to prevent infections. Lastly, there was a presentation on the use of the thrombopoietin-receptor agonist, avatrombopag, earlier during ITP. Even in patients with newly diagnosed ITP avatrombopag was good at increasing the platelet count and could improve the quality of life of patients if used sooner.

## Session 3: ITP in Special Populations

There were two presentations on ITP during pregnancy at this session. The first discussed women who develop ITP during their pregnancy and were followed for 6 months after the baby was born. ITP occurred equally during all trimesters of the pregnancy. When compared to women who had ITP prior to their pregnancy, these women had similar platelet counts and bleeding, however they were more likely to receive ITP interventions. The babies born to these mothers were also at risk for having neonatal ITP and many of the women continued to have ITP following the pregnancy. A second study compared treatment with just prednisone to treatment of prednisone and IVIg for pregnant women with ITP. While the women who got both medications had a faster increase in their platelet count there was no difference in treatment needed at delivery, type of delivery, or in the platelet counts of their babies. These two presentations highlight the importance for doctors to recognize a new low platelet count during pregnancy as ITP and for women with ITP to get specialty care during pregnancy and following delivery.

These updates provide only a brief overview of approximately 200 abstracts related to ITP, including poster presentations on data from the ITP Natural History Study Registry and iWISH study. What an amazing impact to have the patient experience recognized and presented at the meeting. It was wonderful also to see familiar faces like your very own Mervyn Morgan, Caroline Kruse of the PDSA, and Danielle Boyle from ITP Australia at the meeting making sure that the voice of patients is heard by physicians across the globe.

# ASH Review by Mervyn Morgan



A number of ITP Patient Advocates were invited to attend the American Society for Haematology Annual Congress in the USA in December.

I had the pleasure of joining colleagues from Australia and the USA as well as a number of our Medical Advisors and other supporters of the UK and Ireland ITP Support Association.



*Prof David Kuter with ITP Australia CEO Danielle Boyle and ITPSA Mervyn Morgan*

Aside from the publication of an Abstract with a number of co-authors also being members of the ITP International Alliance there were a large number of ITP related presentations covering (but limited to the following):

**Novel Therapeutic Approaches:** Researchers discussed the development and potential benefits of novel therapeutic approaches for ITP. This included presentations on the use of monoclonal antibodies targeting specific immune cells or molecules involved in the

pathogenesis of ITP. These approaches aim to modulate the immune system and restore platelet counts.

**Targeted Therapies:** Presentations highlighted the use of targeted therapies in ITP treatment. This included discussions on small molecule inhibitors that selectively target specific signalling pathways involved in platelet destruction or immune cell dysregulation. These targeted therapies offer potential alternatives to traditional immunosuppressive agents.

**Combination Treatment Strategies:** Researchers presented findings on combination treatment strategies for ITP. This included discussions on the use of multiple therapies with different mechanisms of action to enhance treatment efficacy. Combination approaches aim to address the complex immune dysregulation seen in ITP and improve patient outcomes.

These presentations provided valuable insights into the latest advancements and emerging trends in ITP treatment. They aimed to improve treatment outcomes, minimize side effects, and enhance patients' quality of life.



*ITPSA Mervyn Morgan with Prof Waleed Ghanima, two of the co-authors of the i-WISH 2.0 (World Impact Study) Abstract looking at tolerable treatment options. This Abstract can be downloaded from our website at [itpsupport.org.uk](https://itpsupport.org.uk).*

## ASH Review by Mervyn Morgan cont...



Left: Members of the ITP International Alliance – ITP Australia, PDSA Canada, PDSA USA and ITPSA UK

Right: ITPSA Medical Advisor Prof Nichola Cooper presenting at ASH 2023



In addition, we have two reports on awards that were presented to two friends of the ITP Support Association Dr James Bussell and Dr Terry Gernsheimer (Thanks to Danielle Boyle ITP Australia for these articles).

There are further articles regarding ASH 2023 in this edition of the Platelet, including a Review of the ASH Congress by Dr Cindy Neunert.

## Dr James Bussell ASH Award by Danielle Boyle

### CONGRATULATIONS TO PROFESSOR JAMES BUSSEL FOR HIS GROUNDBREAKING WORK IN THE FIELD OF ITP

Thanks to – Danielle Boyle – ITP Australia for the article.



Professor James Bussell received the Henry M. Stratton Medal for Clinical/Translational science at the 2023 American Society of Haematology Conference in San Diego, California.

James Bussell, MD, recipient of the Henry M. Stratton Medal for translational/clinical science, is being honoured for his invaluable

contributions to the development of agents that increase platelet counts in patients with immune thrombocytopenia (ITP) and other conditions. His achievements include the groundbreaking discovery that giving intravenous immunoglobulin (IVIG) to mothers can raise platelet counts in cases of fetal and neonatal alloimmune thrombocytopenia (FNAIT)—a treatment now used around the world. Dr. Bussell has increased the understanding of how IVIG treatment prevents platelet destruction in ITP, and his work has played a pivotal role in the development of several medications used to treat thrombocytopenic conditions. As professor emeritus of Pediatrics at Weill Cornell Medical School, Dr. Bussell continues to be one of the most prominent investigators in the field of paediatric and adult ITP, having written 242 articles, 142 reviews, and 42 chapters to date.

Perhaps the most inspiring aspect of Dr. Bussell's career, however, has been his extensive work with other researchers and clinicians across the globe. His talent and the ease with which he approaches collaboration have stimulated the development of international consortia for research on ITP and national and international patient support groups that not only disseminate knowledge but encourage participation in research. These efforts have led to the creation of large data banks and have spawned numerous clinical trials. Although he trained as a paediatrician, Dr. Bussell's research has also included adult populations, and this unique approach has increased the speed with which innovative ITP therapies are studied and approved for children.

In collaboration with basic science investigators, Dr. Bussell demonstrated that the SYK kinase inhibitor fostamatinib increases platelet counts in animal models of ITP by inhibiting platelet phagocytosis. This effect was observed in almost all patients included in his initial phase I/II studies in 2009, prompting two large, blinded, placebo-controlled international trials, which were published in 2019 and led to the approval of fostamatinib for the treatment of ITP.

Beyond sustaining grants from major funding agencies including NIH, he has won several prestigious awards, including the King Faisal International Prize for Medicine in 2012, which has often been considered the "Arab Nobel Prize in Medicine." On several occasions, Dr. Bussell has joined the Platelet Disorders Support Association (PDSA), ASH, patients with ITP, and their caregivers to meet with members

of Congress on Capitol Hill and the heads of the U.S. Food and Drug Administration's Office of Haematology and Oncology Products to discuss the unmet needs and burden of disease among those with ITP. In recognition of his outstanding contributions, the PDSA Board of Directors has established an ITP Young Investigator Award in his name. When asked to offer a bit of advice to these young investigators and those considering the field, he urged aspiring haematologists to "follow your gut, take advantage of the opportunities presented to you, and contact the people who can help you achieve your goals, even if they rank much higher than you."

Dr. Bussell has also been an active ASH member, having served as an abstract reviewer, chaired the education session on platelets, and spoken during several education sessions. He also helped to grow the now-established pre-ASH annual meeting breakfast session run by PDSA. Although he cited numerous mentors who have left an indelible mark on his career and shaped his approach to research and practice — including Drs. William Dement, Bill Speck, John Riley, Margaret Hilgartner, Bob McMillan, Ralph Nachman, and Albert von dem Borne — Dr. Bussell recognized without hesitation the one physician-scientist who has had the most outstanding impact on his career: his wife, Charlotte Cunningham-Rundles, MD.

## Dr Terry Gernsheimer ASH Award by Danielle Boyle

### CONGRATULATIONS TO THE RECIPIENT OF THE ROBERT MCMILLAN, MD AWARD FOR 2023 – DR TERRY GERNSHEIMER

Thanks to – Danielle Boyle – ITP Australia for the article.

Dr. Terry Gernsheimer stands as a shining example in the field of immune thrombocytopenia (ITP) research, earning the esteemed Robert McMillan Award in 2023.

This accolade, named after the pioneering Dr Robert McMillan, honours those who emulate his generous spirit, dedication to science, and commitment to improving the lives of individuals living with ITP through



advocacy, research, or service.

Embarking on her medical journey, Dr. Gernsheimer obtained her BS in Biochemical Sciences in 1975, followed by an MD from SUNY (Stony Brook, NY) in 1990. Her career trajectory showcases a commitment to excellence, earning certifications from the American Board of Internal Medicine in 1994 and the American Board of Internal Medicine, Haematology Subspecialty in 2000 and 2011.

Presently, she holds the esteemed positions of Professor of Medicine (Haematology)

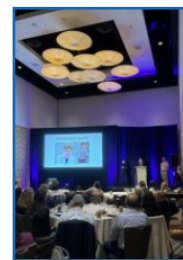
and Adjunct Professor in the Department of Laboratory Medicine and Pathology at the University of Washington. Her influence in the world of ITP extends far beyond these academic credentials.

One of Dr. Gernsheimer's groundbreaking contributions was her pivotal role on the team of Sherrill Slichter and Penn Ballem, where they formally proved that patients with ITP exhibit platelet production defects (J Clin Invest. 1987 July;80(1):33-40). This team also demonstrated the effects of steroids and IVIg on platelet production and survival in ITP, marking a significant advancement in understanding the condition (NEJM 1989).

Her involvement with the Trap Study Group further solidifies her legacy. This collaborative effort resulted in the largest clinical trial to date, showcasing that leukoreduction of platelets significantly reduces platelet alloimmunisation and refractoriness (Transfusion. 1995 Jan;35(1):13-19., N Engl J Med. 1997 Dec 25;337(26):1861-9).

Notably, Terry has gained worldwide recognition for her work in ITP during pregnancy, as evidenced by her contributions to the field (Curr Opin Hematol. 2007 Sep;14(5):574-80). Her involvement in seminal clinical studies played a pivotal role in establishing the efficacy of thrombopoietin receptor agonists (TPORAs) in treating ITP (Lancet. 2008 Feb 2;371(9610):395-403).

Participating actively in international collaborations, Dr. Gernsheimer has been a crucial member of the International Working Groups on ITP (Blood. 2009 Mar



12;113(11):2386-93, Blood. 2013 April 4;121(14):2596-606). Her contributions extend to the International Consensus Report on ITP, a vital document published in Blood Advances in 2019.

Since 2002, Dr. Gernsheimer has served as a medical advisor for the Platelet Disorder Support Association (PDSA). Her unwavering commitment is reflected in her consistent attendance at annual ITP meetings, earning her the admiration of patients within the PDSA organisation. Her clinical expertise in ITP is nothing short of stellar, always going above and beyond to support her patients and earning her the title of a patient favourite.

Dr. Gernsheimer's impact extends beyond the borders of the United States. She plays an active role as a member of the Medical Advisory Board with ITP Australia and New Zealand since its inception in 2019. Her global engagement underscores her commitment to the international ITP community, furthering collaboration and knowledge exchange across borders.

Beyond her scientific accomplishments, Dr. Gernsheimer's character shines through. Known for her highest, most uncompromising standards of integrity, she embodies the spirit of Dr Robert McMillan, whose legacy this award aims to honour. Her multifaceted contributions, spanning research, advocacy, and service, make her a truly deserving recipient of the 2023 Robert McMillan Award.


Congratulations to Terry on this latest accolade. Her journey is a testament to the profound impact that one individual can have on the understanding and treatment

of ITP. Her legacy is not only marked by scientific breakthroughs but also by her unwavering support for patients and her dedication to fostering collaboration within the global ITP community.

While we celebrate her achievements, we recognise the ripple effect of her work, touching the lives of countless individuals living with this rare disease while shaping the future of research and care in the field..






# ITP Patient Convention 2024



**ITP Support Association**  
**Annual Patient Convention 11th May 2024**

@ the Cavendish Conference Centre  
Cavendish Venues, 22 Duchess Mews, London W1G 9DT  
Refreshments and Lunch provided

Tickets on sale now at <https://bit.ly/ITPSALondon2024>  
or scan the QR Code


**SAVE *The* DATE**

## Dates for your Diaries

### In-Person Event

The ITP Support Association 2024 UK ITP Convention will take place on Saturday 11th May 2024 at the Cavendish Conference Centre, Cavendish Venues, 22 Duchess Mews, London W1G 9DT.

The ITP Support Association is the only patient support charity helping those with ITP in the United Kingdom and Ireland, it was formed in 1995 and has been holding patient conventions for many years.

The event will have talks and presentations from a number of the Worlds foremost ITP Experts.

Refreshments and lunch will be available. Doors open at 9:30 on Saturday 11th May 2023 with the first speaker at 10am.

To qualify for the members ticket price you must be a current (paid-up) member of the Association.

To qualify for the Healthcare Professional discount you must be working in a Healthcare Trust.

To register please go to <https://bit.ly/ITPSALondon2024>

### Recent Virtual Events

Remember if you missed any of the recent Virtual Support Group Meetings or you would like to watch them again, recordings are available on-demand from our YouTube Channel at:

<https://www.youtube.com/@ITPSAUK/videos>

# ITSPA Annual Patient Convention 2024

Tickets for our Annual Patient Convention are now on sale to book please visit our website at [www.itpsupport.org.uk](http://www.itpsupport.org.uk) or scan the QR Code (above) with your Smart Device.

Following last years Patient Convention being disrupted by the Rail Dispute hopefully this year will be unaffected, however a Rail strike is announced that will affect travel to London for the weekend of our Convention we will be prepared to refund the convention ticket cost. \*

\*Please be aware that strike action by the Rail Unions has to be notified some weeks ahead.

You will see from the agenda below that that there is something for everyone, we have once again attracted the top experts from around the world to London for our Convention which is taking place at a fabulous venue (Cavendish Conference Centre) in the heart of London.

## Annual ITP Patients' Convention May 11th

9.30 - 10.00 **Registration and Coffee**

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

10.10 - 10.30 **What has changed in ITP over the last 20 years** - Professor David Kuter

10.30 - 11.15 **Breakout sessions – Adult –**  
**Professor David Kuter + Dr Fred Chen**  
**Paediatrics – Dr Cindy Neunert,**  
**Dr John Grainger**  
**Women – Dr Vickie McDonald**

11.15 - 11.40 **Break and Exhibition**

11.40 - 12.00 **How do I approach the adult with newly diagnosed ITP** - Dr Drew Provan

12.00 - 12.20 **The dilemma of the refractory or relapsed patient** - Dr Cindy Neunert

12.20 - 13.30 **Lunch and Exhibition**

13.30 - 13.50 **Why did I get ITP?**  
- Professor John Semple

13.50 - 14.10 **The management of the pregnant woman** - Dr Vickie McDonald

14.10 - 14.30 **An update from the Adult Registry** - Dr Fred Chen

14.30 - 14.50 **Dilemmas of Paediatric ITP** - Professor Nikki Cooper

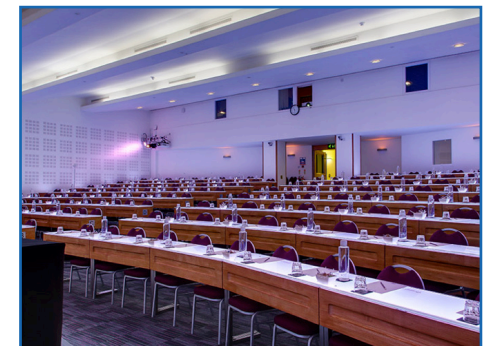
14.50 - 15.15 **Break and Exhibition**

15.15 - 15.35 **The problem of thrombosis in ITP** - Professor Waleed Ghanima

15.35 - 15.55 **Shared decision-making** - Mervyn Morgan ITPSA

15.55 - 16.15 **ITP Forum Update** - Dr Quentin Hill (Remote presentation)

16.15 - 17.00 **Q&A Chaired by Professor Adrian Newland**



The Cavendish Conference Centre Auditorium

# 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.

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



# ITPSA Patient Perception Survey 2024

**ITP Centre & Haematology Unit**  
**PATIENT EXPERIENCE**  
**Survey 2024**

Scan the QR Code with your smartphone

<https://bit.ly/ITPCentre2024>

We are now inviting feedback from ITP Patients about the level of care received at their ITP Centre or Haematology Department at their Hospital and their perception of how ITP affects daily life. Your answers will be kept confidential – only the result summaries will be published.

To take part in the survey please type in the link or scan the QR code with your mobile device, the survey will take a maximum of 15 minutes.

## 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](mailto: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.

**Derek Elston – Patient in long term remission**  
Derek is based in the Northwest.

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

# Self Help Information

## Self Help information by Rhonda Anderson

These days many people have anxieties about their health conditions and find it hard to see solutions. The Expert Patient Programme (EPP), may be able to provide self help for your long term condition. Read on and you may find this very useful if it is commissioned in your area. If not, you could ask for it.

The Expert Patient Programme (EPP) Copied from the website.

<https://www.nelft.nhs.uk/epp/>

The Expert Patients Programme (EPP) is a six-week course for anyone living with one or more long term health conditions such as asthma, chronic fatigue, COPD, depression, diabetes, heart disease, MS, Parkinson's disease, HIV, ME, on-going back pain, ITP, etc.

The course is designed to help you cope with your health condition, find solutions to common problems & feel more in control.

### What can self-management offer me?

People with long-term health conditions face many similar issues such as fatigue, pain, frustration, stress and depression. The course looks at how to manage these whilst working alongside your healthcare providers.

### By participating in the course you will:

- Learn new skills to manage your health condition better.
- Develop confidence in the daily management of your specific condition.
- Meet others and share similar experiences.
- Learn about developing more effective

relationships with health professionals.

### What do we learn?

The course focuses on what you can do, rather than what you can't. Weekly sessions cover useful topics such as managing symptoms, dealing with pain and tiredness, coping with depression and other feelings, relaxation techniques, healthy eating, exercise, setting realistic goals and communicating effectively with health professionals.

### How has it helped other people?

People who have taken part in an EPP course have reported that it has helped them to:

- Feel confident and more in control of their life
- Manage their condition and treatment together with healthcare professionals
- Be realistic about the impact of their condition on themselves and their family
- Use their new skills and knowledge to improve their quality of life.

### Do I need to pay?

No, it is free.

### Do I need to be referred by my doctor?

No, the course is open to self-referrals as well as referrals from doctors and other professionals.

### How is it structured?

Each course runs for two-and-a-half hours a week, for 6 weeks. There is one session a week and refreshments are provided. A maximum of 16 people attend the course. All participants have different conditions.

### Do I need to talk about my own condition?

There will be times where you will be talking about how your condition affects your life and what you would like to change, however it is up to you what you want to share and how much detail you want to give. All discussions are confidential.

### Who are the tutors?

The course is run by a self-care facilitator alongside another trained tutor who themselves have long-term conditions.

### Where are the courses held?

The courses are held at local venues, with facilities such as toilets and disabled access, as well as comfortable chairs and good access to public transport. You are free to stretch your legs, get up and walk around if you need to. It is not a hospital setting.

### Do I have to attend every week?

Yes, it is advised that you do in order to get the most out of the course. We do understand that there may be sessions you will miss due to appointments or feeling unwell.

### What do participants say?

"I've started swimming again which I never thought I would. It's given me a new lease of life!"

"Meeting people has helped me understand more about myself and ways of managing things... It has been a well run course and everyone has been very helpful and caring."

"It has helped me become more aware of my condition and how it affects me, and to feel that I can manage it to some extent through pacing, diet and relaxation techniques."

"There's a mix of people with different

conditions on the course so it's a good leveller."

"It gave me more information and confidence to do normal things in life."

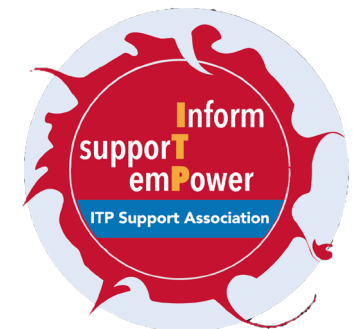
You will need to see if this course is run in your area.

I hope it is, because as a Voluntary Tutor for EPP in the NELFT area, I can vouch for its effectiveness for Long Term Conditions such as ITP.

EPP does not necessarily tell you anything you don't know, but it does help you to deal with your LTC in a positive way.

Very best wishes,

Rhonda





# Florio ITP App



NOW AVAILABLE UK AND IRELAND

ITP patients in the UK and Ireland can now use the florio ITP app, this application has already been rolled out in some European countries and is now available to download in the United Kingdom and Ireland.

The app will enable ITP patients to enjoy the following benefits:



Tracking and Monitoring: The app allows you to track and monitor your ITP (immune

thrombocytopenia) condition conveniently. You can record and keep track of your platelet counts, symptoms, medication intake, and any other relevant information related to your health.

Personalised Reminders: The app can be used to record details of future appointments and laboratory tests, such as date, time and location. This helps you stay on top of your treatment plan and ensures you never miss any important tasks or appointments.

Management: With the florio ITP app, you can log and monitor your symptoms over time. This helps you identify any patterns or triggers, allowing you to better manage your condition and communicate effectively with your healthcare team.

Remember, always consult with your healthcare provider for personalised advice and guidance regarding your condition and treatment.

You can download the florio ITP app from both the Apple App Store and Google Play.

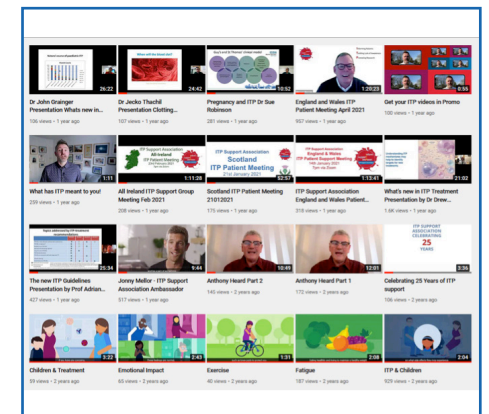
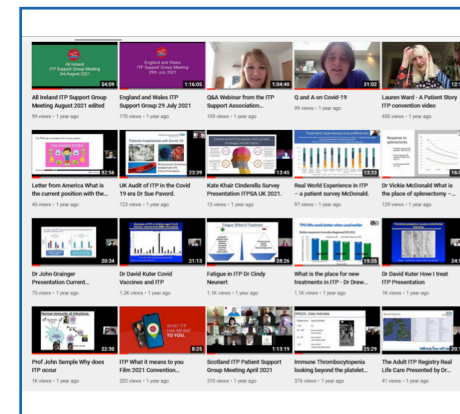
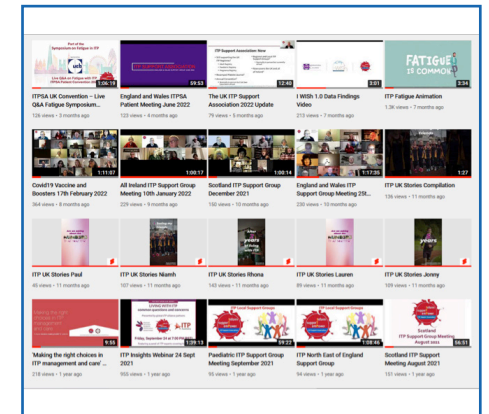
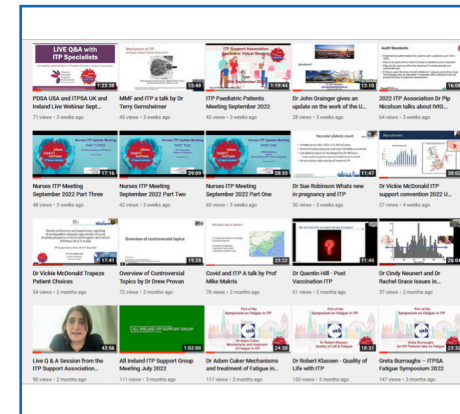
Florio GmbH has checked the article for factual accuracy only, with no editorial control. Florio GmbH is an independently operated subsidiary of Swedish Orphan Biovitrum AB (Sobi)

# Visit our YouTube Channel



The ITP Support Association YouTube Channel has almost 110 videos covering ITP. Plus with now almost 690 YouTube subscribers, we are getting closer to our 1000 subscribers target by next May.

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



## Platform Updates By Anthony Heard

**PLATFORM UPDATES – Trusted sources of reliable ITP information and advice**

We regularly get a number of enquiries and requests asking where the ITP Support Association can be found & where else you can get reliable, up to date information on our enigmatic illness.

So by way of a reminder you can locate the best information on the following seven platforms for the ITP Support Association.

1. The main website and the place to start for all up to date & reliable ITP information - [www.itpsupport.org.uk](http://www.itpsupport.org.uk)
2. Facebook - <https://www.facebook.com/ITPSuppAssoc/> with over 7800 followers
3. You Tube - with 112 ITP related videos , over 58000 views and 766 subscribers - <https://www.youtube.com/@ITPSAUK/videosn>
4. TWITTER - <https://twitter.com/ITPSupportAssoc> with 1822 Followers
5. Instagram - <https://www.instagram.com/itpsupportassoc/> with 1892 Followers
6. LinkedIn - <https://www.linkedin.com/groups/13990747/> with 32 Members
7. HealthUnlocked - a platform written by those living with ITP for those living with ITP - <https://healthunlocked.com/itpsupport> with 4075 Members
8. PRIVATE Facebook Group for ITP Members - <https://www.facebook.com/groups/235978790548730> with 342 Members

**As for other reliable sources the following links are also excellent –**

The Platelet Disorder Support Association - <https://www.pdsa.org/conferences.html>

ITP Australia and New Zealand - <https://itpaustralia.org.au/>

Rare Disease UK - <https://www.raredisease.org.uk/>

ITP International Alliance - <https://www.globalitp.org/>

Since setting up our various social media platforms we have seen huge interest in them and we are delighted that they have been so well received. When we set up some of these platforms back in 2011 the World was a very different place and the amount of interaction with such platforms has obviously dramatically increased.

With the many advances in technology over the years we have continued to try to adjust to these changes. A great example of this is that we have been providing online local support groups via the ZOOM platform since well before the Covid -19 pandemic broke out. These continue to be a huge success and attract an ever-increasing number of attendees.

We fully acknowledge and highly value the more traditional methods of communication and appreciate that we need to provide as many channels as possible to connect with us and with other ITP folk.

So wherever and how ever you wish to get in touch with us or from which channels you want to learn more about ITP from, we will continue to provide it via as many outlets as we can.

Thank you for your support.

## 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 300 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).

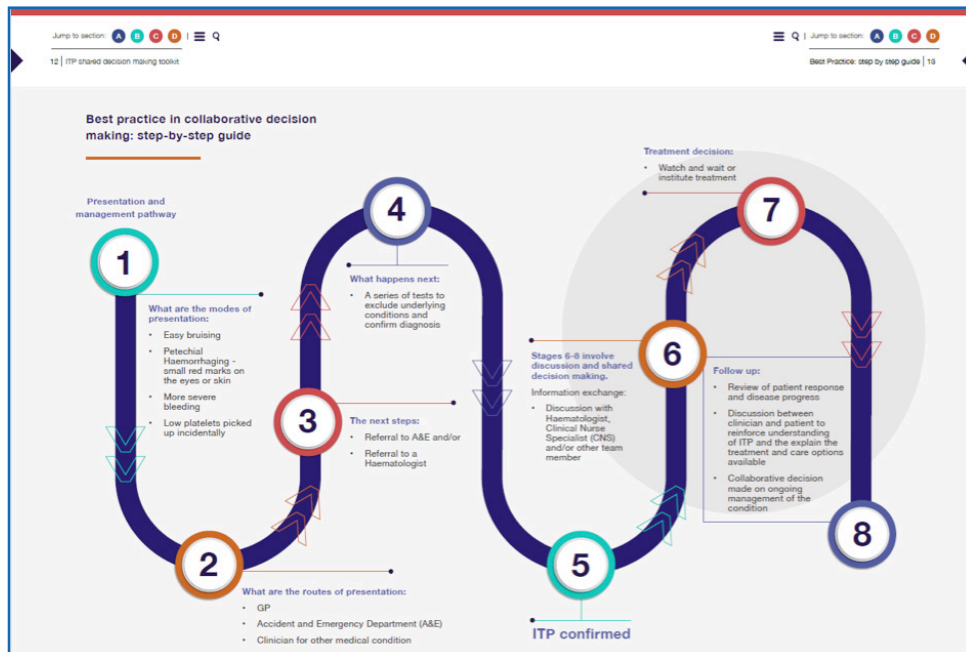
The group is a private place where we can share experiences and help people get a better idea of what you may face during a difficult time.

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.



# 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](http://www.itpsupport.org.uk).

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

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

shortage of platelets and bruising.

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

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

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

The toolkit is a response to the results of a patient

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

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

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

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

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

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

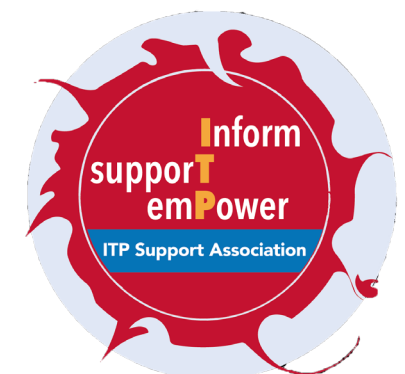
haematologists with a particular expertise in ITP to develop this toolkit that, we hope, will empower patients to hold collaborative and honest discussions with their clinician which in turn will result in better outcomes and quality of life.”

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

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

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

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



# ITP Patient Explainer

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

For people living with ITP



NP-23508 | Date of preparation: September 2022

# ITP Patient Explainer Cont...

## What is the ITP Discussion Guide?

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

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

## How do I use the ITP Discussion Guide?

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

Scan the QR code to complete your own ITP Discussion Guide



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



NP-23508 | Date of preparation: September 2022

# ITP Patient Explainer Cont...

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

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

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

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

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

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.
- Once completed, **tick the stars next to the questions that are most important to you.**
- 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, Sobri AB and Health Unlimited and funded by Sobri 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, Sobri AB and Health Unlimited and funded by Sobri AB | NP-23507 | Date of preparation August 2022

# Fundraisers

## Fundraising



### FUNDRAISING



Eve and Kate are running the Edinburgh Marathon 2024 in support of The ITP Association

By running Edinburgh marathon on 26th May, we hope to raise awareness about ITP and raise funds for the association's vital work. The funds raised will go towards providing educational materials, organising support groups, and funding research initiatives that aim to improve treatments and find a cure for this condition.

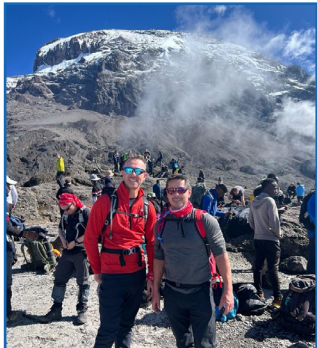
We are reaching out to you today with an ask - please consider supporting us by making a donation towards our fundraising goal. Your contribution will make a real difference in the lives of individuals and families affected by ITP. Together, we can bring hope and support to those who need it most.

Join us in making a positive impact on the lives of individuals living with ITP. Together, we can make a difference!

<https://www.justgiving.com/page/eveandkaterunemf2024>

# Kilimanjaro Challenge

The two heroes in this picture, Richard Price and Richard Hoggart have recently returned from Africa after climbing Kilimanjaro raising money for 4 charities Including the ITPSA), over £8,000 in total, divided equally between the charities. With each Charity receiving just over £2,000 each.



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

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

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

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

## 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](http://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](http://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.

## Scholarship Programme Nominations



### **The UK & Ireland ITP Support Association Academic Scholarship Programme**

Nominations for the 2024 ITP Academic Scholarship Programme are now being accepted.

The ITPSA has been providing ITP patients and family members with reliable information and support through its many channels (website and social media), publications, regular patient meetings and annual conferences. During these difficult times we realise that many ITP patients and their families are finding it a struggle financially whilst living with a chronic disorder, which is why we at the ITPSA have launched its scholarship fund. We also believe that education is the key to success.

### **Who is Eligible for the Scholarship?**

Awards are restricted to Sixth Form students, current College or University students, or adults who have gone back into full time education who have ITP (Immune Thrombocytopenia).

### **How to Apply?**

Please provide a short essay which details how your ITP has resulted in your growth as a person; what you learned about your own strengths and weaknesses. Tell us about your ITP Journey. Please note the winning entries will be published in the Platelet Journal and on the ITP Support Association website and Social Media Channels. Applications must be submitted with the application form and emailed to [info@itpsupport.org.uk](mailto:info@itpsupport.org.uk).

If you feel that having a chronic illness such as ITP has helped you choose a career path, describe how, and explain why you feel this way and what you have done to meet these educational goals. Explain what your plans are for the future in meeting your educational responsibilities, in light of your struggles with a platelet disorder.

The application form is available on our website at: <https://itpsupport.org.uk/the-uk-ireland-itp-support-association-academic-scholarship-programme-2/>

## Raise money by donating your scrap car in aid of ITP!

1. Contact Give a Car on 020 0011 1664 or 'http://www.giveacar.co.uk/how-it-works' and say you wish to donate your scrap car in aid of ITP. It takes a couple of minutes to get your details and answer questions. Once they have your approval, a collection agent will call you in order to arrange a convenient pick-up time.

2. Your car is picked up. A tow truck usually arrives within 1 to 3 days to pick up your car, though in a few rare cases it may take up to 10 days.

3. Your car is sent to scrap or auction. Give a Car then donate all the proceeds, after administrative costs, to the ITP Support Association. Within 6 weeks you will receive a receipt for your donation, and so will we.





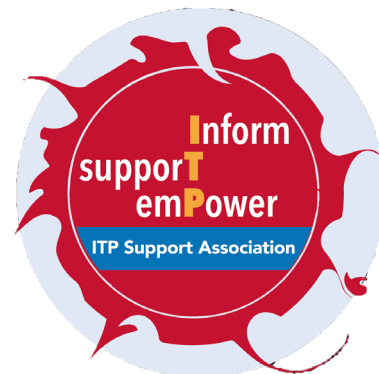
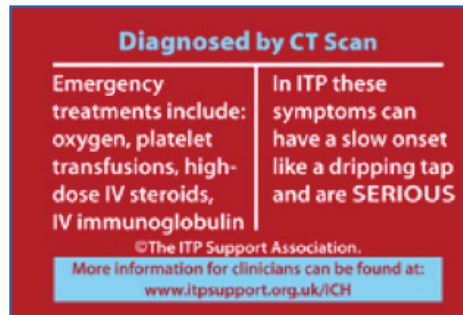
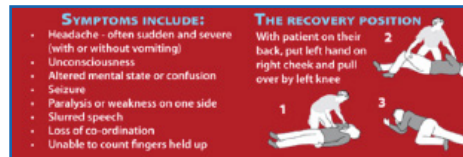
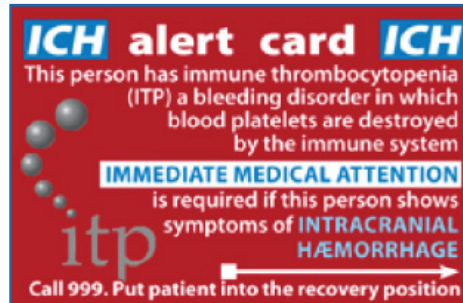
## Order a free ICH alert card

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

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

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

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



## Ways To Donate

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



### Facebook



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

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



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

Go to [www.easyfundraising.org.uk/causes/itpsupportassociation](http://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.

# Publications List

## BOOKLETS

**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.

## ALERT CARDS

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

**ICH alert card** – an alert card demanding immediate medical attention if the holder shows symptoms of intracranial haemorrhage (listed on the card). Also has information for medics.

## ARTICLES PUBLISHED IN PREVIOUS ISSUES OF THE PLATELET

1. Colds and 'flu
2. ITP and skin irritation
3. MMR vaccine and ITP
4. Needlephobia in children
5. Hayfever and ITP
6. ITP & school attendance
7. ITP investigation & treatment procedures
8. Insurance issues
9. Accessing drug information
10. Is drug treatment a risk worth taking?
11. – e ITP pupil moving to senior school
12. Alert medical cards and jewellery
13. Healthy eating with ITP
14. H-pylori (stomach bacteria) & ITP
15. Causes of excess infections in ITP
16. A summary of low platelet disorders
17. Night calls – when to call the doctor
18. Service recruitment & ITP

# Publications List cont...

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

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

# MEMBERSHIP SUBSCRIPTION FORM:

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

YOU CAN PAY ONLINE AT [WWW.ITPSUPPORT.ORG.UK](http://WWW.ITPSUPPORT.ORG.UK)

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

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

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

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

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

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

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

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

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

The ITP Support Association, The Platelet Mission, Kimbolton Road, Bolnhurst, Beds Mk44 2EL

The associations privacy policy is available at: [www.itpsupport.org.uk](http://www.itpsupport.org.uk)

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



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

