



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

Annual Patient Convention – Manchester 2025 – Tickets Available

The Platelet

JOURNAL OF THE ITP SUPPORT ASSOCIATION

MARCH 2025

The ITP Support Association Team

Charity Registration No. 1064480

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GRIFOLS

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From ITP HQ

Welcome to the March 2025 edition of the Platelet Journal.

This edition of the Platelet will have a focus on our forthcoming Annual Patient Convention which is being held at the Bridgewater Hall, Manchester on Saturday 10th May 2025. Details of the wonderful speakers who will be taking part and, importantly, how to book your tickets are also included in this edition.



Also, this year's Annual Patient Convention is also registered for CPD (Continuing Professional Development) Points. If you are a healthcare professional you can earn 6 CPD points by attending our Annual Patient convention.



We also have some wonderful news about the London Marathon, not one but two runners!

Since the last edition of the Platelet, there have been a few changes to our board, we have said goodbye to Trustees, Derek Elston and Colin Williams. Our Charity constitution means that Trustees can only serve for two terms, Derek had achieved that and more, the rest of the board send they're thanks to both Derek and Colin but also to Dereks wife Rosemary for all of their support over many years.



However joining the Trustees is a name (and face) many of you will already know, Anthony Heard. Anthony has been a supporter of the charity and more recently a patient observer on the board. Anthony has provided many useful and interesting articles for these pages plus his support with our presence on social media. Welcome Anthony, thank you for stepping up.

Virtual Patient Meetings

We have held 3 virtual patient meetings since

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From ITP HQ

the last update, England and Wales, Scotland and All-Ireland, thanks must go to our medical advisors, Prof Adrian Newland, Dr Catherine Bagot and Dr Gerard Crotty for fielding some interesting questions at our meetings.

All three virtual events were well supported. The dates for the next round of virtual meetings will be published in April.

Coming soon

We are currently busy working on a number of projects, these include a couple of new publications which will help support the needs of some cohorts of ITP patients and a Survey aimed at those patients who are taking or have taken TPO's as part of their ITP Treatment plan.

Mervyn Morgan CEO ITPSA




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

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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.

30 Years What the ITPSA means to me

2025 is a landmark year for the UK and Ireland ITP Support Association as it celebrates its 30 year anniversary.

The Association, formed in 1995 by Shirley Watson MBE, was the first ITP (Immune Thrombocytopenia) Patient Support Organisation in the World, now as we look to our 30th Year there are more than 30 such ITP patient organisations and groups around the world working together as part of the ITP International Alliance for the benefit of patients.

In the build up to our 30th Anniversary we are asking our members and friends to send us a few words about what the ITP Support Association means to them, you may be a patient, parent, carer, healthcare professional or a fundraiser, please let us know. Please send to: mervyn.morgan@itpsupport.org.uk.

We will collate the reply's and use them in the months ahead and during our 30th year celebration.

Here are a few of the replies we have already received:

The ITP association were the calm in a middle of a storm for me. The support I received from them and you personally in with this scary diagnosis, made so much difference. From the wealth of knowledge and information to the lovely mentor Rhonda. Who gave me over an hour of her time to put my mind at rest. My questions answered every time I reach out with care and compassion. I would not have got through the last 9 months if it was not for the support, care and knowledge of the ITP association.

It's been information, being able to gain knowledge about treatments and support when needed. Knowing that others also have this rare disease and the opportunity to meet them in person and online. Knowing that any query will be answered and expert advice sought if necessary.

Thank you to all at ITPSA, you do a really great job.

The ITP Support Association is an invaluable source of trustworthy information provided by experts.

As a person with ITP for nearly 10 yrs my consultant is only normally available for my scheduled check-ups. Therefore, I find the ITPSA Website, forums and chats so helpful as they answer lots of my questions.

Thank you so much for all your help with this. I really appreciate everything you've done to push things forward. You've gone above and beyond, and I can't thank you enough!

Thanks so much! It'd be lovely to meet up in person. I can't tell you how much you've helped me. It can be a very lonely place with this condition, so being able to speak to someone who understands is invaluable.

I would say finding the support group helped me so much, as no one really seemed to have any real day to day advise, I can remember going to Shirley house to help organise a very early convention and volunteered to do the raffle, it was wonderful to meet other people who had been through it, many times I would telephone Shirley for a chat as we both had children with ITP, my daughter is now married with a three year old and is 37 this year, and must say since having her son her ITP is not as bad, thank you for being there for us all.

Thanks again for being so supportive, it really means a lot to me.

My membership of this organisation gives me access to reliable information about ITP that I can't easily get anywhere else.

I know that the lectures and discussions held at meetings and seminars are given by professionals who have studied the subject and give reliable and up to date information.

I appreciate that I will always get a considered, informed reply to my questions. This is very reassuring when there is such limited knowledge, generally, about ITP.

I would not be without the background support I have received from the association over the last number of years.

Thank you so much for your kind words. I truly appreciated hearing your insights and experiences. I'm so grateful for your support and guidance.



ITP Convention Bridgewater Hall - Manchester



The ITP Support Association 2025 UK ITP Convention will take place on Saturday 10th May 2025 at the Bridgewater Hall, Lower Mosley Street, Manchester, M2 3WS.

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 World's foremost ITP Experts.

Refreshments and lunch will be available.

Doors open at 9:30 on Saturday 10th May 2025 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.

This event is now registered for CPD Credits with the Royal College of Pathologists. Healthcare Professionals will receive 6 CPD credits for attending this event.



ITP Patients' Convention Agenda

Bridgewater Hall, Lower Mosley Street, Manchester, M2 3WS

May 10th 2025 - 9.30 - 10.00 Registration and Coffee

10.00-10.10 Welcome and Introduction; Mervyn

Morgan

10.10-10.30 Unmet Need in ITP; Prof David Kuter, Massachusetts General Hospital, Harvard Medical School



10.30-11.15 Breakout sessions -

- **Adult ITP; Prof David Kuter and Dr Gerard Crotty, Health Service Executive Ireland**
- **Paediatric ITP; Dr Rachel Grace, Harvard Medical School, Boston Children's Hospital, USA and Dr John Grainger, Manchester Royal Infirmary**
- **Women ITP; Dr Cindy Neunert, Columbia University Medical Center, USA and Dr Catherine Bagot, Glasgow Royal Infirmary**

11.15-11.40 Break and Exhibition

11.40-12.00 What is the future of ITP Management; Dr Drew Provan, Barts and the London School of Medicine, Barts NHS Trust



12.00-12.20 Terminology in ITP; Cindy Neunert, Columbia University Medical Center, USA

12.20-13.30 Lunch and Exhibition

13.30-13.50 Health related Quality of Life; Prof Henrik Frederiksen, Odense University Hospital, Denmark.

13.50-14.10 Living with ITP; Dr Andrew Morgan, Clinical Psychologist, Royal Liverpool and Broadgreen University Hospital NHS Trust

14.10-14.30 What can the Clinical Nurse Specialist do for you.

14.30- 14.50 Patient interview; Prof Nikki Cooper, Imperial College London

14.50-15.15 Break and Exhibition

15.15-15.35 An update from the Adult Registry; Dr Fred Chen, Barts NHS Trust



ITP Convention Bridgewater Hall - Manchester

15.35-15.55 *Secondary ITP and inherited platelet disorders; Dr Rachael Grace Harvard Medical School, Boston Children's Hospital, USA*

15.55- 16.15 *Why do platelets go up and down; Prof Jecko Thachil, Manchester Royal Infirmary*

16.15-17.00 *Q&A Session; Chaired by Professor Adrian Newland, Barts and the London School of Medicine, Barts NHS Trust, Chair, ITP Support Association.*



Some topics and speakers may be subject to change.

All sponsors have provided sponsorship towards this independent programme.

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

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

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What is a diagnostic odyssey? By Anthony Heard

What is a diagnostic odyssey? By Anthony Heard

A 'diagnostic odyssey' is the time between having the first symptoms of a condition and receiving a final diagnosis.

Many people with a rare condition face challenges in getting a diagnosis, with more than a third of people having to wait more than 5 years for an accurate diagnosis.

This 'diagnostic odyssey' can have a significant impact on a person's quality of life and wellbeing.

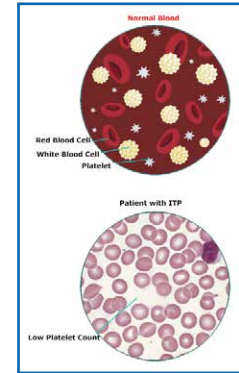
As ITP sufferers we fully understand the complications of getting a diagnosis as our condition is one of diagnosis by exclusion.

This means that all possible reasons for our low platelet count needs to be ruled out before ITP is confirmed.

My own diagnosis took 8 hours on a fraught Friday evening in A&E, numerous blood tests and a Bone Marrow Biopsy. It is fair to say that I have had better Friday nights.

How is ITP diagnosed?

Extract from 'Making the right choices in ITP



Management and Care' page 8. Full document available at www.itpsupport.org.uk

ITP is usually diagnosed by a blood test which shows that the platelet count is low, but the appearance of the blood is otherwise normal and the red blood cells and white blood cells are present in normal numbers.

As outlined in 'other causes of ITP' a low platelet count can be caused by other conditions so a series of tests will be needed to check for other potential causes.

Extra blood tests may also be done at this time to check for rare clotting or immune diseases that can look similar to ITP.

A bone marrow biopsy is usually unnecessary for the diagnosis but may be taken at a later stage if ITP is persistent, in any way not typical, or fails to respond to usual treatments.

Facebook Members Private Group



Join our new ITPSA Facebook Group

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

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

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

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

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

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



Don't Let The Sun Go Down On Me – Anthony Heard



At this time of year, we ITP folk in the Northern hemisphere need to consider taking a Vitamin D supplement as we say goodbye to sunny days and hence the lack of natural absorption of Vitamin D from those warming rays.

For those of us living in colder climes we are all too aware of our long Winters. That miserable time between the end of September and the beginning of April when we are starved of sunshine. All our pictures seem to fade to black and white!

Here in the UK, one of our national pastimes is talking about the weather but I am sure that few people understand the implications of a lack of sunshine on our health.

It is our reduced supply of vitamin D that is impacted by the lack of sunshine that we get during the Winter months that causes us a problem. It can have potentially dangerous implications for our health.

We can synthesise vitamin D3 in our skin from sunshine and this is our main source of vitamin D. However, in the UK and anywhere in the Northern latitudes for that matter this is only possible in the summer months, during the hours around midday (11am-3pm), when sunshine contains sufficient UVB light (290-315 nm).

During the winter, vitamin D can only be obtained from our diet (and supplements), but only a relatively small number of foods contain vitamin D.

So why is Vitamin D important to our health and what problems can it lead to if we do not obtain enough of it?

Vitamin D is needed for maintaining the balance

of calcium and phosphorus in the body, It is essential for keeping bones and muscles healthy and to facilitate the body to take in calcium and phosphorus, which are needed for healthy teeth and bones. It also assists our immune system to fight infections, support nerve function, and help maintain muscle strength to prevent falls.

A deficiency can lead to a loss of bone density which can contribute to osteoporosis and broken bones.

Severe vitamin D deficiency can also lead to other diseases. In children, it can cause rickets which is a rare disease that causes the bones to become soft and bend. In adults, severe vitamin D deficiency leads to osteomalacia which causes weak bones, bone pain, and muscle weakness.

There are surprisingly few sources of vitamin D in our food and so without the sunshine levels that we get in our summer months we will almost certainly see our levels become low during the Winter months, unless we take a supplement.

Good sources of vitamin D from our food are -

Oily fish – such as salmon, sardines, herring and mackerel
Red meat
Liver
Egg yolks
Fortified foods – such as some fat spreads and breakfast cereals. Check the labels!

I take a vitamin D supplement during the Winter and always have done. From October 1st until May 1st, I take a 10ug vitamin D supplement tablet. This is certainly supported by Public Health England who recommend a supplement is taken during these months, when vitamin D synthesis in the skin is not possible.

SO WHO IS AT RISK? -

At risk groups, including people who do not often go outdoors, who reside in an institution such as a care home, or those who normally cover most or all of their skin when outdoors, should take a daily 10

Don't Let The Sun Go Down On Me – Anthony Heard

microgram vitamin D supplement throughout the year.

People with dark skin, including individuals from Black and Minority Ethnic (BAME) groups (e.g. individuals of African, African-Caribbean or South Asian background), should consider taking a vitamin D supplement all year round, as they may not be able to get enough vitamin D from sunlight exposure during spring and summer.

So there we have it, when there is no sunshine because of our rainy or Winter days, we need to do something to boost our vitamin D levels. Taking a supplement of 10ug per day should be sufficient for most of us during the Winter months. This should make up for the lack of the vital vitamin D we can

obtain from the sunshine we might get during the Summer. Eating a sensibly, balanced diet will also help too.

Don't let the sun go down on me - absolutely not ... one tablet per day should solve the problem.

Some useful sources of information on Vitamin D -

<https://www.nhs.uk/conditions/vitamins-and-minerals/vitamin-d/>
<https://www.bda.uk.com/resource/vitamin-d.html>
<https://ods.od.nih.gov/factsheets/VitaminD-HealthProfessional/>
<https://publichealthscotland.scot/media/21950/vitamin-d-and-you-in-english-december-2023.pdf>

PATIENT MENTORS

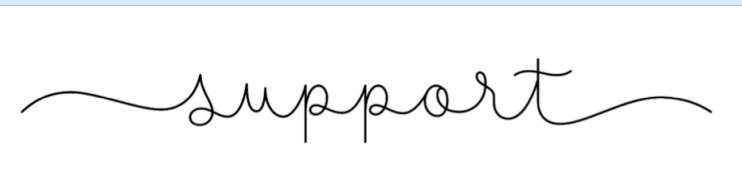
If you need to talk to someone about your ITP we have a small team of Patient Mentors who will be happy to help.

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

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

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

Dianne White – ITP Patient
Dianne is based in the Northwest



Shared Decision Making Document available in Six Languages



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

To download the English Language version click this link: [Making the right choices in ITP management and care.](#)

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

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

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

shortage of platelets and bruising.

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

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

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

The toolkit is a response to the results of a patient

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

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

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

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

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

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

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

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

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

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

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



ITP Patient Explainer

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



NP-23508 | Date of preparation: September 2022

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, Sobi AB and Health Unlimited and funded by Sobi AB | NP-23507 | Date of preparation August 2022

ITP Discussion Guide

Managing ITP effectively

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

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

☹️ 1 2 3 4 5 😊 ★

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

☹️ 1 2 3 4 5 😊 ★

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

☹️ 1 2 3 4 5 😊 ★

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

☹️ 1 2 3 4 5 😊 ★

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

☹️ 1 2 3 4 5 😊 ★

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

☹️ 1 2 3 4 5 😊 ★

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

☹️ 1 2 3 4 5 😊 ★

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

☹️ 1 2 3 4 5 😊 ★

Notes:

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

ITP treatment and your goals

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

YES NO

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

Priority discussion points for your next consultation

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

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

And finally...

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

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

Buzzy Kits

Information on the Buzzy® Kits for Paediatric ITP Patients.

WHAT IS BUZZY?

BUZZY® is a small vibrating bee with blue ice-pack wings. He helps block sharp pain and provides distraction when giving injections or other medical procedures.

Just like cool running water soothes a burn, Buzzy® uses a combination of cold and vibration to replace pain with temperature and movement.

Buzzy® confuses your body's own nerves and distracts attention away from the pain, thereby dulling or eliminating sharp injection pain. In the same way that rubbing a bumped elbow helps, or cold running water soothes a burn.



BUZZY® was invented by Pediatric Emergency Doctor and Pain Researcher Amy Baxter. She invented Buzzy® to help her children overcome their fear of needles.

Buzzy® is now used in medical practices, vaccination clinics, hospitals, dental practices, and homes by both adults and children. Over 20 independent clinical trials prove Buzzy® works!

HOW DOES BUZZY WORK?

Gate Control Theory of Pain

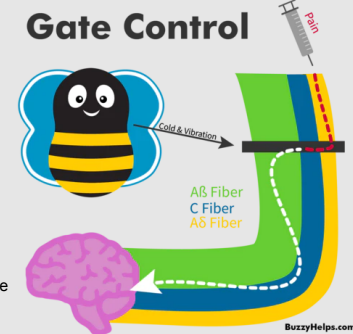
The gate control theory is the basis for the design of Buzzy®. The premise is that when nerves receive non-painful signals such as vibration or cold, the brain closes the gate on pain signals. For example, if you hit your finger with a hammer, you might instinctively begin to rub it, shake it, or run it under cold water. You are sending non-pain signals through your nerves to close the gate on the pain signals.

Descending Inhibitory Controls

The second part of Buzzy efficacy, and the reason it can help even when distant from the site of procedural pain, is something called Descending Noxious Inhibitory Control, or DNIC. While gate control happens locally (confusing nerves right where the pain happens) another effective mechanism of pain control uses the brain's ability to dampen out unwanted signals. Instead of happening right where the nerves are, though, an intense degree of cold can work anywhere on the body.


The idea is like putting your hand in a bucket of ice water. Whoa, it's cold! But you can handle the amount of cold initially. Studies have found that when someone's hand is in ice water, they can handle more intense pain everywhere else in the body, probably because the sensation of ice is so intense it doesn't leave as much room for the brain to notice pain as sharply other places.

It is as if when one sensation is very intense, the brain turns the volume down on sensations anywhere in the body. In scientific terms, intense cold activates a supraspinal modulation raising the body's overall pain threshold.



ITPSupport.org.uk

Buzzy Kits



Helping to take the sting out of ITP.


HOW TO USE BUZZY?

Step 1 - Freeze the Ice Wings
Wings will stay frozen 10 minutes at room temperature. For best pain relief, the wings must be frozen solid to avoid absorbing vibration.

Step 2 - Attach Wings to Buzzy
Slide the ice wings through the elastic strap on the back of Buzzy.

Step 3 - Place Buzzy
For injections, place Buzzy on the injection site for 30-60 seconds. Then move Buzzy up and secure there during the injection. Buzzy must be placed proximal to the pain to be most effective. Buzzy goes between the pain and the brain.

Step 4 - Turn Buzzy On
Once Buzzy is being held in place either by a comfort strap, tourniquet, or by hand, press the button or switch on the top of Buzzy. Hold Buzzy in place for a minimum of 3 minutes.



WHEN CAN BUZZY BE USED?

Buzzy can help in a range of areas. Some of these can include:


- Immunisations
- Blood tests
- Finger sticks
- IV lines
- Insulin injections
- Glucose tests
- Dentistry treatment
- First aid at home – including removal of splinters, bee stings
- Medical treatments (cancer patients)
- Flu injections
- Injected medicine
- Wart treatment
- Biopsies
- Cannula changes
- Juvenile Arthritis
- Travel immunisations
- Beauty therapy procedures
- Lumbar punctures

ABOUT THE ITP SUPPORT ASSOCIATION

The UK and Ireland ITP Support Association is a registered charity for those with ITP, it was formed in 1995 and was the first ITP Support charity in the world.

With the help of its team of medical advisors and volunteers it has since grown into one of the leading ITP patient support organisations in the world and is proud to have been a founding member of the International ITP Alliance.

The organisations funding comes from a variety of sources but mainly from charitable events that patients and their carers undertake, donations and from unrestricted grants from pharmaceutical companies. The organisation is not dependent on funding from any one company. If you would like to make a donation to the ITP Support Association please visit [justgiving.com/itpsupportassociation](https://www.justgiving.com/itpsupportassociation).

ITPSA Scholarship Program



The UK & Ireland ITP Support Association Academic Scholarship Programme 2025

After the success of our Scholarship Programme in 2023 and 2024 we are pleased to announce that nominations for the 2025 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.

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.

ITPSA Academic Scholarship Programme Application Form Click here <https://bit.ly/4htuFRL> or scan the QR Code.

Previous Scholarship Recipients

- Your Name could be here -
- ITP Scholarship Recipient 2025
 - Emma Roger-Lund – ITP Scholarship Recipient 2024
 - Lauren Wooldridge – ITP Scholarship Recipient 2023
 - Luke O'Neill – ITP Scholarship Recipient 2023



NEW - Medical Emergency Card



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

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

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



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

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

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



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

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

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



London Marathon 2025



In the December edition of the Platelet, we announced that we had been successful in the Ballot for a place in the 2025 London Marathon and even more pleased that ITP patient Tom O'Neill has agreed to run on behalf of the ITPSA.

Click this link to be taken to Tom's London Marathon Fundraising Page: <https://bit.ly/4eHpsEE>

Tom's ITP Story, A few years ago, Tom of hospitalised for a week with a platelet count of 9 and diagnosed with ITP.

Thankfully, with the help of ITPSA Medical Advisor Dr Thachil at the Manchester Royal Infirmary after a very hard first year his condition (Platelet Count) had remained stable until a recent relapse which was supported by Prof Nichola Cooper. Thankfully Tom is now back in training.

We can now also announce that another runner and ITP patient who already had a place in the London Marathon has agreed to run on our behalf. Thank you to Matthew Charman, Matt has a JustGiving page on this link <https://bit.ly/4gaoSPR>.

Matts ITP Story, I was diagnosed with ITP in 2021 after having Covid and for the first few years really struggled to manage it. I was an active 26-year-old before I had ITP, but I struggled to even walk up the stairs after I was diagnosed. I was off work for 6 months and

the fatigue that came with the ITP meant I struggled physically and mentally. It did take a long time to get my treatment right after I was given lots of steroid treatments (far too many in my opinion) which didn't work and weekly blood tests and results which just increased the anxiety around the condition. I am now on Eltrombopag which has managed to push my levels back up into the normal range (my levels were as low as 9) and I now only have my levels checked every 3 months.

I think it would have really helped to talk to others with ITP while I was really struggling as I had never heard of the condition before and of course didn't know anyone else that had ITP (especially as someone in my twenties). At the time I wasn't aware of the ITP association then and think it's much needed and would be useful to give support to others that have been recently diagnosed.

At one stage I felt like I wouldn't ever be able to take part in a running event again due to my ITP and the fatigue, so I think it would be good to raise money for the charity, and show that someone with ITP can run a marathon and live a normal life although it might not feel like that at first.

You can show your support for Tom and Matt as they run in the London Marathon by pledging a few pounds as they look to raise money for the ITP Support Association.

You can show your support for Tom and Matt as they run in the London Marathon by pledging a few pounds as they look to raise money for the ITP Support Association.



Skydiving for ITP

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

Now you can!

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



HOW SKYDIVING WORKS CHARITY GUIDE

SKYLINE SKYDIVING

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

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

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.

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

HOW SKYDIVING WORKS CHARITY GUIDE

SKYLINE SKYDIVING

What Skyline Provides:

- We add you to www.skylineparachuting.co.uk and that gets 17,000+ visitors per month.
- We have a dedicated email address where participants can contact us directly with any skydiving questions.
- 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 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 cover all administration of the event including rescheduling if bad weather or cancellations.
- We send all confirmation details from here bespoke to each airfield.

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

Plasma Donation

NHS

All types can save lives

Your plasma can treat 50 diseases

Join us at 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

Leaving a Legacy



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

There are 3 main types of gift you can make:

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

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

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

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

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

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

make a new will.

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

Suggested wording for making your gift to the ITP Support Association

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

Wording for a residuary gift

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

Wording for a gift of money or an item

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

Note

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

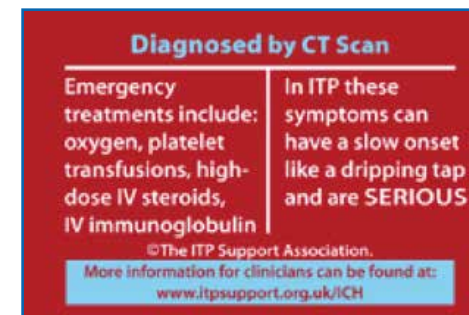
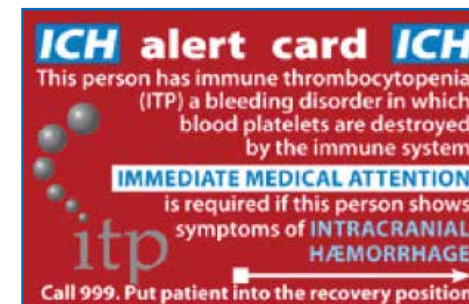
Order a free ICH alert card

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

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

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

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



Ways To Donate

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



Facebook



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

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



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

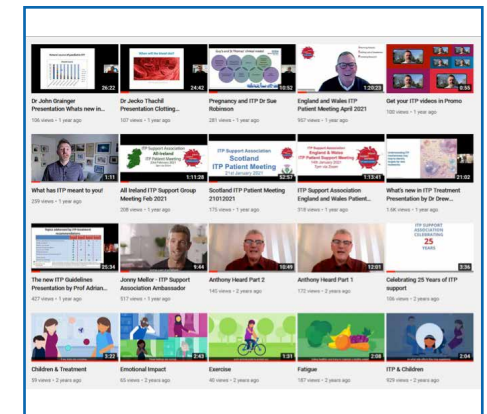
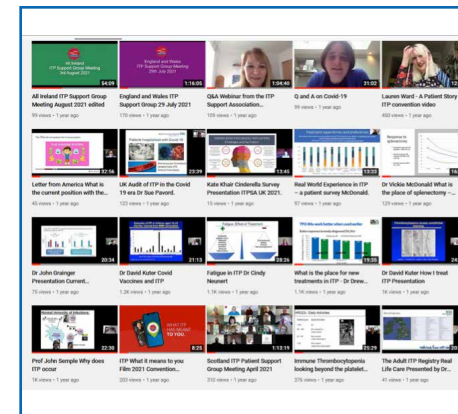
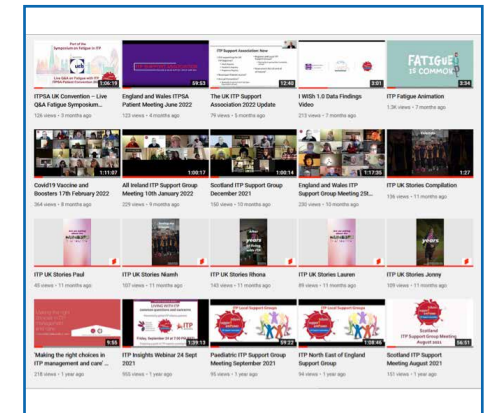
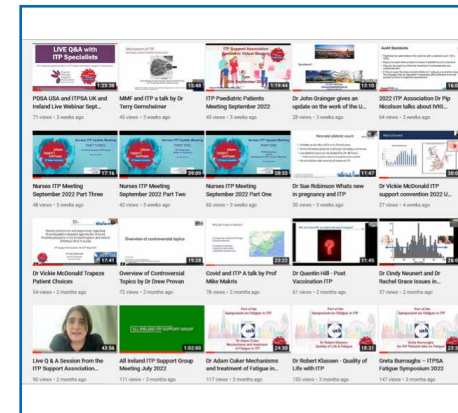
Go to www.easyfundraising.org.uk/causes/itpsupportassociation and use the links on the easyfundraising site to take you to your chosen retailer. You'll get access to hundreds of exclusive discounts and voucher codes. Join the increasing number of supporters who have raised hundreds of pounds for the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

Visit our YouTube Channel



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

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



Publications List

BOOKLETS

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

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

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

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

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

Know about ITP – core information booklet.

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

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

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

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

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

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

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

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

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

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

Choosing your sport – which sports are safe with ITP?

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

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

FACTSHEETS

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

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

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

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

ARTICLES PUBLISHED IN PREVIOUS ISSUES OF THE PLATELET

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

Publications List cont...

26. How is ITP diagnosed?

27. ITP – in dogs!

28. Complications of ITP

29. Flying & ITP

30. Who needs Vitamin D supplements

31. Why don't we see an immunologist

32. What does the ITP Support Association do?

33. Sustained responses with TPO drugs

34. Is splenectomy still a valid treatment today?

35. Where are we with ITP today?

36. Are young platelets better?

AMERICAN PERSPECTIVES

1. A history of ITP

2. ITP in pregnancy

3. What is a platelet?

4. How is ITP diagnosed?

5. Non-intervention in childhood ITP

6. Activity restrictions in ITP children

7. How many platelets are enough?

8. Splenectomy and ITP

9. Can I die from ITP

10. → The child newly diagnosed with ITP

11. Surgery in the patient with ITP

12. Are alternative & herbal remedies safe?

13. Use of steroids – a boon and a bane

14. Immunoglobulin – good and bad news

15. Intravenous Anti-D – another treatment

16. Chronic ITP – disease or risk factor?

17. Platelet counts – how useful are they?

18. ITP, sports, and sports injuries

19. After failure of splenectomy & steroids

20. ITP in the elderly

21. Rituximab for ITP

22. ITP and tiredness

23. Viruses and childhood ITP

24. Increasing platelet production

25. What happens to adults with ITP

26. ITP and 'cure'

27. What is a clinical trial?

28. → The relationship between ITP and lupus

29. ITP in adolescents

30. → The development of new ITP drugs

31. Menstrual periods in women with ITP

32. Coping with prednisolone – book review

33. Assessment of bleeding severity in ITP

34. Steroid side effects

35. Splenectomy for children with ITP?

36. What happens after a child recovers?

37. Prevention of infections in asplenic

38. Who cares for patients with ITP

39. Who needs the new TPO drugs for ITP

40. TPO drugs in children & adolescents

41. Platelets & walnuts (food intolerance case)

42. Let's let ITP kids be normal

43. Silent haemorrhage in ITP

44. When bad bleeding happens

45. How often does ITP occur

46. How do haematologists treat ITP patients

47. Low platelets in children- is it always ITP?

48. Low platelets in adults- is it always ITP?

49. ITP: It's not only about bleeding

50. Vitamins, alcohol & ITP

51. Familial (hereditary) thrombocytopenia

52. → The full blood count – what does it tell us?

53. Abnormal blood clots in ITP

54. Treatment of ITP children, Who and when

55. Immuno suppressive therapy

56. Platelet counts during pregnancy

57. Vaccinations – An ounce of prevention

58. Spinal anaesthesia, and childbirth

59. ITP and Depression

60. Adherence to ITP therapy

61. Bone marrow biopsy and ITP

62. Don't forget splenectomy (in adults)

63. Splenectomy for children with ITP

64. I have ITP. Should I be taking this blood thinner?

65. ITP, Platelet Counts, and Pregnancy

66. ITP and New Treatments: The view

from your side of the pond

67. New Drugs for ITP- Why wait?

68. How do ITP patients know

what's the right thing to do?

69. Understanding the Immune System

70. New Drugs for an "Old" Disease

71. Different Bleeding Symptoms

Despite Similar Platelet Counts

72. COVID-19 and ITP

73. Teaching a New Dog a New Trick

74. COVID-19 Vaccination: What you Need to Know

75. Participating in Research in ITP

76. What is vaccine-induced immune

thrombotic thrombocytopenia (VITT)

and is there a connection with ITP?

77. Are people with ITP immunocompromised?

78. Revisiting Splenectomy for Treating ITP

79. Fatigue

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

MEMBERSHIP SUBSCRIPTION FORM:

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

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

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

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

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

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

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

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

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

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

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

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

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

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



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

