



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



The
Platelet

JOURNAL OF THE ITP SUPPORT ASSOCIATION

JUNE 2024

The ITP Support Association Team

Charity Registration No. 1064480

THE ITP SUPPORT ASSOCIATION HQ

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

TRUSTEES

Professor Adrian Newland CBE (Chair)
 Derek Elston
 Xenia Norman
 Colin Williams
 Anthony Heard (Patient Observer)

OFFICE

Chief Executive
 Mervyn Morgan
Deputy Chief Executive
 Dianne White
Office & Fundraising Administrator
 Liz Gooch

VOLUNTEERS

Social Media
 Anthony Heard
 Mervyn Morgan

Group Liaison
 Derek Elston

Patient Mentors
 Rhonda Anderson
 Derek Elston
 Karen Smith

Website

Mervyn Morgan

MEDICAL ADVISORS (Adult ITP)

Prof. Adrian C. Newland CBE
 MA FRCP FRCPath
 Dr. Drew Provan
 MD FRCP PRCPPath
 Dr. Jecko Thachil
 MRCP FRCPPath
 Dr. Will Lester
 MBChB(hons), BSc, MRCP, FRCPPath, PhD
 Dr. Nichola Cooper
 MA, MBBS, MD, FRCP, FRCPPath
 Dr. Gerard Crotty
 MB BCh BAO, FRCPPath, FRCPI
 Dr. Catherine Bagot MBBS
 Dr Vickie McDonald
 Prof. David Kuter
 Louise Taylor ITP Nurse Consultant

MEDICAL ADVISORS (Childhood ITP)

Dr. John Grainger
 MBChB MD MRCP FRCPPath
 Dr. Mike Richards
 MA BM BCh DM MRCP FRCPPath
 Dr. Cindy Neunert
 MD MSCS

AMERICAN PERSPECTIVE (Contributors)

Dr. Cindy Neunert
 MD MSCS
 Prof. Spero R. Cataland
 MA FAAP (USA)
 Dr. Adam Cuker
 MD MS
 Dr. Rachael Grace
 MD MMSc

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

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

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

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

From ITP HQ

Welcome to the June 2024 edition of the Platelet Journal.

At the time of writing this introduction we have just finished one of the busiest periods for many years.

Not only did we hold our Annual Patient Convention at the Cavendish Conference Centre in London but in the days leading up to our convention we also had the ITP International Alliance Meeting with representatives from ten countries taking part, plus myself and Dianne White took part in the ITP Research Day meeting, held in London with many of the UK's top ITP experts, and that is not all, we then had the ITP Update Day, held the day before our Convention but at the same venue, this was with many of the world's top ITP experts. It was Three Days of wall-to-wall ITP. It will take us months to unpack all the information that was shared.

In this issue of the Platelet you will find a report on the ITP Support Associations Annual Patient Convention and the International Alliance Meeting.

Please note that the Annual Patient Convention was recorded and we will be making each of the talks available on our YouTube Channel in the runup to ITP Awareness Week in September.

There are two surveys mentioned in this issue, the first is the ITP Patient Perception Survey which will be closing at the end of June, so if you have yet to take part please do so now.

The second survey is the ITP Impact Survey, looking at the impact our Shared Decision-Making resources have made, such as the ITP Discussion Guide. Please take the time to take part in this survey, it will only take 5 minutes.

Finally, don't forget you can book your tickets for our ITP Patient Convention 2025 which is being held at the Bridgewater Hall, Manchester, we have an Earlybird ticket offer, so book now and save money.

'Silver Standard' for Excellence
 in Industry Award

ITP Support Associations
 Platinum Sponsor for 2024



Mervyn Morgan CEO ITPSA

Contents

3	From ITP HQ
4	ITP Patient Convention Review 2024
6	ITP International Alliance Meeting London 2024
6	Save the date – Patient Meetings
7	What Low Energy is Like by Dee Jones with a reply by Prof Newland
10	Scholarship Programme
11	My life with ITP by Ria
13	Patient Perception Survey 2024 – Closing soon
13	ITP Patient Mentors
14	EHA Adolescent and Young Adult Programme
15	Our 'Digital Reach' continues to spread
16	Platform Updates by Anthony Heard
17	Facebook Members Private Group
18	ITP Impact Survey 2024
19	Shared Decision-Making Document
21	Patient Explainer – ITP Discussion Guide
24	ITP Discussion Guide
26	Fundraising and In Memory
28	Sky Diving for ITP
29	Plasma Donation
30	Leaving a Legacy
31	Order a free ICH alert card
32	New Medical Emergency Card
33	Ways to Donate
34	Publications List
36	Membership Form

ITP Patient Convention Review 2024

ITP Support Association Annual Patient Convention 2024

The 2024 ITP Support Association Annual Patient Convention held at the Cavendish Conference Centre in London was a gathering of patients, healthcare professionals, and experts in the field of Immune Thrombocytopenia (ITP). The convention aimed to provide a platform for sharing information, raising awareness, and promoting support for individuals living with ITP.



During the convention, attendees had the opportunity to participate in various educational sessions, interactive workshops, and panel discussions led by renowned specialists in ITP. These sessions covered a wide range of topics related to ITP diagnosis, treatment options, management strategies, and the latest advancements in research.



The convention also featured a small exhibition area where pharmaceutical companies could talk with patients. This provided attendees with valuable opportunities to connect with industry professionals,

explore new treatment options, and access support networks.



In addition to the educational and networking aspects, the convention also included breakout sessions covering Adult, Paediatrics and Women, plus a Q and A to allow patients to interact with each other and with Healthcare Professionals. These events allowed patients and their families to connect with others who understand the challenges of living with ITP and provided a platform for sharing personal experiences and stories.



The purpose of the 2024 ITP Support Association Annual Patient Convention at the Cavendish Conference Centre in London was to bring together individuals living with Immune Thrombocytopenia (ITP), healthcare professionals, and experts in the field to achieve several objectives:

- **Education and Information Sharing:** The convention aimed to provide attendees with valuable knowledge about ITP, including its diagnosis, treatment options, and management strategies. Through educational

ITP Patient Convention Review 2024

sessions, workshops, and panel discussions led by specialists, attendees had the opportunity to learn about the latest advancements in research and gain a deeper understanding of the condition.

- **Awareness and Advocacy:** The convention aimed to raise awareness about ITP within the medical community, as well as among patients, their families, and the general public. By promoting a better understanding of the condition, the convention sought to reduce misconceptions and stigmas associated with ITP and advocate for improved support and resources for affected individuals.

- **Networking and Support:** The convention provided a platform for patients, their families, and healthcare professionals to connect and build a supportive community. Attendees had the opportunity to network with industry professionals, share personal experiences, and access support networks. This sense of community and connection can be invaluable for individuals living with ITP, as it allows for the exchange of information, emotional support, and the sharing of coping strategies.

- **Access to Resources:** The convention featured an exhibition area which included an interactive wall that patients could use to show their two main ITP symptoms.



Danielle Boyle, CEO ITP Australia supported the UK ITP Convention with the Interactive Wall

In summary, the purpose of the 2024 ITP Support Association Annual Patient Convention at the Cavendish Conference Centre in London was to

educate, raise awareness, foster support, and provide resources for individuals affected by ITP.

Overall, the 2024 ITP Support Association Annual Patient Convention at the Cavendish Conference Centre in London was a significant gathering that aimed to empower and support individuals affected by ITP. It provided a platform for education, collaboration, and advocacy, ultimately contributing to the advancement of knowledge and improvement of patient outcomes in the field of ITP.



We were blessed with a stella field of many of the worlds ITP experts both in-person and on-line.

Joining me for this picture are Dr John Grainger, Prof Adrian Newland, Prof John Semple, Dr Drew Provan, Dr Fred Chen and Dr Cindy Neunert. Also presenting but not in the picture were Prof David Kuter, Dr Vicky McDonald, Prof Nikki Cooper, Prof Waleed Ghanima and Dr Quentin Hill.

Join us in Manchester for our ITP Support Association Annual Patient Convention at the Bridgewater Hall on Saturday 10th May 2025



Early bird ticket price now available for our ITP Support Association Annual Patient Convention 2025 at the Bridgewater Hall Manchester. Book Early and Save. <https://bit.ly/ITPSA2025>

ITP International Alliance Meeting London 2024



Members of the ITP International Alliance London 2024

The ITP International Alliance held a meeting in London a few days prior to the ITP patient Convention. The event which had representatives from 10 countries taking part was an opportunity to start looking at the knowledge and resources that could be used to support associations from new countries coming on board in the future.

The group already has some wonderful resources available which has been translated into many languages but there is an opportunity to do more, hence the first part of this meeting focused on this objective.



Dates for your Diaries

The following meetings will be taking place or are planned for the months ahead. Final dates will be published on our website and on social media once they are finalised.

Nottinghamshire ITP Group Social Meeting, 6th July 2024 at 2pm.

The Unicorn Hotel Gunthorpe, 1 Trentside, Nottingham, NG14 7, United Kingdom

England and Wales ITP Group Meeting Next Meeting: August 2024 TBC

This will be an online Zoom Meeting, This meeting is open to those with ITP and family members of ITP patients.

Broomfield Hospital ITP Group Meeting,

Next Meeting: 13th September 2024 – 15:00 to 17:00hrs
Broomfield Hospital, Court Rd, Broomfield, Chelmsford CM1 7ET
Broomfield invited patients

Scotland ITP Group Meeting, Next Meeting: September 2024 TBC

This will be an online Zoom Meeting, This meeting is open to those with ITP and family members of ITP patients.

Royal London Hospital ITP Patient Meeting, September / October 2024 TBC

Royal London invited patients

All Ireland ITP Group Meeting, Next Meeting: October 2024 TBC

This will be an online Zoom Meeting, This meeting is open to those with ITP and family members of ITP patients.

Recent Virtual Events

Remember if you missed any of the recent Virtual Support Group Meetings or you would like to watch them again, recordings are available on-demand from our YouTube Channel at:
<https://www.youtube.com/@ITPSAUK/videos>

What Low Energy Is Like by Dee Jones

I slept through the night. It's a beautiful, sunny spring day. And I awake utterly exhausted.

Yesterday I awoke exhausted. And the day before that.

I've done nothing physical to bring this on — utter exhaustion is the main effect of my auto-immune condition, and it halts my life in its tracks. I used to live my life; I now just exist, the days moving past me, always falling behind.

I must stay on top of: cooking; getting groceries; bill-paying; laundry, washing dishes; urgent repairs & house maintenance.

I try to keep pace with: pilates classes (to stay mobile) and the occasional film (to stay sane).

But of the things I can no longer manage, there are too many to list.

My exhaustion is from a condition called ITP (Immune Thrombocytopenia). It leaves me utterly depleted but when people see me — up, dressed, looking passable, sounding fine — they don't see my exhaustion so when I tell them I'm exhausted, some of them think I'm just not trying hard enough.

ITP exhaustion isn't caused by intense physical activity or lack of sleep. And it isn't cured by long naps. For most of us with ITP, exhaustion becomes our permanent state, and when I do exert myself by, say, standing a long-time cooking, my energy the following day is typically much worse.

Most people's platelets are between 150 and 450, and their energy levels are fine. My last platelet count was 31. The time before that it was 22. My energy levels are not fine. When I get ready to go to pilates, some days I've barely the strength to dress, let alone walk to the bus stop.

There is no cure for ITP; the most we can hope for is a long period of remission. There are treatments to help raise platelets, but they come with side effects which, for some of us, are stronger than the desired effect of raising the platelets. You can decrease the dose to minimise the side effects, but then you also minimise the desired effect, so you're back to Square One.

I'm reluctant to try a new treatment because if I can't cope with its side effects (which was the case with Romiplostim and also Mycophenolate mofetil), then that's one further option that's no longer available to me. There's a big psychological difference between thinking you have other options available, and in knowing that you don't.

So, I carry on, pushing myself from one day to the next, trying to will my body to correct itself. I'm currently on 175mg/day Azathioprine (immuno-suppressant) and, as kiwi are thought to help raise platelets, I try to eat 4 a day.

A drop in platelets is a known side effect of many vaccines, but no one told me this when I had my flu vaccine in November 2019. Automated texts that prompt you to come for a vaccination are triggered when the vaccination programmes are ready to begin — they are not linked to one's medical records so there's no accompanying text warning ITP patients that their platelets might drop significantly after a vaccination. And there's nothing advising people who are feeling very tired, to first have a blood test to ensure their vaccination can be as safe as possible for them. Two days after my flu vaccine, my platelets were 36; eight weeks before, they were 108. So a big drop in a short time.

For the past year, my platelet levels have remained stubbornly low. So, I don't risk lowering them even further with vaccinations & boosters, where they could drop to just 1 or 2 platelets. It's hard enough trying to raise my platelets from their current low

What Low Energy Is Like by Dee Jones

levels. So, I have not been vaccinated, due to this risk.

Before we had Covid vaccines, we were told that we'd need to learn to live with Covid. But now we have vaccines, and any helpful information for people like me on how to safely navigate our lives — unvaccinated in a now mostly vaccinated world — has disappeared. In the absence of this information, I wear facemasks: on the bus; in pilates class; in the cinema; and I keep a distance from people, as best I can, and try to stay near where fresh air is circulating.

Last week on Women's Hour (18-March-2024), I heard this issue being discussed and they invited people to join the discussion. I texted the following, and they read this out:

Thank u 4 acknowledging that some of us cannot b safely vaccinated, & 4 asking how we r.

I wait 4 warm days so I can safely share a meal outdoors with a friend.

Two days later I went with a friend to a cafe that I knew had covered outdoor seating but when we got there, found their back garden was roped off, under construction. They had indoor seating, but all the windows were closed, and the room was filling up. It had a high ceiling, and the door to the room was open. Is this sort of environment safe for an unvaccinated person with ITP? Living with very low platelets and chronic exhaustion is crap but I am ever aware that, were I to catch a bad dose of Covid, it would be much worse, so I do whatever I can to avoid contracting a virus (or the next Covid variant). But where do I find the current information to help guide me? In the end, my friend and I sat outdoors in a light drizzle, at a table without an umbrella.

On Jim Al-Khalili's The Life Scientific on the 12th of March, he interviewed Sir Jonathan Van-Tam,

deputy chief medical officer during the Covid pandemic. Sir Jonathan touched on the subject of fine particles in the air versus big droplets, but I was left unclear as to which spreads the virus/variants, and how best to avoid becoming infected. I would like to know what the advice is for those of us whose main defence is facemasks, distancing, and ventilation. If I knew how to safely navigate my life, then I'd know what questions to ask before attending a venue, and bits of my old life might be able to return. (I would love to be able to safely swim again, but with swimmers going past me, blowing out their breaths at me, is this safe? Doesn't seem as though it would be.)

Much is made in the media regarding how best to tempt people back to venues that they used to attend before the pandemic. I think that giving people proper advice on how to stay safe, would be a big help. (It might also relieve some pressure on the NHS.) In the absence of any proper advice on how to keep safe, many — especially those who've been through a severe bout of flu or Covid — simply stay away.

And for people who don't know that their platelets are already low, they'll be unaware that they're more vulnerable than others. They won't know that, for them, a bad dose of a virus or Covid — or a flu jab or Covid jab — could trigger the start of ITP. It would be so helpful if epidemiologists were again tasked with advising us on how best to stay safe. Simply telling us to get vaccinated is not a one-size-fits-all solution. After all, of those whose ITP was the result of a vaccination, how many might have been spared this diminished life had they been advised before being jabbed, to get their bloods checked first? That's a lot cheaper than our NHS Haematology departments dealing with ever more ITP patients.

If anyone can point me in the right direction, to the web site that carries current advice on how unvaccinated people can best keep safe from

catching Covid, do let me know.

Reply from Prof Adrian Newland

The report here from Dee Jones illustrates just how debilitating the fatigue in ITP may be and the impact on quality of life. This is a very difficult area and one we discussed considerably at the recent Patients' Convention. There are no easy answers or solutions. Only about a third of ITP patients experience fatigue and it is not always associated with the platelet count. It is true that for a number of patients the fatigue comes on as the counts fall and disappears as the counts rise and with 'true' remission fatigue is rarely present. By true remission I mean a complete cessation of platelet destruction. In some patients with a platelet response their platelets may still be being destroyed and we know that this associated with the production of chemicals known as inflammatory cytokines which are associated with fatigue. This does mean that some patients who appear to respond may still find fatigue remains their main complaint. It is important that there is a thorough assessment as several of the treatments we use may also cause fatigue and this can often be minimised.

With regard low platelets following immunisations it is well known that vaccinations are associated with thrombocytopenia. This was first noticed with the MMR vaccine where it impacts in 0.1 to 4 per 100,000 vaccinations. It is invariably mild and transient and rarely requires treatment. We also see it very occasionally with Flu and Pneumovax in our ITP population. It is also recognised post Covid vaccinations where the national data collections have identified it in 1-10 per million doses. The risks of thrombocytopenia following Covid infection occur in over 25% of those infected and the platelets reach lower levels and the affect is more long-lasting.

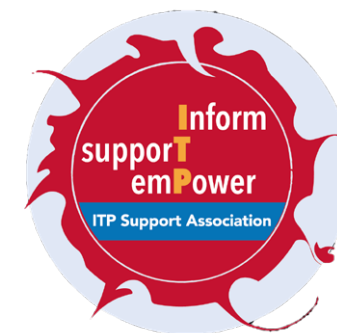
The most effective way to prevent infection is to undergo the vaccine programme. The ITPSA collected data from our members following vaccination and found a small incidence of

thrombocytopenia. This was not associated with any severe effects and in general was transient. Interestingly in a similar number of patients the platelet count actually rose. Larger, more controlled studies published comparing unselected patients with ITP and comparing with healthy people showed no significant difference between the two groups.

The use of masks in preventing infection is marginal at best. Their main use is in preventing the wearer from infecting those around them, rather than for protection. For the latter masks known as FFP2 or 3 should be used and will provide some personal protection, preventing liquids or particles contaminating the face but these need to be worn properly and replaced regularly. The best protection is common sense and a full vaccination programme.

Several of these aspects are covered by publications on the ITPSA on our website and have also been discussed in presentations at previous Conventions and the presentation will be available on-line.

Professor Adrian Newland



Scholarship Programme



The UK & Ireland ITP Support Association Academic Scholarship Programme Nominations for the 2024 ITP Academic Scholarship Programme are now being accepted.

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

Who is Eligible for the Scholarship?

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

How to Apply?

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

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

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

My Life With ITP by Ria

My life with ITP@autoimmunedisordersandri



I was diagnosed with ITP in May 2017 aged 16.

It started when I was on a family holiday in Sri Lanka, I noticed random bruises on my legs and began to have some random lightheaded spells one of which sticks

in mind was at the airport on the way home, my head was spinning.

A few days after landing back in the UK I went to see my GP and explained my symptoms, as a re-sult they did some blood tests.

I can't recall how long it took for the results to come back but I had just got home from school when my mum rang me and kept asking me if I had had a shower and was out my uniform, the next minute my mum and dad came home from work, this is when mum told me the hospital had rang and they needed me to go to hospital straight away.

When we got to the Children's ward, I was told my platelets were 8 - at this point neither me or my parents knew what a platelet was or what this meant. The next 2 weeks consisted of numerous further blood tests daily along with other examinations to rule out other conditions such as Men-ingitis or Leukemia.

I also had to go and have my blood pressure taken daily for a couple of weeks at which point I was prescribed Prednisolone to get my platelets back up to a safe level. It took a few weeks for me to be referred to the correct specialist in Haematology and I can honestly say I wouldn't have wanted a different Haematologist.

Over the past 7 years I have all sorts of tests carried including a Bone Marrow biopsy and hun-dreds of further blood tests and treatments such as Prednisolone, which I have continuously

been on and off as my body responds well to it so we use it to get my platelets stable until we seek other options.

In September 2016, 6 months prior to my ITP journey, I found out I had Scoliosis and needed full spinal surgery to correct it. Therefore, I had to stay on Prednisolone for a longer term for the sur-gery to go ahead safely. Which thankfully it did at Birmingham's Children's Hospital, with the on-call Haematology team available if they were needed.

However, I ended up staying on Prednisolone for around 2 years which consequently brought side effects I wasn't aware of before such as huge weight gain, stretch marks, hair thinning and major mood changes. We then decided to try and wean off Prednisolone once they were consistently stable and they stayed within normal range for 6 months, unfortunately I then relapsed and ended up back on them which confirmed I have Chronic ITP.

Another treatment I tried was Eltromoplag a single tablet once daily which worked really well for me and kept my Platelets stable for around 18 months until I got diagnosed with bilateral Pulmo-nary Embolisms in May 2023 which ended up plummeting my Platelets once again as I had to commence on Apixaban (a blood thinner), unfortunately when trying to up my Eltromoplag dose it caused excruciating side effects and back pain so the decision was made to come off due to the side effects and the potential risk of clots if my platelet count went too high.

Once again, I was put onto Prednisolone and have been on it since June 2023 although now thank-fully weaning off again as my most recently tripled treatment has been Rituximab which is also a drug used to treat types of blood cancer, but that has also been proven to stabilise chronic ITP.

It consisted of 4 rounds once a week for 4 weeks and although my Platelets are within

normal range now we can't be certain if it's the Rituximab or the Prednisolone or a mix of both as it generally takes several for Rituximab to fully work, however I am feeling hopeful and praying that this does the trick or even just gives my body a break for a period of time.

Unfortunately, treatment options are becoming quite limited as I was also recently (January 2024) diagnosed with Triple + antiphospholipid syndrome (APS), which is the reason for my PE'S and some treatment to treat ITP may cause me to clot further, I have now commenced lifelong War-farin (blood thinner) for my APS.

My life since diagnosis has generally consisted of blood tests every 1-2 weeks, clinic appointments every 6-8 weeks and any treatments in between! I have got used to blood tests as it really doesn't phase me anymore. I have managed to continue life more or less normally by going to sixth form and university and qualifying as a healthcare professional - Operating Department Practitioner (ODP).

I have found my ITP manageable with regards to personal life and work. It is just hard to explain to people who have no idea about ITP and the problems and effects it can have, especially from being diagnosed at the age of 16 where life is supposed to begin, and you're meant to be out having fun.

I feel like I have missed out on a big chapter of my life as the past 7 years have continuously consisted of tests and appointments but also having to turn down things because I'm physically not well enough to do it. Trying to comprehend that you have a fault in your body which will most likely never be cured is hard but I'm so thankful for my amazing family, friends and Haematologist who have all been my biggest supports throughout.

I feel my Haematologist and Haematology nurses have become what feels like an extended part of my family, they always do whatever they think is best for me but also allowing me to decide if I think it's the right choice, allowing me to ask questions via appointment or phone and even trying to make my life easier by doing things such as booking a blood test

appointment if I can't access it myself. Having health professionals like that really does make it all so much easier and without them and their prompt decisions I probably wouldn't be here to tell my story. However, life has become a lot more difficult since having Rituximab and being diagnosed with APS along with having Bilateral PE's, the combination has begun to have a huge effect my life, including having to reduce my work hours in order to manage daily life and realising these blood disorders won't go away, I just have to try and live and enjoy life as much as I can while managing them.

I have also recently made an Instagram page @autoimmunedisordersandri to document my life with both ITP and APS, along with treatment I'm having, side effects, any symptoms for both disorders and being able to connect with others going through the same. Although I have done quite a lot of research regarding my blood disorders to deal with them as best I can, I am still trying to figure life out living with two blood disorders that are connected to each other but also complete opposites - I can't get my head around it myself so trying to explain to others is a whole other story!

I am very thankful for pages and charities like The ITP Support Association which not only supply a wide range of information about ITP but also share stories like mine where patients all over come together, making them realise they're not alone and others are going through the same.

Love, Ria x



ITPSA Patient Perception Survey 2024

ITP Centre & Haematology Unit

PATIENT EXPERIENCE

Survey 2024

Scan the QR Code with your smartphone

<https://bit.ly/ITPCentre2024>

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

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

PATIENT MENTORS

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

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

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

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

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

EHA Adolescent and Young Adult Programme



Back in January we nominated two young ITP patients from the ITP Support Association to the EHA Adolescent and Young Adult (AYA) Patient Advocates Training Program.

It was congratulations to Rhona Bowie and Ella-Sophia Ellis who have both been successful in being selected as part of this prestigious training programme.

The initial in-person training took place over two days in Munich Germany in March.

The following is a report on the training weekend from Jan Geissler who was leading the training on behalf of the EHA.

FYI the EHA training programme for adolescent and young adults (AYA) patient advocates kicked off in the last two days. This weekend, we had our first meeting with 15 young patient advocates from CML Advocates Network, Global MPN Advocates Network, Acute Leukemia Advocates Network, CLL Advocates Network, Myeloma Patients Europe (MPE), ITP Support Association, European Sickle Cell Federation (ESCF) and the PNH Global Alliance.

As you know, the objective is to strengthen

patient advocacy groups to better address the specific needs of young patients and survivors affected by different hematological diseases. The training aims to equip our trainees with the essential knowledge and capabilities needed for impactful advocacy and foster the collaboration with the EHA AYA Taskforce. The training programme is designed as a hybrid model of in-person virtual sessions.



Over the last two days the advocates have jointly identified specific needs e.g. in terms of treatment and research, being able to perform at school or work, fertility, survivorship as well as sexual and mental health. We brainstormed about potential advocacy actions that could address those. We also held a training about patient advocacy and using evidence and had two young haematologists training about malignant and non-malignant blood diseases.

What an amazing group of young patient advocates. Thanks to those who nominated these amazing advocates! Next we'll have two virtual sessions and then a face to face during the EHA congress to do further trainings and poster walks.

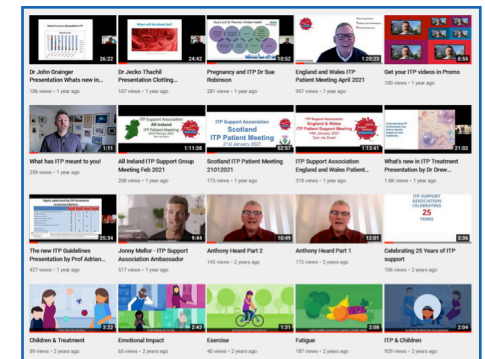
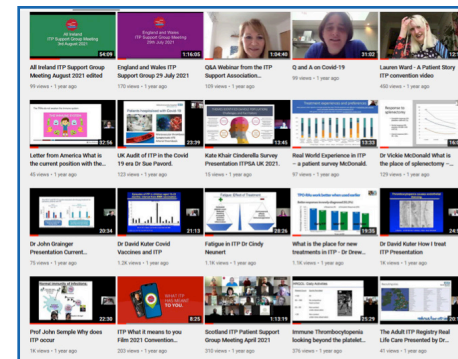
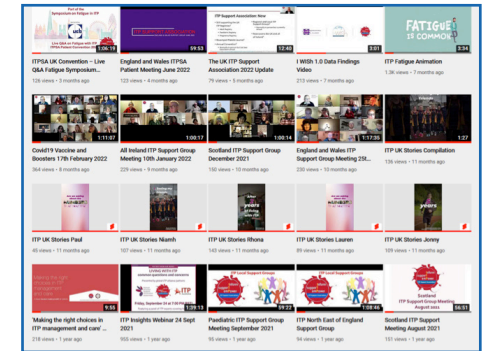
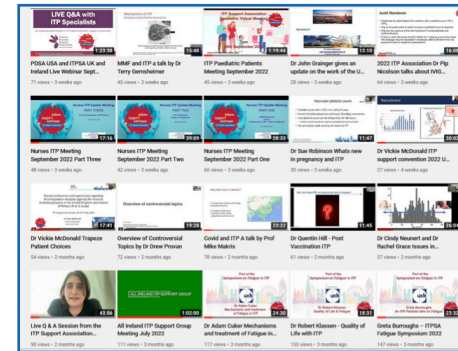
Our Digital Reach Continues To Grow

- OUR Digital Reach Continues to grow 8,000 + Facebook Page followers
- 400 Private Facebook Group Members
- 2,000 + X (Formerly Twitter) followers
- 2000 + Instagram followers

- 4,000 members on Healthunlocked
- 900 YouTube Channel Followers
 - 26k views in past twelve months,
 - 1300 hours viewing in past twelve months
- 13,000 Website visitors per month



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



Platform Updates by Anthony Heard

PLATFORM UPDATES – Trusted sources of reliable ITP information and advice

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

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

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

As for other reliable sources the following links are also excellent -

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

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

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

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

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

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

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

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

Thank you for your support.

Facebook Members Private Group



Join our new ITPSA Facebook Group

We now have an ITP Support Association private group, you can share your experiences or ask other ITP patients questions. Almost 300 ITP Patients have already joined and are sharing their

knowledge and experiences with ITP,

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

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

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

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



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

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

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

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



ITP Impact Survey

Shared Decision Making Document available in Six Languages

Introducing the ITP impact survey

Measuring the impact of shared decision-making in ITP and the ITP Discussion Guide

Completing this short survey is easy and should only take 5 minutes of your time.

<https://bit.ly/3Vm5NCO>

INTROUCING the ITP Impact Survey

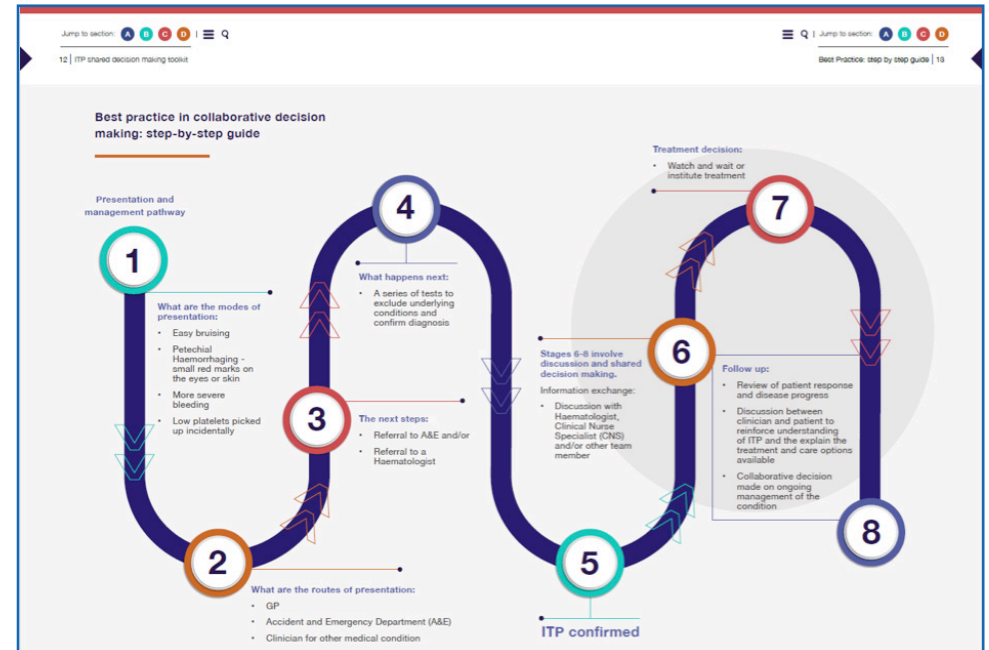
Many of you would have seen and used our ITP Discussion Guide, we are now looking to measure the impact of this resource with this survey.

Measuring the impact of shared decision-making in ITP and the ITP Discussion Guide.

Clinical guidelines recommend shared decision-making within ITP care.

Through the ITP impact survey, we want to gain a deeper understanding of your experience of shared decision-making within ITP, as well as your experience of using the ITP Discussion Guide to prepare for your healthcare appointments.

To take part in the survey scan the QR Code or click this link <https://bit.ly/3Vm5NCO>.



'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

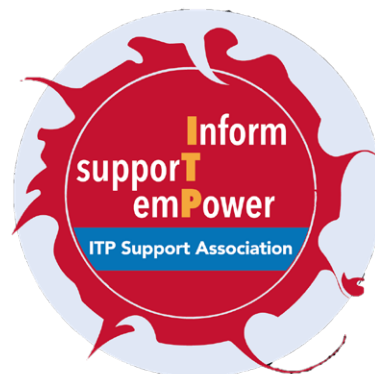
haematologists with a particular expertise in ITP to develop this toolkit that, we hope, will empower patients to hold collaborative and honest discussions with their clinician which in turn will result in better outcomes and quality of life."

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

ITP Patient Explainer Cont...

What is the ITP Discussion Guide?

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

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

How do I use the ITP Discussion Guide?

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

Scan the QR code to complete your own ITP Discussion Guide

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



NP-23508 | Date of preparation: September 2022

ITP Patient Explainer Cont...

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

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

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

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

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

NP-23508 | Date of preparation: September 2022

ITP Discussion Guide

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.
- 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.

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

Fundraising & In Loving Memory



FUNDRAISING

Laura's fundraiser for ITP Support Association



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

Congratulations to Eve Probart and Kate Hare for running the Edinburgh Marathon on 26th May and raising £904. Thank you to everyone who donated.

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



Huge congratulations to Laura Danskin Bidy who ran in the Rob Burrow Leeds Marathon on Sunday 12 May 2024 to raise awareness and money for ITP.

Her son, Horatio has ITP, he has just turned six and already in his little life has spent too much time in and out of hospital- he now has ITP. Unlike the others that were viruses' that went away and he recovered over time from, he's stuck with this one and there is no cure. Laura raised an incredible £5,442

Philippa's fundraiser for ITP Support Association



Fundraising & In Loving Memory



Philippa Jervis also ran in the Rob Burrows Marathon on 12th May.

Her son's best friend has ITP. Philippa raised £550 for the ITP Support Association.

Thank you to everyone who has been raising money for the ITP Support Association, we do not have enough space in the Platelet to list you all but every pound will help us support patients with ITP.

IN MEMORY

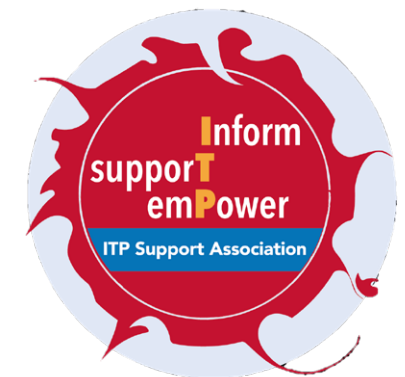
Raising money for the ITP Support Association in memory of Ron Chamberlain

Jill Chamberlain writes: We lost Dad (Ron) suddenly in March 2024, soon after his diagnosis with ITP (Immune Thrombocytopenia), an autoimmune disorder. He was admitted to hospital a week earlier with critically low platelets and was undergoing treatment to stabilise them when he suffered a brain bleed. The condition, unfortunately, made it impossible for the doctors to do what they usually would do to attempt to save his life, and he passed away after a short stay in ICU.

We, his family, would like to support this organisation that provides funding for research into the disorder and supports patients living with it. We hope that maybe some day a faster method of replenishing

platelet counts might be found, so that fewer people suffer a similar fate to Dad in the future.

To date Jill has raised £975 in memory of her Dad.



Sky Diving for ITP

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

Now you can!

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



HOW SKYDIVING WORKS CHARITY GUIDE

SKYLINE SKYDIVING

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

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

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

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.
- We and our airfields manage the event for you and your supporters so you can concentrate on your inhouse events and/or other major donor gives.
- We send all confirmation details from here bespoke to each airfield.

- You will receive a bespoke booking link provided by Skyline to use on your website/social media to get people signed up to skydiving.
- We cover all administration of the event including rescheduling if bad weather or cancellations.

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

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.

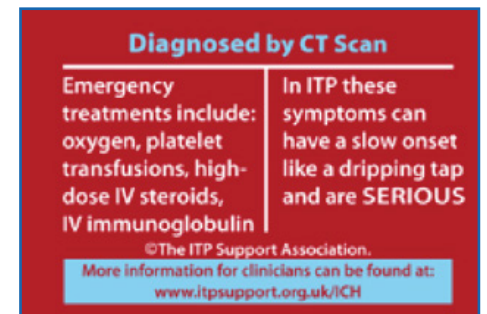
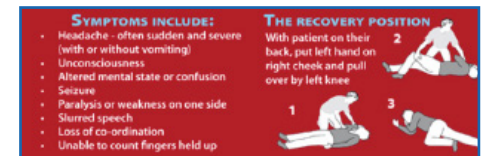
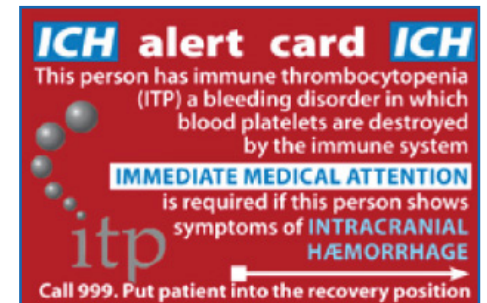
Order a free ICH alert card

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.



NEW - Medical Emergency Card



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

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

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



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

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

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



Remember, the ITP Emergency Card is just one tool to help ensure your safety and proper medical care. It's still important to communicate your medical history and conditions to your

healthcare providers during regular visits, and to carry any additional identification or documentation that may be required in your specific situation.

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



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.

Publications List

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.

BOOKLETS

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

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

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

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

Know about ITP – core information booklet.

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

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

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

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

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

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

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

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

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

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

Choosing your sport – which sports are safe with ITP?

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

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

FACTSHEETS

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

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

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

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

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

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.

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	*After 31 st January 2020 *£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

