



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

## 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



# The Platelet

JOURNAL OF THE ITP SUPPORT ASSOCIATION

DECEMBER 2023

# The ITP Support Association Team

Charity Registration No. 1064480

## THE ITP SUPPORT ASSOCIATION HQ

**The Platelet Mission**  
**Kimbolton Road, Bolnhurst,**  
**Beds. MK44 2EL (UK)**  
**Tel: 01234 376559**  
**Web: www.itpsupport.org.uk**  
**E-mail: info@itpsupport.org.uk**  
**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

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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.



## 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

# From ITP HQ

Welcome to the December 2023 edition of the Platelet Journal. 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 in this edition.

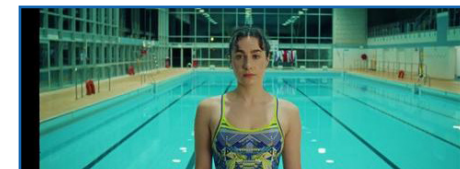
Plus, we can also announce that we will also be holding an in-person ITP patient day in Liverpool on 1st March at the Line Hotel, details in this edition.

ITP Awareness Week 2023 was a huge success around the world with all of the leading ITP Patient Associations taking part and raising awareness about the condition, its symptoms, diagnosis, and treatment options. The aim of awareness week is to educate everyone who is affected by ITP about the condition and its impact on individuals' lives. In the UK during Awareness Week, we had a number of events taking place including an international webinar titled '**Your voice matters!**'

A webinar for people living with ITP and their caregivers. As part of ITP Awareness Week 2023, members from the International ITP Alliance came together to produce a webinar for people living with ITP and their caregivers. The webinar was led by ITP experts, including ITP Medical Advisors Dr Cindy Neunert and Prof Nichola Cooper and members of the ITP International Alliance (Australia, Italy, USA and the UK) exploring Shared Decision Making best practice in ITP care, including personal tips and experiences. Thanks must go to our friends at ITP Australia & New Zealand, Platelet Disorder Support Association, AIPIT and Sobi for supporting the co-creation. The webinar can be viewed at [https://youtu.be/3AheiD19T88?si=5\\_fzZDXtQK-qoOff](https://youtu.be/3AheiD19T88?si=5_fzZDXtQK-qoOff)

We also held a Paediatric ITP meeting on Zoom with Dr John Grainger. The video of this meeting is also available on our YouTube Channel along with over 100 other ITP videos.

## NO BAD BLOOD - A film by UK ITP Patients



We are also very proud of a short video produced for ITP Awareness Week called 'No Bad Blood', a film featuring ITP patients.

We would like to thank all of the ITP Patients who are featured in this film plus a huge thankyou to all who put their names forward, we may well be looking to do more of these in the future, so next time 'it could be you!'

You can download a copy of the Shared Decision-Making document for FREE from the ITP Support Association website at <https://bit.ly/3INsdKe>

Our ITP Discussion Guide is also available to download from <https://bit.ly/3RlOiyE>

If you require a hard copy of the above mentioned documents, please email [info@itpsupport.org.uk](mailto:info@itpsupport.org.uk) with your details.

This film was co-created by SOBI and the UK and Ireland ITP Support Association.

If you have not seen the film 'No Bad Blood' yet then please visit our YouTube channel, people have called it inspiring <https://youtu.be/iUUI3agddIM>

Also made available on our YouTube Channel during Awareness Week were the talks and presentations from our Patient conference held at the Royal College of Pathologists in May this year.

The goal of ITP Awareness Week is to foster understanding, support, and advocacy for those living with ITP and to provide resources for individuals affected by the condition. It is an opportunity to promote awareness, dispel misconceptions, and encourage early detection and appropriate management of ITP.

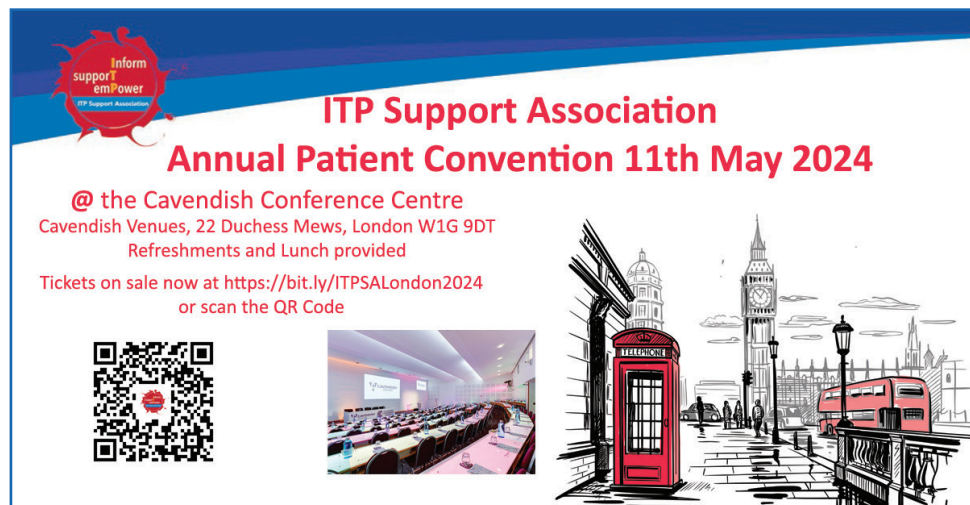


Mervyn Morgan CEO IPTSA

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# ITP Patient Convention 2024



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**@ the Cavendish Conference Centre**  
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# ITP Patient Support Day



Supported by the: **Inform support emPower**

**ITP Patient Support Day**

Friday 1st March 2024  
1pm to 4pm  
Free Event  
Refreshments on arrival  
Open to ITP (Immune thrombocytopenia)  
Patients and family members

**The Liner Hotel**  
Lord Nelson Street  
Liverpool L3 5QB

Please join us face to face for this patient focused meeting that will have both education and patient support focused sessions

To register visit <https://bit.ly/ITPLiverpool2024>  
or scan the QR Code




L I V E R P O O L

## ITP Patient Support Day, Liverpool, Friday 1st March 2024

We are pleased to announce that the ITPSA will be supporting a ITP Patient Support Day at the Liner Hotel, Lord Nelson Street, Liverpool, L3 5QB on Friday 1st March 2024 1pm to 4pm. The venue is 3-minute walk from Lime Street Station.

Free event, refreshments on arrival, open to ITP patients and their family members.

Please join us face-to-face for this patient-focused meeting that will have both education and patient support-focused sessions.

The meeting is organised by Rosalyn Davies ITP Specialist Nurse, with support from the ITP Support Association. The event is limited to 50 places, so if you register but cannot attend, please let us know so the place can be available to others.

To register go to <https://bit.ly/ITPLiverpool2024>

# 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.*





## Breathing – By Rhonda Anderson

### How do you breathe?

We seem to be experiencing more stress than we would like, so I hope the following will aid your relaxation and enjoyment of life.

Many people do not breathe correctly, or are aware that they can concentrate on their breath for better health and wellbeing.

I have taught some of these techniques to participants, and they have found them very helpful to alleviate stress, aid relaxation and for distraction from every day pain.

Breathing techniques are powerful tools for relaxation and stress control, offering a simple yet effective way to manage the demands of daily life. By harnessing the innate connection between breath and emotions, individuals can cultivate a sense of calm and balance, promoting both mental and physical well-being.

One popular and accessible breathing technique is diaphragmatic breathing, also known as deep belly breathing. This method involves inhaling deeply through the nose, allowing the diaphragm to expand and the abdomen to rise, and exhaling slowly through the mouth. This deliberate and intentional breathing pattern engages the body's relaxation response, reducing the heart rate and promoting a sense of tranquillity. Practicing diaphragmatic breathing for just a few minutes can be a quick and effective way to alleviate stress.

Another effective technique is the 4-7-8

breathing method, championed by Doctor Andrew Weil. Inhale quietly through your nose for a count of four, hold your breath for a count of seven, and exhale audibly through your mouth for a count of eight. This technique helps regulate the breath, promoting a sense of calm and reducing anxiety. The extended exhale also stimulates the body's relaxation response, making it an excellent tool for managing stress in various situations.

For those seeking a more structured approach, progressive muscle relaxation combined with breathing can be highly effective. This involves tensing and then gradually releasing different muscle groups while maintaining a focus on deep, rhythmic breathing. The combination of muscle tension release and controlled breathing helps to release physical and mental tension, promoting a profound sense of relaxation.

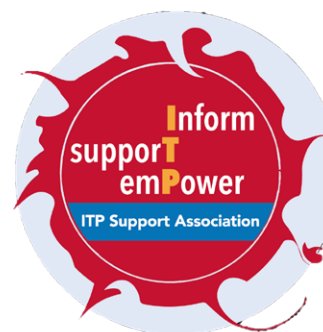
Mindful breathing, rooted in mindfulness meditation practices, is another technique that emphasizes present-moment awareness. It involves paying close attention to each breath, observing the sensations as air enters and leaves the body. Mindful breathing encourages a non-judgmental awareness of thoughts and feelings, allowing individuals to detach from stressors and foster a more balanced perspective on their circumstances.

Box breathing, also known as square breathing, is a structured technique that involves inhaling, holding the breath, exhaling, and holding the breath again—

all for equal counts. This method promotes relaxation by regulating the breath and bringing attention to the present moment. It can be particularly effective in high-stress situations, offering a quick and accessible way to regain composure.

Incorporating these breathing techniques into a daily routine can significantly contribute to stress management and relaxation. Whether practiced as part of a morning routine, during breaks at work, or before bedtime, intentional breathing provides a valuable tool for navigating the challenges of life with greater resilience and calmness. As individuals explore and integrate these techniques into their lives, they empower themselves to take an active role in promoting their overall well-being.

Rhonda Anderson



## 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.



# Florio ITP App - Preview



## COMING SOON TO THE UK AND IRELAND

Very soon ITP patients in the UK and Ireland will be able to use the florio ITP app, this application has already been rolled out in some European countries, 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.

Keep checking our website [www.itpsupport.org.uk](http://www.itpsupport.org.uk) and social media channels for details of when the florio app will become available.

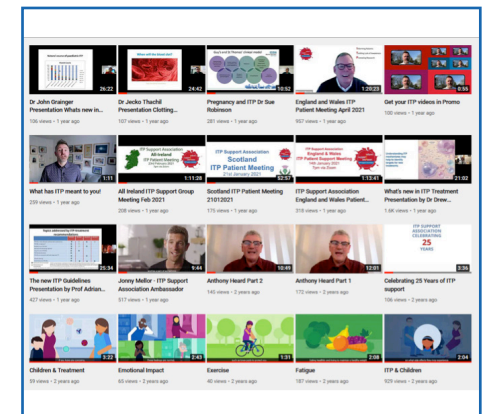
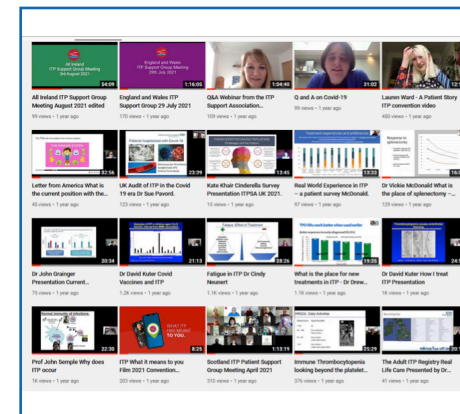
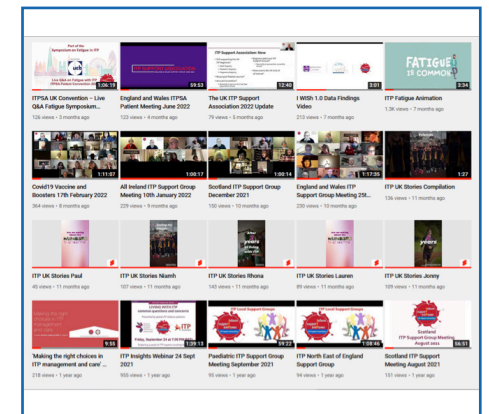
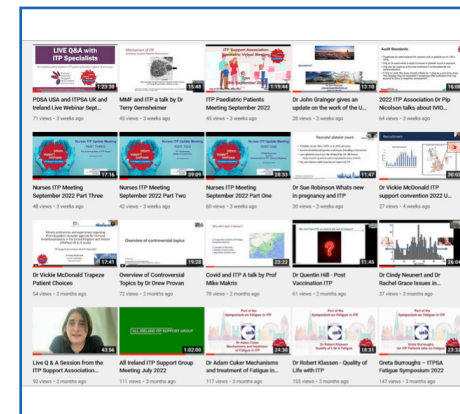
**Florio GmbH has checked the article for factual accuracy only, with no editorial control. Florio GmbH is an independently operated subsidiary of Swedish Orphan Biovitrum AB (Sobi)**

# 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>





## IN PLATELETS AGE and SIZE REALLY DOES MATTER by Anthony Heard

All of us purple people know that ITP is a condition where, even though our platelet production is increased from our bone marrow, our misguided immune system destroys platelets even more rapidly hence leading to thrombocytopenia and the telltale symptoms we all recognise.

Right so far are you with me? OK... well, we have also discovered that in general and I say the words again to emphasise the point. IN GENERAL, we folk with ITP do not have the same bleeding tendency as those with the same degree of thrombocytopenia caused by a bone marrow issue/problem.

So, we purple folk in general don't tend to bleed as much as those with bone marrow/platelet production issues. Our problem is one of destruction rather than production (in general terms). Also, the platelet count in us purple people is actually a poor predictor of whether or not we are actually likely to suffer any bleeding be it internal (brain bleeds or internal organs) or external (nose bleeds, gum bleeds etc).

So, what does all this mean? In a nutshell in ITP because we are having to produce so many more platelets because our misfiring immune systems keeps destroying them it means a much higher proportion of our platelets are YOUNG. Well so what one might say? Well so good actually. Younger platelets are more capable of stopping bleeding than older ones and this may explain the general tendency for less bleeding in ITP patients than those with platelet production/bone marrow deficiencies.

So, in platelets the younger the better and so platelet age really is a definite factor. But it's not just about age, it's also a size issue too. Platelets decrease in size as they get older, so the younger platelets are bigger and are therefore more effective in the clotting process.

Now there is a test which can be done to measure the average size of our platelets called the Mean Platelet Volume (MPV). It takes into account the different sizes of platelet circulating in our blood. So, if the younger platelets are more predominant our MPV will be greater but if the number of younger platelets is fewer our MPV will be lower.

It is as if the ITP Gods have granted us a back handed bonus, a compensatory gift of younger, bigger

more efficient platelets in exchange for mistakenly destroying them. One heck of a quid pro quo!

In ITP sufferers our MPV is normally higher than average (again I use the words normally higher with caution). Now this measure should not be looked at in isolation and cannot be relied upon in itself BUT it can be viewed at in combination with other evidence/symptoms that the patient is showing.

Just to get a bit more complicated here is another set of initials to get thinking about in respect of the age of our platelets.... IPF which stands for Immature Platelet Fraction. This looks at the number of young platelets circulating in our blood system, and it can give an indication of whether or not there is a likelihood that even with a low platelet count there is likely to be bleeding or not.

With IPF and MPV all this is just another aspect of estimating/predicting whether or not the patient is at risk from bleeding or at least getting a better idea of the bleeding propensity.

So, what can we conclude about the age of our platelets?

1. In general, YOUNG platelets are more plentiful in ITP sufferers because we produce more of them to replace those being destroyed by our misfiring immune systems.
2. YOUNG platelets tend to be bigger and therefore are more efficient in the clotting process.
3. Testing can be done in the lab to check the volume of YOUNGER platelets and age of them in our systems. Hence it gives more information to our specialists when they consider whether or not we each have a greater or lesser propensity to bleed even with lower platelet counts.
4. This is an area still developing all the time and we are getting more ammunition to be able to design treatments specifically for patients as individuals.
5. Age and Size really does matter with platelets.

As we are discovering more about our illness, we are hopeful to better tailor treatments to the individual sufferer with more precision.

## Global ITP Awareness Week in Bangladesh



Greetings! This is Nabila Chowdhury, Assistant Manager, Oncology PMD from Beacon Pharmaceuticals, Bangladesh.

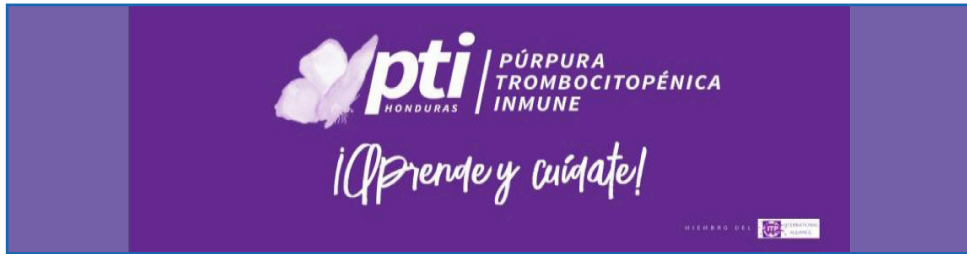
I am a pharmacist and very much inspired by your activities in Global ITP Awareness Week. We deal with Medicines like Eltrombopag, Rituximab for ITP patients. Therefore, every year with the hematologist patients and in our office, we Celebrate Purple Day to increase the awareness of ITP.

Just like to share with you some photos of our Celebration of ITP Awareness Week 2023. We sport purple for ITP from Bangladesh

Thanks again for encouraging us to create awareness worldwide.



# PTI Honduras Welcome



We would also like to welcome a new ITP Patient group to the ITP International Alliance family: Pti Honduras, an organisation setup by Stephanie Kafie. They have a fantastic website at [ptihonduras.com](http://ptihonduras.com)



# 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.



### 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.

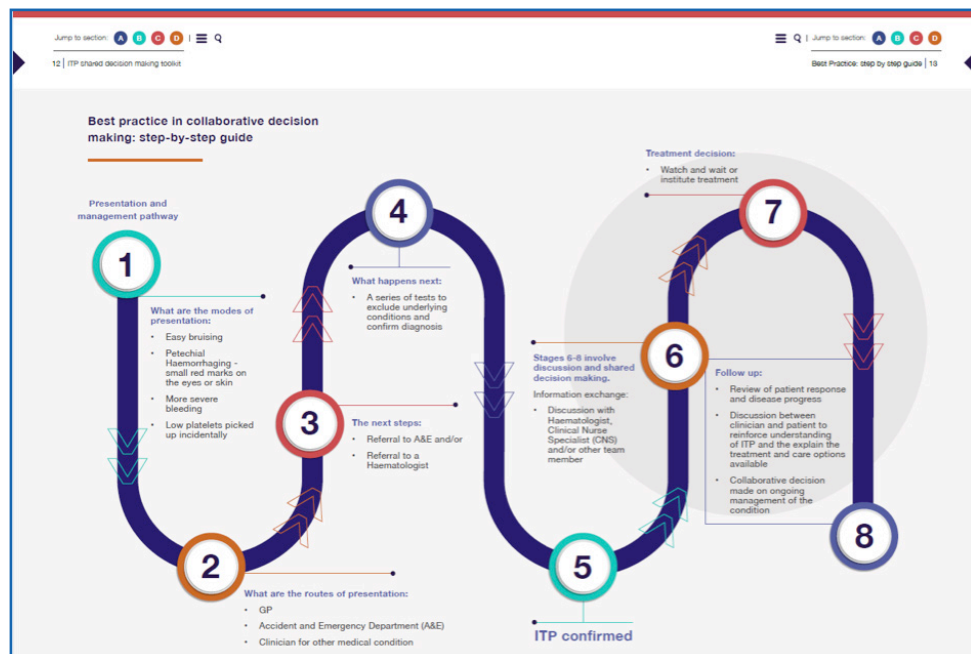
If you would like to speak to one of our ITP Patient Mentors email [info@itpsupport.org.uk](mailto:info@itpsupport.org.uk) with your details and we will put you in touch

**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.

## 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

# ITP Patient Explainer Cont...

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

## 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...

# Fundraisers & In Memoriam

## 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

## Fundraising



### FUNDRAISING

We would like to thank all who have been raising money for the ITP Support Association, without your help we would not be able to do what we do.

- Joanne McManus – £132.00
- Atlas Trading Limited - £86.68 from collection box
- Burford Trust - £500.00
- PayPal Giving Fund - £592.50
- Facebook - £397.63
- JustGiving donations - £1601.31
- Total JustGiving Donations in the past 12 months totals over £9,000

See the Kilimanjaro Challenge, coming soon, details in this edition  
The charity has now enrolled with Skyline events so people can do a sponsored charity skydive on behalf of the association (see the advert in this edition).



### IN MEMORY

£233.00 in memory of Paul McManus

Will Bequest in memory of Rosemary Fenwick - £2500.00

Will Bequest in memory of Mrs Searle - £5000.00

Much Loved - £283.26 anon donation

£17 in memory of Caroline Kaye

In memory of Vic Barfoot. The association sends its sincere condolences to the family and friends of Vic.



# Kilimanjaro Challenge

# Sky Diving for ITP



# AIN'T NO MOUNTAIN HIGH ENOUGH

## We're raising £2,500 for good causes by climbing Kilimanjaro

Richard Hoggart and Richard Price are embarking on a 10-day trip and 7-day trek on the 18th January, climbing the highest free-standing mountain in the world where the summit is close to 6000 metres above sea level:

"We are sleeping on the mountain each night, with most nights sub-zero before tackling summit night at midnight and trekking for around 15-16 hours in temperatures as low as minus 20 degrees, up the final part where we will see sunrise and then decent the mountain the same day.

We are raising funds for several charities namely: **The Hinge, The ITP Support Association, SMA UK, Coeliac UK.**

We have raised funding for the whole trip and so anything we raise will be shared with the above charities. If you donate and want to help a particular charity just mention in the comments, otherwise we will split the fundraising equally!"

We have completed our warm up walk of the Yorkshire 3 Peaks and Rich P has recently tackled Ben Nevis, we will be utilising the next few weeks to prepare, practice and train.

Be great if you can support us in any way, you can, money, best wishes, a like on social media or good luck message.

Thanks.

Just Giving - Scan Me



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 coverage 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.
- 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 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.

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

## Is there a relationship between food and ITP?

I have decided to repeat some information about ITP and food, for the benefit of those new to ITP, and who are not aware that food is not a known factor in ITP.

During our ITP Zoom calls, the question of diet and ITP often arises.

The short answer is that there is no evidence that food causes or cures ITP.

Recently people have said that following a certain exclusion diet has helped them. This may be so, everyone is different, and as long as you are not excluding important elements in your diet, then follow it for your own health, comfort and peace of mind.

Every ITP patient is different and every person will react to food and drugs differently. Experiment safely, and if you find it helpful, then continue to exclude that which bothers you. This does not mean that what has helped you will help others, and that you have found the miracle cure. Beware of anything that makes claims to cure you, especially if you have to hand over any money. There is much on the internet that makes claims that are not true. However, you may also find helpful information. Anything that sounds too good to be true, probably is. Be discerning when searching the net. Stick to NHS sites and other reputable ones.

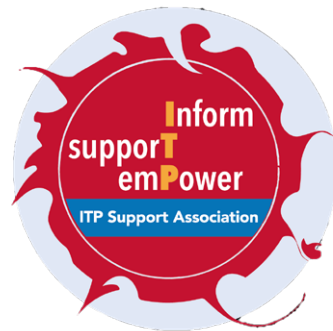
[www.nhs.uk/conditions/food-allergy/](http://www.nhs.uk/conditions/food-allergy/)

It is important not to decide that this or that is causing your ITP, or your platelets to drop. Infections have been known to lower

the platelet count. To decide that it is the antibiotics that have been prescribed to combat the infection, are the cause of your ITP, is jumping to conclusions.

Enjoy your food, breathe mindfully and take time to enjoy the life you have.

Rhonda Anderson



## Gut Instinct by Anthony Heard

OMEPRAZOLE and the potential problems with Proton Pump Inhibitors

For many of us living with ITP one of the drugs that we may have encountered on our purple journey is Omeprazole.

Just one of a class of drugs known as Proton Pump Inhibitors (see link at the end of this article for a full list), Omeprazole reduces the amount of acid our stomach makes. Unfortunately when we are prescribed Prednisolone and in my case Mycophenolate Mofetil (MMF) for our ITP it can cause other potential problems like acid reflux, indigestion, heart burn.

So Omeprazole is mainly used to help reduce the acidic effect of steroids and other drugs like MMF on the stomach. For patients started on steroids such as Prednisolone or MMF the use of Omeprazole is often advised to prevent ulcers from forming in the stomach or gut lining. The dose of a 20mg tablet once a day before breakfast is the regime many of us ITP folk will be familiar with.

As previously stated Omeprazole is a type of medicine called a proton pump inhibitor (PPI). Proton pumps are enzymes in the lining of our stomach that help it make acid to digest our food. Omeprazole prevents proton pumps working properly which reduces the amount of acid the stomach makes thus balancing out any excess acid which we may produce from Prednisolone or MMF use.

So far so good BUT - in addition to reducing stomach acid, unfortunately Proton Pump Inhibitors can also do potential harm. Now this does not mean that they always will be damaging because we are all made differently and respond to drugs in various ways. Short term usage of the drug usually does not cause any significant issues.

**The potential problems that Omeprazole and Proton Pump Inhibitors may cause (especially if taken for long periods) are as follows-**

1. Mal absorption of certain key Vitamins like Vitamin B12 and Vitamin B9 (Folate)

2. Low Magnesium levels
3. Gut infections
4. Bone fractures
5. Iron deficiency
6. Calcium deficiency
7. Nausea, vomiting, constipation, tummy pain
8. Kidney and liver problems

**For a fuller list please see the attached two links...**

- A. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7887997/>
- B. <https://www.nhs.uk/medicines/omeprazole/side-effects-of-omeprazole/>

Now there is nothing to say that any of these issues will manifest themselves in those of us on Omeprazole (especially short term) but it is my belief that is worth knowing what the issues are and checking with our specialists how the drug may be impacting our wider health.

In my case it was back in 2020 that I had a slight fall in my Vitamin D and Vitamin B9 (Folate) count. My specialist could not instantly tell what might have caused this but we ended up feeling that my being on Omeprazole was probably the reason why I was struggling to absorb enough of these key vitamins from my diet.

I was prescribed Vitamin D and Vitamin B9 (Folate) supplements which I still take daily even though I have not been taking Omeprazole since 2020. I now take Gaviscon if I get any signs of indigestion or acid reflux. My Vitamin D and Folate levels are well above normal now and my specialist tests them half yearly.

My ITP is being controlled by Mycophenolate Mofetil which does cause acid reflux/indigestion but nowhere near as much as the Prednisolone did in my case.

So hopefully my experience back in 2020 will be helpful for others who are taking Omeprazole or any of the other Proton Pump Inhibitors (PPI's).

## Plasma Donation



**All types can save lives**

**Your plasma can treat 50 diseases**

Join us at [blood.co.uk/plasma](http://blood.co.uk/plasma)

Save lives Give plasma

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

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

Book an appointment at [www.blood.co.uk/plasma](http://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](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.



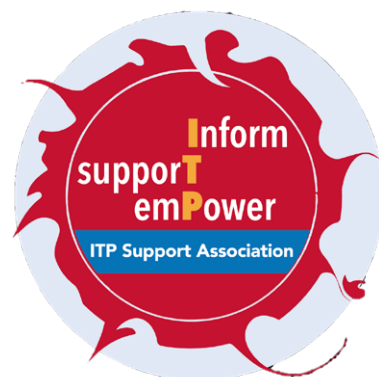
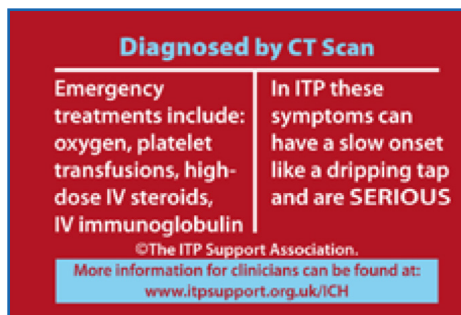
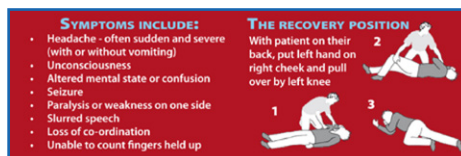
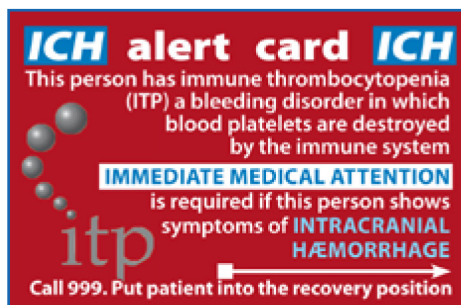
## Order a free ICH alert card

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> <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)

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

