

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





TOURNAL OF THE ITP SUPPORT ASSOCIATION

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Charity Registration No. 1064480

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From ITP HQ

Review of the year

As 2025 draws to a close it's sometimes good to look back, 2025 was a busy, and very outward-facing year for the ITP Support Association. Between a large number of in-person events, plus our continuing programme of virtual patient meetings, research partnerships and new patient support initiatives, the charity reinforced its role as the UK & Ireland's central patient organisation for people living with immune thrombocytopenia (ITP).



Our headline event of the year must be our Annual Patient Convention, held on 10 May 2025 at the wonderful Bridgewater Hall in Manchester. The convention continued the charity's long tradition of bringing patients, carers and clinicians together: slides and recordings from the sessions were made available afterwards, and the Royal College of Pathologists approved the meeting for CPD credits — underscoring the event's dual value for patients and professionals. The conference content included expert panels, updates on treatments and ample time for patient questions, helping to translate recent clinical advances into practical information for attendees You can look back on the Manchester event by going to our YouTube Channel, all the speakers talks were recorded.

Throughout 2025 we maintained an active schedule of regional patient meetings run virtually (and where appropriate, in person). Notable examples include the Ireland Meeting with Dr Gerard Crotty, Scotland meeting with Dr Catherine Bagot and the England & Wales patient meetings featuring Prof. Adrian Newland and members of the ITPSA board — which tackled topics from steroid use to drug side-effect profiles and answered many patient questions. These meetings reinforced the charity's

ongoing emphasis on accessible, expert-led patient education. All of these regional meetings have been recorded and are available to view on our YouTube channel.

In addition to our normal schedule of virtual meetings we also held three special sessions covering ITP and Stress, looking at the phycological impact of ITP on the patient, these were chaired by Dr Andrew Morgan, who also took part in a brilliant session at our Manchester conference.

I myself and two of our young advocates had the opportunity to take part in the EHA Patient Advocates training programme, which I must say was an excellent opportunity to learn and network with other rare disease organisations.

Likewise, we also chaired a session on ITP at the British Society for Haematology (BSH) congress that was held in Glasgow, this was with two of our medical advisors and one of our young patient advocates.

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GRIFOLS

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

From ITP HQ

ITPSA continued to support research and patient-informed data collection in 2025. The association published and promoted results from the ITP Centre Patient Perception Survey (the 2024 survey summary remained a focus during 2025 outreach), which highlights patients' experiences of care, information needs and quality-of-life issues — data that can shape service improvement and advocacy priorities. The charity's research page and related outputs make clear that ITPSA positions itself as a bridge between patient experience and clinical research.



One of the main highlights of 2025 was our 30th Anniversary Reception held at the House of Commons in July, What a wonderful way to celebrate 30 years years of the UK and Ireland ITP Support Association. Thank you to all the guests who took part, medical advisors, nurses, board members past and present, patients, fundraisers, plus the members of parliament, firstly Richard Fuller MP for sponsoring the event, Alistair Strathern MP plus Lord Lindsay.

Beyond events, ITPSA kept updating its core patient resources in 2025: factsheets, the ITP Discussion Guide, shared decision-making toolkits and an accessible COVID-19 hub remained available on the website, we continue to get questions about COVID-19 and the vaccines. These resources support patients making treatment decisions and help clinicians communicate more clearly — an important ongoing role for a condition where individualised choices matter.

A notable 2025 initiative was the UK & Ireland ITP Support Association Academic Scholarship Programme (nominations and awards activity for 2025 were actively promoted). The scholarship fund reflects the charity's wider commitment to supporting patients and families beyond medical care, recognising the financial pressures that can accompany long-term illness and helping recipients pursue educational goals. We are pleased to announce that we will be supporting one of our young patient advocates with her forthcoming PHD studies

Fundraising activity and legacy giving were also highlighted during the year as mechanisms to sustain services and research grants. Thank you to the hundreds of people who have made donations to support our work during 2025.

Awareness and campaigning: ITP Awareness Week and #LiahtUp4ITP

As a founding member of the ITP International Alliance the ITPSA continued to coordinate national

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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.

From ITP HQ

(UK and Ireland) awareness activity in 2025, promoting the Global ITP Awareness Week and the #LightUp4ITP campaign, some people said it could not be done, but we did manage to get a number of buildings lighting up purple during awareness week. Awareness Week remains a useful annual moment to increase public and professional recognition of ITP, encouraging earlier diagnosis and improved local services.

Governance and transparency — annual report and accounts

ITPSA published its Annual Report and Accounts to March 31, 2025, offering transparency about objectives, trusteeship and financial stewardship. The report restates the charity's aims — relief of sickness and support for patients and families — and provides a formal record of activity and finances for members, funders and stakeholders. This continued reporting is important for accountability and for building trust with the ITP community.

Impact — where the charity made a difference

- Education and empowerment: recordings, slides and the discussion guide extended the reach of expert knowledge to patients who cannot attend live events.
- Patient voice into services: the Patient Perception Survey and routine feedback loops reinforced the charity's role in collecting and amplifying patient experience.
- Practical support: scholarships and fundraising efforts gave greater attention to the socioeconomic dimension of living with ITP.

Across 2025 the ITP Support Association combined its long-standing patient-facing work (conventions, regional meetings and resources) with focused initiatives (scholarships, patient-reported surveys and awareness campaigns). The combination of education, research support and practical assistance reinforced ITPSA's role as a central, trusted organisation for people with ITP in the UK & Ireland. The association's annual report and public materials make the year's activity visible and provide a solid basis for further impact in 2026.

Thank you to all of our sponsors and supporters, in particular thank you to Sobi for being our Platinum Sponsor for the past three years and welcome to Argenx who will be our new Platinum Sponsors as we head into 2026.





'Silver Standard' for Excellence in Industry Award



ITP Support Associations Platinum Sponsor for 2025



ITP Support Associations Platinum Sponsor for 2026

Mervyn Morgan CEO ITPSA



ITP and Me - An ITP Book For Young Adults and Teenagers

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



Then this book is for YOU!

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

Filled with the real-life experiences of teenagers with ITP, you'll find everything you need to know about the condition, along with lots of helpful advice. A vital source

of support, this book tackles the tough issues and unique challenges that young people face when dealing with a potentially life-changing diagnosis.

 $48\,\text{pages}$ of information that will help guide you along your ITP journey.

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

SCAN ME



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

If you are a patient and would like a hard copy, they are free, all we ask is a £3 donation to cover the cost of postage and packing, email us your postal address to <code>info@itpsupport.org.uk</code> and make the donation via our JustGiving page at Donate – Donation amount – JustGiving

Acknowledgements

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

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

Ariana Silva

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

PATIENT MENTORS

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

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

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

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

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



Save The Date





To register your place at the meeting use this link or scan the QR Code.

https://bit.ly/3Mh3nTU



VIRTUAL PATIENT
MEETING (ON ZOOM)
TUESDAY 24 FEBRUARY 2026
WITH DR CATHERINE BAGOT
REGISTER NOW

Bringing patients and specialists together for support, education and research

To register your place at the meeting use this link or scan the QR Code.

https://bit.ly/4icAfco



The date for the All-Ireland ITP Patient meeting will be published in the New Year.

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The ITPSA 2026 UK ITP Patient Convention



To Book your tickets use this link https://bit.ly/49AINZJ
Or scan the OR code below:

The ITPSA 2026 UK ITP Patient Convention will take place on Saturday 27th

June 2026 at the Royal College of Pathologists in London.

Scan me

The ITP Support Association 2026 UK ITP Convention will take place on Saturday 27th June 2026 at the Royal college of Pathologists, 6 Alie St, London E1 8QT.

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

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

Refreshments and lunch will be available.

Doors open at 9:30 on Saturday 27th June 2026 with the first speaker at 10am.

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

We will be announcing the list of Expert Speakers in the coming weeks.

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

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

Your voice matters in shaping the future of ITP research!



We're inviting patients, families, and carers to share ideas for possible new research projects into Immune Thrombocytopenia (ITP).

What questions do you want answered?

#ITPCommunity #ResearchMatters

In recent years in addition to our support for the ITP Registries, we have supported various projects covering a range of ITP related issues including:

- Brain microbleeds and MRI in thrombocytopenia (£20,000)
- ITP in pregnancy: UK management study (£16,000)
- A blood test to predict steroid response (£24,740)
- Fatigue and immunomodulation in ITP (£8,500)
- · Novel antiplatelet antibodies in ITP (£60,000)

No idea is too big or too small. Whether it's about symptoms, treatments, mental health, or quality of life—we want to hear from you with your ideas.

Comment below or message us with your ideas!

#ITP #PatientLedResearch #RareDisease #ITPCommunity #ResearchMatters

Got an idea for ITP research?

We've funded studies on fatigue, pregnancy, MRI, bone marrow, and more. Now we want YOUR input!

What should researchers explore next in ITP?

Please email your ideas for research to info@ itpsupport.org.uk and we will collate all the responses and discuss with our medical advisory team.

Calling all ITP warriors!

What would YOU like researchers to study next? We've helped fund: ₫ A test to predict steroid response

MRI scans for brain microbleeds

& ITP in pregnancy

Antibody discovery

Fatigue and immune response

Now it's your turn. What questions do you want answered?

Share your ideas in the comments!

Pippa's ITP Story and what a story it is!! Part 1



Pippa is 11 years old turns 12 in December. She has been involved in horses from a baby and has a natural affinity with them. Obviously barrel racing is not a very well-known sport here in the UK and we tried it at a local venue about 5/6 years ago and she was hooked from then on in and has been the only thing she wants to do. She started on a lead rein to now representing the UK on an international stage.

She took her own pony Jubbly who she has owned nearly 18 months to France last year to compete against lots of different nationalities at the equita Lyon show competing in the NBHA European Cup where she did very well with a couple of placings resulting in a little bit of prize money to take home.

She is a part of the 4 strides barrel racing team who gives her all these opportunities to race nationally and internationally. We have had a busy year this year attending lots of demonstrations around the country and we head off to Italy for the European championship in just a few weeks' time.

She will for the first time ride a hire horse at this competition and she only gets 15 minutes each day for two days to get to ride it before the competition where she will get 3 runs over 3 days to set her fastest times.

She is super excited to do this as it's yet another achievement to go out and ride a horse she has never sat on before and have a shot at the Europeans too.

She will not let ITP stop her and she is an inspiration to all of us that know her. Her sheer dogged determination and never give up attitude is humbling and she still has the hugest hearts too with everything that she has been dealt.

And as you will see in the pictures she will always wears purple on her or Jubbs whenever she competes.



Check out the March 2026 edition of the Platelet for Part 2 of Pippa's story

Meet Captain Platelet And The Hemoheroes!

Explore our free printable activity pack from the ITP Support Association—designed to spark creativity and teach kids about blood health.

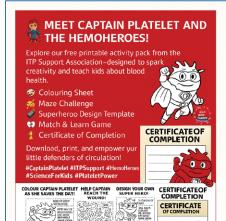
Includes:

- S Colouring Sheet
- · Maze Challenge
- Superhero Design Template
- · Match & Learn Game
- Certificate of Completion

Download, print, and empower your little defenders of circulation!

Scan this QR Code to download. Suitable for ages 5 to 10

#CaptainPlatelet #ITPSupport #HemoHeroes #ScienceForKids #PlateletPower





Facebook Members Private Group



Join our new ITPSA Facebook Group

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

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

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

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

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

Or https://www.facebook.com/groups/235978790548730

Shared Decision Making Document available in Six Languages



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

To download the English Language version click this link: Making the right choices in ITP management and care.

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

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

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

shortage of platelets and bruising.

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

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

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

The toolkit is a response to the results of a patient

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

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

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

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

The ITP Expert Working Group and partners are calling for this best practice guidance to be adopted across all healthcare settings in the UK.

Professor Adrian Newland, Chair of the ITP Support Association, said:

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

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

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

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

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

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



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ITP Patient Explainer

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

For people living with ITP





ITP Patient Explainer Cont...

What is the ITP Discussion Guide?

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

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

How do I use the ITP Discussion Guide?

- 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
- 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.





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

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.
- 3 Bring your completed guide to your next appointment and discuss it with a member of your care team:
 - Use the guide to outline your top care priorities and go through your other issues in turn
- Help your care team to understand your goals and what's most important to you in your daily life.
- 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

For example, going on a cycling holiday in three months.

Living with ITP

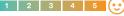
Living with ITP can affect your wellbeing and how vou cope with everyday activities. Use the scales below to rate how ITP affects your day-to-day life. Circle the score that best reflects how you feel.

Coping with ITP symptoms

How have ITP symptoms impacted your daily life in the last month (including fatigue, bleeding, bruising, etc.)?











Feeling on top of things

Do you feel able to carry out everyday tasks like washing yourself, dressing up, cooking, DIY, doing household chores and shopping?











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









Do you feel you can pursue the activities you enjoy the most?











Do you feel you can spend time with or care for family and friends in the way you want to?





Performing well at work or school

Do you feel you can excel in your work and/or studies?



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







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

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

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ITP Discussion Guide Cont...

Managing ITP effectively

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

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













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

ability to pursue your personal goals?

NO (

personal goals.

to you.

appointment.

And finally...

Does ITP or ITP treatment currently affect your

Use this space to write down how ITP affects your

Priority discussion points for your next consultation

Look back over the guestions and tick the stars highlighting the elements that are most important

Use this space to write down the 1-3 most important

topics you would like to discuss at your next ITP

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













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











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











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











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

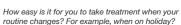
























Overall, how satisfied do you feel with your treatment and/or care?







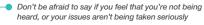












Ask for an explanation of anything you don't understand

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

NEW - Medical Emergency Card



NEW - ITP Medical Emergency Card credit card size, the patient can add their own medical details, includina GP Details. Contact Emergency 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 medical history and conditions to your healthcare providers durina 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.





Notes from this year's ITPSA Zoom Meetings

We have had some helpful and supportive Zoom meetings with our very generous Doctors this year. We thank them most sincerely for their time and expertise. Where else could you get a whole hour of professional time devoted entirely to you and your questions and concerns?

The videos are available on the ITP website at https://itpsupport.org.uk

However, I will make a summary of a few topics that have come up.

From the patients' point of view, I always like to give practical hints on how to manage troublesome issues which often get an airing.

The ones that I am going to concentrate on in this article are managing fatigue related symptoms with two strategies, Spoons and the Pomodoro Method, and also visit what Brain Fog is and management strategies.

There is plenty of information on the net, but please do make sure you are looking at NHS sites or similar ones that are straight forward and honest. You should never have to pay for this free and quality information.

Spoon Theory

The Spoon Theory technique is a parcelling out of the



energy that you estimate you have on a daily basis. This can be physical, mental or emotional energy. Each spoon is a metaphor for an amount of energy that you can visualise and use. With a Long-Term Condition such as ITP, you may find that your fatigue is not predictable from day to day, so each day decide how much energy you have for your essential

daily tasks in a number of spoons. Getting out of bed in the morning and having a wash may take one spoonful of energy, or even more. You can estimate how many spoons of energy you have for the coming day. Say it is 10 to last you from getting up to going to bed. Spreading out your energy by dishing out the spoons can be very helpful so that you have rest periods in between doing all your tasks. Evaluation of how it is going through the day can also work. Having a shower may take more or less energy than you thought. Adjust your allocation based on how you feel as the day progresses. This will take time and practise and it may be helpful to use a notebook to keep track and compare each day. You will probably find that you can do more than you thought, but if not, go with the flow and adjust your energy levels and spoons of energy to suit.

Be Kind To Yourself! Listen to your Body! This is very important!

Do not judge yourself too harshly. It is fine to give up on a task if it is too costly in the currency of spoons. The trick is not to run out of spoonsful of energy before the day is done. Adjust to rest or do an easy task instead of an energy sapping one, or stop altogether and go to bed, if necessary.

Pomodoro Method

I like to use the example of cleaning the bathroom to explain this method, as I use it.



Estimate how long the task is going to take, say 15 minutes.

Put a timer on for 15 minutes, start the task and work on it until the timer rings, then stop. Hopefully you will have finished, but if not, decide if you will continue. Again, estimate how long to finish, say 5 minutes, put the timer on and so on...Hopefully you now have a lovely clean and sparkling bathroom! It can be

amazing how a bit of housework can make you feel so good!

I find that with the timer it makes me get on with the job quicker, without distractions, as I try to beat the clock! Silly isn't it, but amazing how much you can get done in a concentrated 15 minutes.

Another method I use I call 'Hours'. This is on days when I am home and want to get a lot of things done. I allocate hours to various things, usually timed by a load of washing or radio programmes. I have allocated some time to this article. Before that, I was making a quilt and before that, doing 2 classes at the gym and also some cooking.

To be honest with you, I am not very good at allocating my time. Everything takes me a lot longer that I estimate. So, estimation can be a tricky game. Do not be discouraged if you find it hard to do accurate estimates, be flexible and reallocate to a different day.

Fixed deadlines are different. I am very much a last-minute merchant, so yes, this article needs to be finished soon! Now I have told you all my secrets, but I hope it will show that these things are not necessarily easy but can help. Remember you are in control and these techniques are only there to help you, not stress you.

Brain Foa



What is Brain Fog?

Basically, it is the feeling that there is something wrong with the way your brain is working, that is different from before. You feel you cannot think as well as you once did. Your thinking is not as clear as it was. You forget things more easily and so on.

This does often happen with age, but also with illness and with some medication and stresses.

There are excellent websites on Brain Fog. https://www.bbc.co.uk/news/articles/c87ydw7xdxvo

This article attracted me because it has ways to combat Brain Fog.

Do not get too excited, it is all the usual suspects, such as Nutrition, Good Sleep, Hydration, Control of Stress, Relaxation, Exercise and so on. All good advice and we can all sharpen up our self-care routines, no matter how good we are to ourselves.

https://www.royaldevon.nhs.uk/media/crofdc2q/7-session-4-cognitive-difficulties.pdf

This website has a great list of things to help you improve your concentration and memory. Always look for props to help you on your way to daily peace and happiness. Making lists I find helpful, although I do know people who run a mile from lists. We are all different and what will help one will not necessarily help another. I would always add that doing something you enjoy is very important to your general health and wellbeing. Relaxing in ways that you know work, are always worth revisiting.

Doing things for others increases endorphins in the brain which are the feel-good factors we experience and can make us feel a lot better about ourselves.

https://www.nhsinform.scot/long-term-effects-ofcovid-19-long-covid/signs-and-symptoms/longcovid-brain-fog/

Long Covid exposed brain fog as a symptom and since then it seems to be taken more seriously. This website gives very clear information and when you should seek help.

I hope these notes have been interesting and if you have any helpful experiences of your own to add, please do contact our Editor Mervyn Morgan at ITP HQ so they can be included in future editions of The Platelet.

With my very best wishes for the festive season, and peace and happiness in your pursuits of health and wellbeing now, and in the future.

Rhonda Anderson November 2025

Meet The New ITPSA Trustees

Agne Zice - Trustee and ITP Patient



Agne was born and educated in Lithuania before moving to the UK in 2009 to pursue her university studies. She graduated from City University of London with a degree in Media Studies and Sociology and has since built a career in commercial

contract management across various industries. She currently works in the renewable energy sector for an arm's length government body, supporting the UK's journey to net zero.

Agne was diagnosed with Chronic ITP in March 2021, which came as a significant and unexpected shock. The ITP Support Association provided her with vital support during that time, making the charity especially close to her heart. Before her diagnosis, she was a regular blood donor in both Lithuania and then the UK. She is passionate about giving back and volunteers with The Felix Project, a charity that rescues surplus food and redistributes it to over 1,200 community organisations across London. She also leads food bank drives in East London in collaboration with her employer.

Outside of work, Agne enjoys yoga, weightlifting, cycling, walks, reading, and spending time in Fuerteventura. As a young Lithuanian female professional, she is proud to contribute to the trustee board and hopes to bring fresh perspectives and energy to the Association.

You can connect with her on LinkedIn or via the ITP Support Association Facebook group to learn more about her journey.



Professor Nichola Cooper – Trustee and Medical Advisor

Professor Nichola Cooper trained at Cambridge University and Barts and the London School of Medicine and Dentistry. She completed her haematology training at University College Hospital and subsequently gained research experience at Cornel Medical College, New York and the Institute of Child Health, University College London. Professor Cooper has been one of our medical Advisors for many years and has recently joined the ITP Support Association Board as a Trustee.



Richard Blake - Trustee and ITP Patient

I was born in Luton 70 years ago and brought up in Hitchin in North Hertfordshire. I qualified in law at the University of Westminster

and was called to the Bar in 1982. Practiced at the Criminal Bar. It was a complete shock at the age of 50, about to be appointed a District Judge, to receive an urgent call from my GP. Following a recent blood test, he needed to see me urgently. Like in the next hour! My cholesterol test had shown I had a platelet reading of 37. Within a few days I saw a wonderful consultant who has looked after me for the last 20 years. At what was a very frightening time the ITP support Association was a massive support. I'm delighted to repay the debt I feel by being a trustee of the Association.

The diagnosis did not affect my appointment I spent much of my career based at Westminster Magistrates Court dealing with crime and extradition.

I am now retired living near Ringwood on the Hampshire/Dorset border with my partner Jonathan and our Jack Russell 'Dudley'. With a platelet count hovering around 85. Some things seem to have improved with old age.

I look forward to meeting members of the Association and working for the charity.

Share Your Patient Story



Read more patient stories here

Living with a rare disease in the UK and Ireland and anywhere in the world can be extremely isolating for many patients and caregivers.

While each of our patient stories are as individual as we are, patients can still pick out similarities in other peoples ITP journeys which helps them to connect, even when you feel isolated and alone.

Share your patient story by sending it to >>>> info@itpsupport.org.uk

Try out the new ITPSA REDBUBBLE Store

Try out the ITPSA new branded gift items from our REDBUBBLEstore.



They include a design by ITPSA Medical Advisor Dr Drew Provan. By shopping with us you are helping to support the work of the ITPSA in raising awareness for Immune Thrombocytopenia with the profits from each sale going directly to our cause.

















Social Media Update



Social Media - 9000 + followers on Facebook and growing.

You will be aware that we made a change as to how we managed our social media Accounts back in the Summer.

This update will just focus on Facebook:

For the 2 months prior to the change, we had the following Metrics from our Facebook page:

- Views 39k
- Likes 772
- Comments 65
- Shares 115
- Followers 8220

For the 2 months following the change, this was the result:

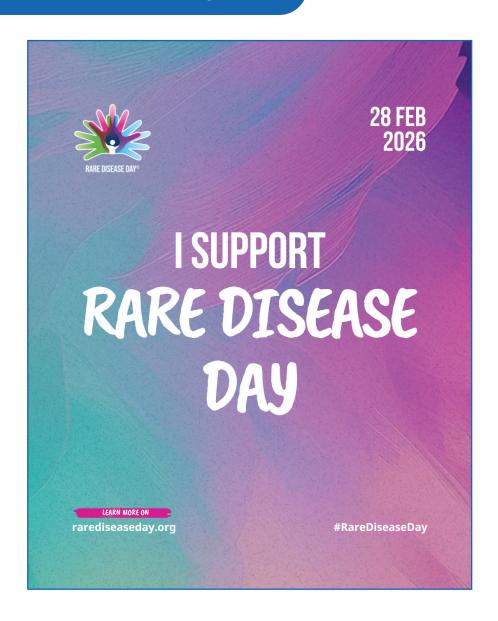
- Views 448k + 409k
- Likes 6118 +5346
- Comments 535 +470
- Shares 1588 +1473
- Followers 8881 + 661

The growth of the metrics on Facebook has been amazing; this is in the main to the more focused look to our posts on this platform.

Overall, we are very pleased with how this is going, in addition we are also starting to grow our presence on Instagram, which was hardly utilised under the old system. Plus, we now have our own Business Page on LinkedIn, rather than a group.

A huge thank you to everyone who has supported us during this transition.

Rare Disease Day 2026



Fundraising News

What a year it has been, thank you to everyone for your ongoing support.

PayPal Giving Fund Donations – for Jan to date - £2,129.91

Facebook Donations – for Jan to date - £2,842.75

JustGiving donations- Jan to date - £16,505.52

Fundraisers – Just a few of the 14 fundraisers that have been on JustGiving in the past few months.



Mark Bloodworth – Took part in the North Downs 50 Ultra Challenge and raised £2,185 with the help of 79 supporters. Marks 13 year old son, Jackson, was diagnosed with this condition in August last year and it has profoundly affected him, and our family.



Vanessa Shepherd

– did what
many would call
unthinkable and had
a Sober October by
not having a drink
for the whole month,
the result of which,

aside from savings at the bar was £575 raised with the help of over 40 friends.

Sarah Tansey – took part in the Cardiff Half Marathon in October and raised £240 thanks to the help of 20 supporters.





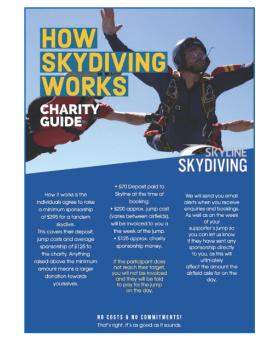
Skydiving for ITP

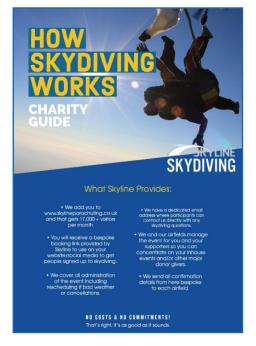
Do you fancy doing something different to support the ITP Support Association?

Now you can!

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







Plasma Donation



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

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

Book an appointment at www.blood.co.uk/plasma

In Loving Memory



This has been a sad period for many of the ITP family, the following much loved friends and family members have sadly passed:

Peter Hinchley Andrew Smetham Dr. Margaret Pelling Jean Audrey Kennedy

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 aift.

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.









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Ways To Donate

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



Facebook



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

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



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

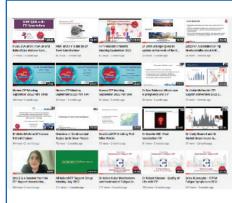
Go to www.easyfundraising.org.uk/causes/itpsupportassociation and use the links on the easyfundraising site to take you to your chosen retailer. You'll get access to hundreds of exclusive discounts and voucher codes. Join the increasing number of supporters who have raised hundreds of pounds for the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

Visit our YouTube Channel



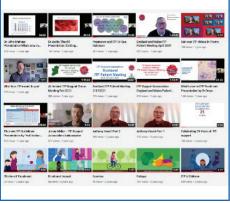
The ITP Support Association YouTube Channel has almost 140 videos covering ITP. Plus, with now over 1,000 YouTube subscribers, thank you to everyone for helping to reach this milestone.

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

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

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 auide - 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

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?

1. A history of ITP

2. ITP in pregnancy

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

13. Use of steroids – a boon and a bane

15. Intravenous Anti-D – another treatment

16. Chronic ITP – disease or risk factor?

17. Platelet counts – how useful are they?

19. After failure of splenectomy & steroids

20. ITP in the elderly

23. Viruses and childhood ITP

24. Increasing platelet production

25. What happens to adults with ITP

26. ITP and 'cure'

27. What is a clinical trial?

28. The relationship between ITP and lupus

29. ITP in adolescents

30. ¬The development of new ITP drugs

31. Menstrual periods in women with ITP

32. Coping with prednisolone - book review

33. Assessment of bleeding severity in ITP

34. Steroid side effects

35. Splenectomy for children with ITP?

36. What happens after a child recovers?

37. Prevention of infections in asplenics

38. Who cares for patients with ITP

39. Who needs the new TPO drugs for ITP

41. Platelets & walnuts (food intolerance case)

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. Fatique

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.

AMERICAN PERSPECTIVES

3. What is a platelet?

12. Are alternative & herbal remedies safe?

14. Immunoglobulin – good and bad news

18. ITP, sports, and sports injuries

21 Rituximab for ITP

22. ITP and tiredness

40. TPO drugs in children & adolescents

42. Let's let ITP kids be normal

COO ITP ITP 34

MEMBERSHIP SUBSCRIPTION FORM:

PLEASE USE THIS FORM TO PAY BE CHEQUE, POSTAL ORDER OR STANDING ORDER YOU CAN PAY ONLINE AT WWW.ITPSUPPORT.ORG.UK

SECTION 1: MEMBERSHIP DATABASE CONTACT INFORMATION Please complete this section

	TITLE	Mr Mrs Miss Dr Other	
	NAME		
	ADDRESS		
	ADDRESS		
	POSTCODE	TELEPHONE	
	EMAIL		
	Let us keep in touch	Opt in Please tick the box Email Post Phone	
SECTION 2: PLEASE INDICATE YOUR ITP STATUS Please tick the appropriate box This assists us if we need to produce statistics about our membership for health organisations or pharma companies			
Person with ITP (ongoing or in episodes) In remission from ITP Parent of ITP child			
	Family member	er of someone with ITP Friend or other Health Professional	
SECTION 3: PAYMENT Please tick the appropriate box(es)			
Please Gift Aid my payment (Please complete the gift aid form if you haven't sent us one before)			
I wish to pay by standing order (Please complete the standing order form)			
	I wish to pay by cheque (Please complete the section below. We are grateful for added donations)		
	MEMBERSHIP	*After 31* January 2020 *£15 UK *£20 Overseas FOR OFFICE USE	
	GENERAL DON	ATION	
	RESEARCH DO	NATION	
	TOTAL ENCLOS	ED	

Please return this form with your cheque or standing order form to:-The ITP Support Association, The Platelet Mission, Kimbolton Road, Bolnhurst, Beds Mk44 2EL The associations privacy policy is available at: www.itpsupport.org.uk

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



