



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

ITP AWARENESS WEEK EDITION

Cover image ITP International Meeting



The Platelet

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

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

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



From ITP HQ

This edition includes reports on four of the international patient focused ITP meetings for 2023, the PPTA Congress in Lisbon, the EHA Congress in Frankfurt and the ITP International Alliance Meeting and Platelet Disorder Support Association Convention in Chicago.

Coming up in September, its ITP Awareness Week.

Keep checking our website and social media channels



for all the Awareness Week updates.

'Silver Standard' for Excellence in Industry Award



We are pleased to share the news that our ITP Shared-Decision-Making materials (the discussion guide and explainers) have won a prestigious award in the UK. The project achieved the 'Silver Standard' for Excellence in Industry – Patient Partnerships at the Fourth Annual Patient Partnership Index Awards.

<https://patientpartnershipindex.co.uk/ppi-2023-results/>

The ITP Support Association, the whole team at Sobi and all who worked on this project thank you for this award.

To find out more about the ITP Discussion Guide click the following link:

<https://itpsupport.org.uk/the-new-itp-discussion-guide/>

ITP Support Association Annual Patient Conference 2024 and 2025



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From ITP HQ continued...

ITP Support Association is pleased to announce that the venue & location for our 2024 Annual Patient Convention is The Cavendish Conference Centre, London, WIG 9DT.

We would like to thank all who took part in our patient survey which enabled the ITPSA Board to select locations for the next two years. The event will take place on Saturday 11th May 2024. Tickets will go on sale later in the year. #ITPLondon2024



We can also announce that the venue & location for our 2025 Annual Patient Convention is Bridgewater Hall, Manchester, M2 3WS. The event will take place in May 2025. #ITPManchester2025

Special thanks must go to all the fantastic fundraisers who have gone that extra mile to support the Association, again details are included within these pages.



This is also a sad time as we announce that Liz Gooch, who has been the engine in the ITPSA Office for around 10 years is standing down from her current role with the Charity looking after Admin and Fundraising, but she will still be looking

after the post and any shop orders. We would all like to thank Liz for all of her work and support over many years, she has made a real difference.

ITP Support Associations Platinum Sponsor for 2023.



We have been working with Sobi on a number of projects in recent years, these include the ITP Discussion Guide, details of which can be found in this edition of The Platelet. They also supported our activities during ITP Awareness Week 2022, and I am pleased to say that as part of this sponsorship we are also working on some very exciting projects for Awareness Week 2023.



Mervyn Morgan CEO ITPSA



American Perspective

Adam Cuker, MD, MS - Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA, USA

My coauthors of The American Perspective and I have written a number of past columns about current treatments for ITP, clinical trials on novel and emerging ITP therapies, and how to select the best treatment for an individual patient. But not everyone with ITP requires treatment. Some patients do very well with observation alone. The goal of this article is to describe my approach to determining whether an adult patient with ITP needs treatment (the rules are different for kids and won't be addressed here).

Goals of treatment

In deciding whether a patient needs treatment, it is helpful to consider the goals of treatment. In my view, there are three main goals:

1. To prevent bleeding
2. To improve quality of life
3. To minimize side effects and burdens of treatment

Let's take a closer look at each of these goals. First, I aim to prevent bleeding, especially serious bleeding. The platelet count is by no means a crystal ball, but it is a crude predictor of bleeding risk in ITP. For example, serious spontaneous bleeding occurs almost exclusively when the platelet count is less than 20 k/uL and usually when it is less than 10 k/uL. At the same time, individuals with platelet counts of 50 k/uL or greater usually have mild or no bleeding symptoms. Beyond platelet count, other patient characteristics influence bleeding risk. Elderly individuals are at greater bleeding risk as are patients who require treatment with blood thinners or patients who have certain chronic illnesses such as kidney or liver disease. Patients who have jobs, hobbies, or lifestyles that put them at risk of trauma may also have a higher bleeding risk.

Second, I treat to improve my patients' quality of life. Many patients with ITP suffer from non-bleeding symptoms such as fatigue or anxiety around unstable platelet counts. Some report that they feel more energetic and less anxious, and generally have a greater sense of well-being, when they are on treatment.

At the same time, some patients dislike treatment. They may have difficulty tolerating medications due to side effects. They may also find taking regular medication to be inconvenient or costly. Thus a third key goal is to minimize side effects and burdens of treatment.



Putting it all together

Hopefully you now appreciate that deciding who should and shouldn't be treated is about much more than just the platelet count. It requires a detailed discussion with the patient about their treatment goals, bleeding symptoms, medical history, medications, occupation, hobbies, non-bleeding symptoms, tolerance and side effects of past therapies, and their feelings about being on regular treatment.

The accompanying figure shows how I attempt to put all of this information together. As the figure shows, almost all individuals with a platelet count less than 10 k/uL require treatment whereas almost all patients with a platelet count of 50 k/uL or greater do not. Between these values, decisions about treatment are individualized based on a number of factors related to bleeding risk, quality of life considerations, and patient values and preferences.

Many of my patients like this model, not only because it helps us to arrive at a treatment decision that aligns with their goals, but also because it gives them a sense of ownership and active participation in their management. If this model appeals to you, please feel free to discuss it with your doctor. I hope that it will help lead you to a treatment decision that makes sense and feels right.

PPTA Congress Report

PPTA Congress June 2023

Dianne White represented the ITP Support Association at this year's PPTA Congress which was held in Lisbon, Portugal, here is Dianne's report on the event.

Since being diagnosed with ITP for the second time in 2013, my ITP condition has given me some new experiences.....good and bad, on the negative side too many hospital visits to a wonderful teaching hospital, unbelievable fatigue that nobody "gets" except other ITP sufferers, horrendous anxiety over "scores on the door", excruciating bone marrow extraction, steroids, IviG transfusions, blood transfusions, A & E, Intensive Care (wonderful care, but it has to be said not one of my highlights!), non stop bleeding episodes, the wonder of tranexamic acid tablets, newer drugs, TPOs, blood clots, gut problems, too many antibiotics, to name but a few !!!



On the positive (and to quote Monty Python) and looking on the "bright" side, with no intention whatsoever, I have been blessed and humbled to be asked to be involved in Clinical Governance at a Centre of Excellence, Patient Panel Chair, I have led an ITP Support Group in the North of England – thwarted somewhat by the arrival of Covid, I have sat on a recent Nice Committee Appraisal as the Patient Advocate for one of the new TPOs and also now have progressed from being a

Patient Observer Trustee of the ITPSA, to a Board Member and also had involvement in educational work with some of our drug companies and of course the ITP Discussion Guide.

What I did not expect was to be asked to attend the IPPC(International Plasma Protein Congress) 2023 Congress in Lisbon in June!

So of course, I went off, very early on a Sunday morning, courtesy of the much maligned Easyjet, to Lisbon to attend this Congress.

PPTA(Plasma Protein Therapeutics Association)

The PPTA is a key player in the Plasma Industry, with an extensive network of human Plasma collection centers and manufacturers. Collaborating with numerous stakeholders (we at ITPSA are one) and policy makers to establish rightful standards and programmes for donors and patients is at the core of their work. This year's congress focused on the revision of the EU Legislation impacting the Plasma industry, the industry's commitment to donor health, as well as the actions taken by member states to increase Plasma collection.

The Conference itself was made up of c.250 delegates, representing a mix of academics, ethicists, economists, industrialists, manufacturers, researchers and clinicians, from international destinations.

Why do people give plasma?

People give plasma for different reasons. One reason is that it helps save lives. For many people with rare diseases and chronic conditions, plasma-based therapies are the only way to treat their condition or disease. Plasma is also given to trauma patients and burn victims to help with blood clotting and to boost their blood volume, which can prevent and treat shock.

How is plasma used?

When you give your plasma, it is combined with plasma donated by thousands of other people.

PPTA Congress Report

The proteins in plasma are extracted and become therapies and medications to treat these conditions. It takes many people giving plasma to extend the life of a single person with a rare condition.

Did you know?

- 130 plasma donations will treat 1 person with primary immunodeficiency for 1 year. 1
- 465 plasma donations will treat someone with chronic inflammatory demyelinating polyneuropathy treatment for 1 year. 2
- 900 donations will treat 1 person with alpha-1 antitrypsin deficiency for 1 year. 1
- 1,200 plasma donations will treat someone with hemophilia for 1 year. 1

Some of the therapies created using plasma restore healthy proteins and treat people with bleeding, clotting, lung, autoimmune, genetic, and other conditions, such as:

- Alpha-1 antitrypsin deficiency
- Von Willebrand disease
- Antithrombin III deficiency
- Kawasaki disease
- Hereditary angioedema
- Idiopathic thrombocytopenic purpura
- Immune deficiency
- Diseases of the nervous system, such as polyneuropathies and myasthenia gravis

Source plasma is also used for:

- Tetanus treatment. People who have received a tetanus vaccine carry antibodies in their plasma that can help others. These antibodies, found in plasma, can be given to infected patients as a lifesaving treatment. In some cases, it is the only treatment option for this debilitating infection.
- Rabies treatment. Antibody infusions are one of the treatments available for people with rabies infection. When people who are immunized against rabies give plasma, their antibodies can be used to develop immunotherapies for rabies and many other

kinds of infections.

- Pregnant people. Pregnant people with a particular condition called Rh sensitization need plasma protein therapies to protect their baby. The antibodies in these therapies can prevent severe pregnancy consequences associated with the condition, including fetal brain damage and death.

Blood Plasmapheresis is the removal, treatment and return or exchange of blood plasma or components thereof to and from the blood circulation. Derivatives from the Plasma are manufactured and used specifically for various rare conditions – IviG transfusions being used for ITP.

In the UK there are approximately 17,000 patients reliant upon plasma products and there are only three centres to donate plasma here in the UK, in Birmingham, Reading and Twickenham.

Between 1998 – 2021 Plasma production in the UK was ceased.

The Plasma is used to either boost the immune system or calm down the immune system when it is attacking someone's own body.

Plasma is a yellowish liquid in the blood that carries platelets, red and white blood cells around the body and makes up approximately 55% of our blood, it contains antibodies, known as immunoglobulins, which fight infection. It is these antibodies that are made into medicines to help people with rare diseases, immune disorders and genetic conditions.

The 2 day conference was extremely interesting and worthwhile and some good contacts were made.

Easyjet were wonderful and even managed to land ahead of time on both flights and yes, I did get a few hours to have a look at Lisbon, a lovely, friendly city, that I hope I get the opportunity to revisit myself.

EHA Congress Report

EUROPEAN HAEMATOLOGY ASSOCIATION - CONGRESS JUNE 2023, FRANKFURT.

Continuing our aim to be represented at the major ITP related meetings Derek Elston attended the EHA Congress both as the Chair of the EHA Patient Advocates Committee and a representative of the ITP Support Association.



The EHA Patient Advocacy Committee with the President and the two previous presidents.

Congress this year was held at Frankfurt Messe, the conference plaza in the center of Frankfurt. This impressive conference center has developed and grown in recent years with extensive additional space being provided, nearly all air conditioned around the central theatre hall. Statistics indicate that 15,000+ people from all over the world had registered for attendance at congress, a record for EHA. Sadly, there were not as many ITP patient groups from within Europe attending as usual, but my wife and I were very pleased to be joined by Barbara Lovrencic from Italy.

The patient advocacy committee (PAC) was located within the information hub in a central location in the exhibition hall. This accommodated all the different haematological condition groups allowing information material to be displayed and available and for meeting medics and

pharma companies alike within a pleasant environment surrounded by Pharmaceutical Company stands etc.

The program was scheduled over five days starting on Thursday 8th June with a selection of satellite symposiums from 08:00 through to 20:45. These were provided by various organizations including one session by Grifols entitled Re-thinking Immune Thrombocytopenia (ITP) Management. How Real-World Evidence Enhances Clinical Benefit. This session was chaired by Dr. Drew Proven and was supported by Dr. Guillaume Moulis from Toulouse and Maria Eva Mingot Castellano from Seville. A most interesting session, well supported by delegates. In addition to these symposiums there were four Young EHA research meetings on a variety of cancer subjects.

Friday the 9th comprised 52 presentations spread over 13 conference halls between 08:00 and 17:45. These sessions were of varying types and included reports from scientific working groups including one on bleeding and thrombosis. The Patient Advocacy Committee hosted two joint presentations while being directed at malignant conditions, much related to non-malignant conditions like ITP. The subjects covered were Novel Clinical Trials in Haematology – the comparator challenge and the need for new formats. The second symposium was entitled From Approval to Access – Optimizing treatments and appraisals. Both sessions were a great success with over 300 attendees at each.

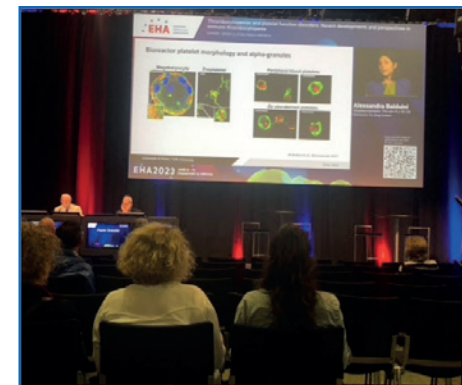
The days sessions were followed by the poster Session between 18:00 and 19:00. We estimated approx. 2000 posters covering many haematological conditions and the research and reports relevant to each. This is always an impressive part of congress affording delegates to meet and discuss their content with the authors and their peers.

The Patients Advocacy Committee held their annual meeting during the afternoon and being the chair, I was able to welcome the newly elected

EHA Congress Report

President of EHA, Professor Antonio Almeida to his first meeting as President, together with his predecessors, Professor Elizabeth Macintyre and Professor John Gribben. This meeting was attended by many of the secretariate of EHA and I was delighted to have a near 100 percent attendance of patient advocacy members, each bringing their own perspective of advocacy relative to the condition they represented to the table. Saturday the 10th, being the second main day of congress, was equally well populated with 60 sessions being held within 17 different congress halls around the plaza.

Early evening a Novartis sponsored session was held entitled - Update in Haematology. This again was a very well supported satellite symposium with presentations from Dr. Drew Proven and Dr. Walleed Ghanima supported by Professor John Semple in the auditorium. This presentation considered the outlook for new medications and development in research. A very interesting session which provided me with the opportunity to publicly thank Drs Proven, Ghanima and Semple for all the work and effort they put in for the benefit of the patients.



Sunday commenced for me at 08:00 in the Goodman Hall where I was co-chairing a scientific working group session with Professor Paolo Gresele entitled Thrombocytopenia and Platelet Function Disorders. The three speakers

were Professor Alessandra Balduini, Professor John Semple and Nichola Cooper. Their subjects were Allessandra – Bone marrow production and the effects of Eltrombopag. Professor John Semple How infections can induce platelets to self-destruct. Dr Nichola Cooper looked in detail at Cognition impairment. I am very pleased to say, all three speakers reported on the importance that patients play in their work as scientists and haematologists.

As you can imagine, being a scientific working group session, the content being delivered by these three scientists was extremely technical but again was attended by over 300 delegates who were obviously interested in the science concerning platelets.

Overall, the congress was a success for all who contributed and supported the event. By attending many different parts within the congress halls, we estimated that we had walked some 35 miles in 5 days! We were delighted to meet some of the ITP Support Association medical advisers who were contributing or just visiting, like Drs Sue Pavord and Gerard Crotty.

Next year congress is in Madrid on June 13 – 16th. Another very impressive and large conference venue.



ITP International Meeting Chicago 2023

Prior to the PDSA Convention in Chicago the International ITP Alliance held their second meeting of the year, Mervyn Morgan represented the ITP Support Association at the meeting.

The ITP International Alliance meeting is an important event that brings together organisations and individuals from around the world who are dedicated to supporting and advocating for people living with immune thrombocytopenia (ITP). This meeting had representatives from 12 Countries, overall, the Alliance has a membership of over 30 countries.



The ITP International Alliance Members who attended the Chicago Meeting

The ITP International Alliance meeting serves as a platform for collaboration, knowledge sharing, and collective action in the ITP community. It typically includes representatives from patient advocacy groups, healthcare professionals, researchers, industry experts, and other stakeholders.

One of the primary goals of the meeting is to provide an opportunity for organisations and individuals to exchange information and best practices. This included discussions on the

latest research findings, treatment options, and advancements in the field of ITP.



Mervyn Morgan represented the UK and Ireland ITP Support Association

The meeting also focuses on fostering collaboration among different organisations and stakeholders. Participants have the chance to network, build relationships, and form partnerships that can (and have) lead to joint initiatives and projects aimed at improving the lives of individuals with ITP. This collaborative approach helps unify efforts and enhances the overall impact of the ITP community's advocacy and support activities.

Overall, the ITP International Alliance meeting is a vital gathering that promotes collaboration, knowledge exchange, and advocacy for individuals living with ITP. It aims to bring together various stakeholders to collectively work towards advancing research, improving treatment options, and enhancing support for the ITP community.

The next meeting of the ITP International Alliance is planned to take place in London in May 2024.

PDSA Annual Patient Convention 2023

The ITP Support Association was represented at the Platelet Disorder Support Association Annual Convention held in Chicago by Mervyn Morgan.



The PDSA Conference is an event organised by the Platelet Disorder Support Association, like the UK ITP Support Association the PDSA is a non-profit organisation that aims to educate and support individuals living with platelet disorders. This conference typically brings together healthcare professionals, researchers, patients, and caregivers from around the world to discuss the latest advancements in the field.

During the conference, attendees could take part in a wide range of activities. These included educational sessions and workshops led by experts in the field, where participants can learn about the latest research, treatment options, and management strategies for platelet disorders. These sessions covered topics such as immune thrombocytopenia (ITP), thrombotic thrombocytopenic purpura (TTP), and other related conditions.

Just like our own Patient Conferences the PDSA conference also provides a platform for networking and sharing experiences. Participants have the opportunity to connect with fellow patients, caregivers, and healthcare professionals, fostering a supportive community. These also included panel discussions, support group meetings, and interactive sessions where attendees can ask questions and exchange knowledge.

In addition to the educational aspects, the PDSA Conference also featured exhibits from pharmaceutical companies related to platelet disorders.

Overall, the PDSA Conference in Chicago, like similar events, aims to provide an inclusive and informative environment for those affected by platelet disorders. It offers opportunities to learn, connect with others, and stay updated on the latest advancements in research and treatment options.

We would like to thank the PDSA team for making the conference a wonderful event for all who attended.

PATIENT MENTORS

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

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

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

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

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

Tim Beatie – ITP Patient
Tim is based in the Southwest and is a former Rugby Coach and Player



Congratulations to Marilia Lia - PTI Brazil



Marilia Lia started PTI Brazil in 2016 after experiencing Immune Thrombocytopenia, which left her hospitalised and with a platelet count in single figures.

Recently, for the information and ongoing support that she is providing ITP Patients and their families throughout Brazil, Marilia was named as an honouree at the 'Women of Distinction' Ceremony by the City Council of São Paulo.

Marilia has been a valued part of the ITP Global Alliance since 2018, which includes over 30 countries all working together to improve the lives of people living with Immune Thrombocytopenia.

Congratulations to Marilia on your dedication to the cause and your ongoing hard work and efforts.

Article copied with permission from ITP Australia.

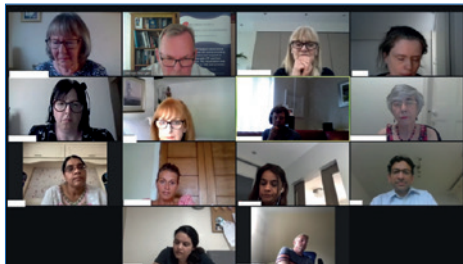
Editor's note, during our lifetimes we meet a number of people who's light shines brighter than most, Marilia is one of those people, I am proud to call her a friend.

Update from the ITP Global Alliance, the International Alliance keeps growing as we welcome Honduras ITP to the family of Nations. Honduras ITP is run by Stephanie Kafie, you can find out more about the latest member by visiting their website at <https://ptihonduras.com/>

Learn more about the ITP Global Alliance by visiting <https://bit.ly/44kMyuB>

Virtual Group Meetings

Virtual Group Meetings Resume



Our programme of ITP Patient Meetings on Zoom has resumed, you will find the recordings of our recent Scotland Meeting with Dr Catherine Bagot and the England and Wales meeting with Prof Adrian Newland on our YouTube channel.

Our next meeting will be our Paediatric ITP Group Meeting at 7pm on Wednesday 27th September with Dr John Grainger, this meeting is part of ITP Awareness Week, you can register for this meeting by going to our website at www.itpsupport.org.uk.

Cyclic Thrombocytopenia

Cyclic thrombocytopenia (CTP) is a very rare blood disorder characterized by periodic fluctuations in platelet counts. Each of the fluctuations is usually over a period of 3-5 weeks. The levels that the platelet counts reach have been reported as from $10 \times 10^9 /L$ at the lowest and climbing to $330 \times 10^9 /L$ at the peak. Therefore, patients may oscillate between periods of severe thrombocytopenia, with all its implications, or rebound recovery to levels where there is an increased risk of thrombosis.

Due to the symptoms following the low platelet counts, CTP may be misdiagnosed as immune thrombocytopenia (ITP). However, distinct from ITP, CTP generally responds poorly to most treatments used successfully in ITP such as corticosteroids, splenectomy, and intravenous immunoglobulin. There is no clear idea of the cause of CTP although (as in ITP) autoimmune platelet destruction is thought likely, but bone marrow abnormalities with poor megakaryocyte function, infectious causes and hormonal changes have all been considered as potential mechanisms.

Interestingly, CTP was more commonly found in females, a predominance disproportionately in favour of pre-menopausal women, and these fluctuations of platelets are often in phase with the menstrual cycle, suggesting an association of the hormonal cycle with fluctuations in the platelet count. A possible pathogenesis of CTP and suggests promising therapeutic strategies for the disease.

Making the correct diagnosis can be difficult and any patient diagnosed with ITP, who shows unexpected fluctuations in their count should be considered as having CTP and a platelet count diary should be maintained, if possible off all treatment, to follow the trend in the counts. Treatment can be difficult and steroids are often

given initially but there is anecdotal evidence that thrombopoietin receptor agonists, such as romiplostim and eltrombopag, may be helpful in reducing the fall in the counts but they may have the unwanted effect of markedly increasing the peaks. They should be used with caution and only under close medical supervision and it goes without saying that treatment should only be considered if there is a bleeding risk. Unfortunately, many patients fail to respond to any therapy. The disease is chronic and may go on for years although occasional examples of spontaneous remissions have been recorded.

Professor Adrian Newland



ITP September Awareness Campaign



The 2023 Global ITP September Awareness Campaign is upon us. Here's why it is so important and why we should all make an effort to get involved.

Please check the ITP Support Association website at www.itpsupport.org.uk and www.globalitp.org for further details of how to take part.

WHY IS ITP SEPTEMBER AWARENESS IMPORTANT?

One of the main lessons that I have taken from my ITP journey is that we all need to make more people aware of this very little known, enigmatic illness. Like most ITP sufferers, before I was diagnosed with it, I had never heard of it and frankly I really couldn't believe that I had it.

After my diagnosis, I just couldn't believe that I had anything as serious as ITP. I thought that the hospital had made a mistake. Maybe they had confused my blood test results with somebody else. Once it became clear that I really did have ITP, then I got angry.

Why me, how can I have ITP? I had never been ill before, never smoked, never taken any drugs and always drank alcohol at sensible levels. I had lived my first 46 years without ever being in a hospital for anything other than a few stitches from football/soccer related injuries.

Well, so what? ITP does not care much about who it chooses and when. Unfortunately it can develop in anyone at anytime at any age and of any ethnicity, although we do know that it occurs more in women than men. In short, ITP is not terribly fussy, it can choose anyone, we are all fair game.

In adults it is usually more stubborn than in children. It tends to disappear (often without treatment) in many children, as suddenly as it turns up. In adults it is rarer to see it go into spontaneous remission. But it doesn't mean that we cannot live very full and positive lives.

SPREADING AWARENESS GETS RESULTS

There are certainly plenty of grounds for

optimism and it is clear that our ITP Awareness campaigns have borne fruit. When the annual September campaign started back in 2010 things on the purple front were very, very different.

When I think back to 2006 and my diagnosis there were far fewer treatments available for ITP (For example - TPO drugs had not been rolled out) very few support groups, and certainly very limited numbers of blogs, social media groups, vlogs, let alone research on the scale we have now.

It is worth remembering that until the TPO drugs were introduced the only treatments available for ITP WERE NOT actually designed to treat ITP. All of those options were actually borrowed from other illness/conditions and were not specifically designed to treat ITP at all. Now we have the TPO drugs which have been specifically developed for the treatment of our condition.

So things have improved dramatically and as evidence of this I would urge anyone living with ITP to watch the many video films on the ITP Support Association YouTube Channel which explain the many treatment options now available to us.

The whole approach to ITP is so much more positive, more patient focused and inclusive. It is just so much more optimistic and encouraging.

Making an effort to spread awareness has undoubtedly played a big part in moving research, treatments & knowledge further forward.

There is no better reason to get involved this September than knowing any contribution we make is improving things for us living with ITP now, and helping those who may follow in our footsteps in years ahead.

However, we cannot be complacent, it is up to us to keep making others aware of our condition.

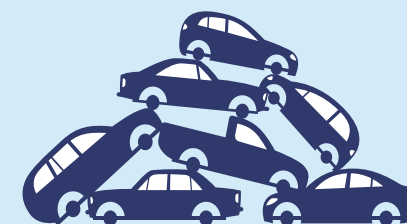
We know what it is like to live with it day to day and it is we who can tell others what to expect. If we don't inform people, then who will?

So please do help in this September Awareness campaign, try to get involved even if it is to take just one or two small actions.

September awareness week runs from the 25th to the 29th.

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 Support Association Convention Recordings

ITP Support Association Convention Recordings Available On-Demand from 25th September 2023

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



As part of this years ITP Awareness Week we are making available on our YouTube channel all the recordings from our Annual ITP Patient Convention which was held at the Royal College of Pathologists in May 2023.

All 12 talks including the Question-and-Answer Session will be available to view from Monday 25th September 2023. Visit <https://www.youtube.com/@ITPSAUK>



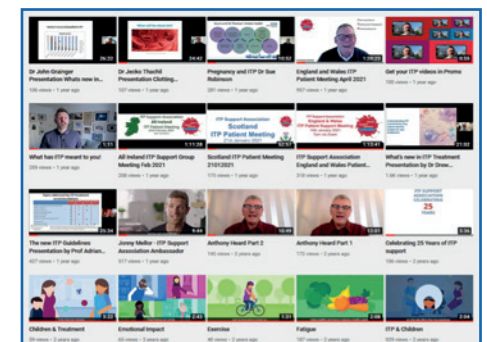
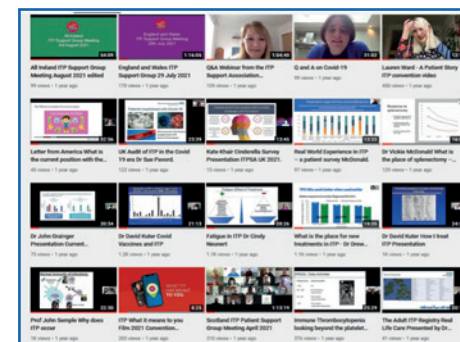
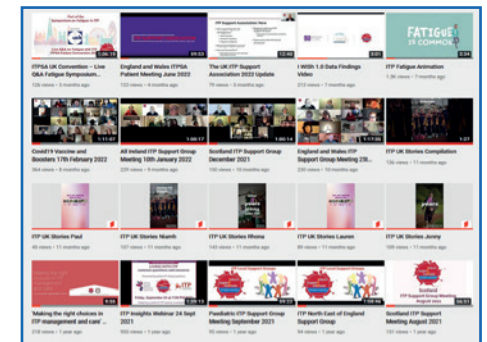
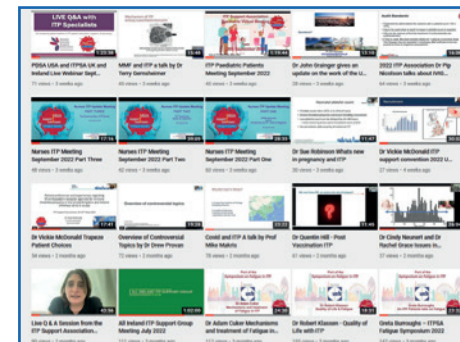
Visit Our Youtube Channel

Visit the ITP Support Association YouTube Channel

We have our own YouTube Channel with numerous helpful, informative & interesting videos covering a wide range of ITP related issues - <https://www.youtube.com/channel/UCRkHWfVYAAIKKbJfI4L37g/videos>

or go to our website at www.itpsupport.org.uk and click on the YouTube Social Media icon under the top menu. We have over ninety ITP related videos available and are adding more all the time.

Please subscribe to the channel.



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.



Fundraisers & In Memoriam

Fundraisers

The charity has now enrolled with Skyline events so people can do a sponsored charity skydive on behalf of the association (see the advert in this edition)

Helen Butcher donated £50.00 from proceeds selling sheep's wool to local allotment holders. She aims to sell more wool in the future and donate proceeds to ITP. Helen's daughter has ITP.

Marie Price along with 4 other family members completed the "Three Peaks Challenge" in April. The proceeds were split between ITP and Coeliac UK, and we received cheque for £507.50. Marie's 8-year-old daughter Layla was diagnosed with Coeliac disease and ITP in February.

The Sisterhood at Hope Baptist Church donated another £100.00 in May this year. One of the congregation's nephews has ITP.

Atlas Trading Limited - £276.75 from collection box

Amazon Smile - £193.08 (we believe this is the final payout)
Facebook - £304.35
Just Giving donations - £2,654.12

In Memory:

Donations in memory of Patricia Paul raised £87.50

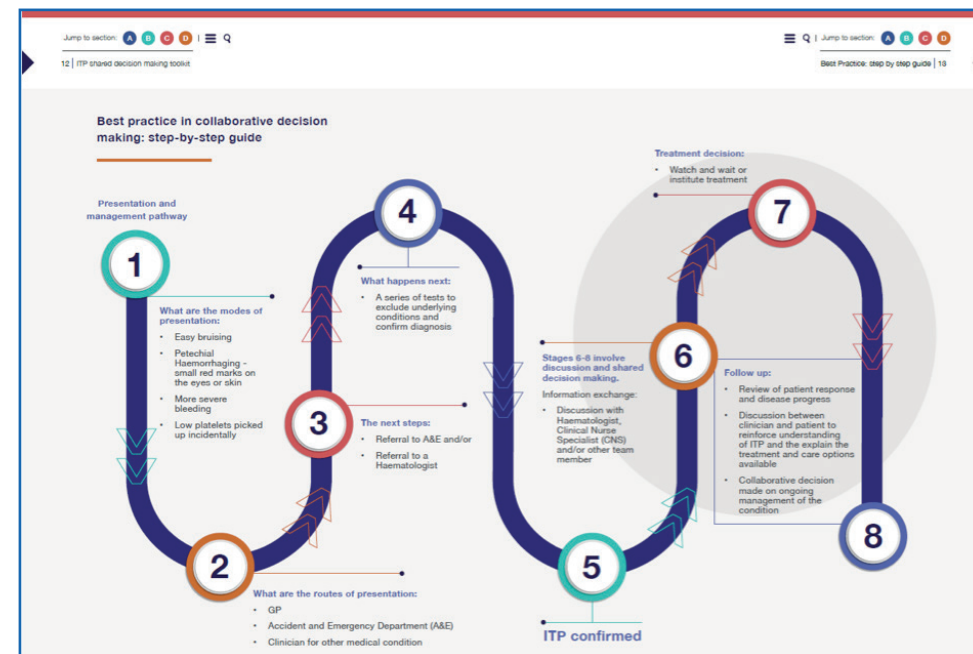
Sharon Treen, whose son, Joshua Murray died aged 22 from ITP last year, has fundraised again. She has kept donations going on her fundraising page from last year and raised an additional £1,780.

Donation of £271.65 - L2D ltd (no more details)

GFK £100.00 anon donation

Much Loved - £489.36 anon donation

Shared Decision Making Document available in Six Languages



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

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

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

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

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

shortage of platelets and bruising.

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

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

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

The toolkit is a response to the results of a patient

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

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

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

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

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

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

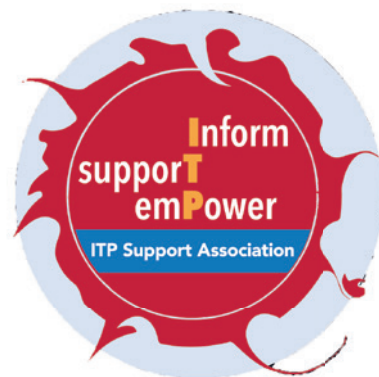
haematologists with a particular expertise in ITP to develop this toolkit that, we hope, will empower patients to hold collaborative and honest discussions with their clinician which in turn will result in better outcomes and quality of life.”

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

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

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

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



ITP Patient Explainer

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



NP-23508 | Date of preparation: September 2022

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 Cont...



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.
- 2 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.
- 4 **Make a joint decision** on your future care plan.

Today's date:

Note down today's date so you can look back and track how you're feeling over time.

____ / ____ / ____

My goals

First, write down your short-term goals; the things that are most important to you right now (this week / month).

For example, having a nice walk with the dog this week.

Then, write down your longer-term goals; the things that are most important to you in the future (next 6 months).

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

Living with ITP

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

Coping with ITP symptoms

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

☹️ 1 2 3 4 5 😊 ★

Feeling on top of things

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

☹️ 1 2 3 4 5 😊 ★

Having emotional wellbeing

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

☹️ 1 2 3 4 5 😊 ★

Pursuing hobbies

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

☹️ 1 2 3 4 5 😊 ★

Spending time with friends and family

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

☹️ 1 2 3 4 5 😊 ★

Performing well at work or school

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

☹️ 1 2 3 4 5 😊 ★

Taking part in sports and exercise

Do you feel you can reach your sport and exercise goals?

☹️ 1 2 3 4 5 😊 ★

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

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

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 coverage sponsorship of \$125 to the charity. Anything raised above the minimum amount means a larger donation towards yourselves.

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

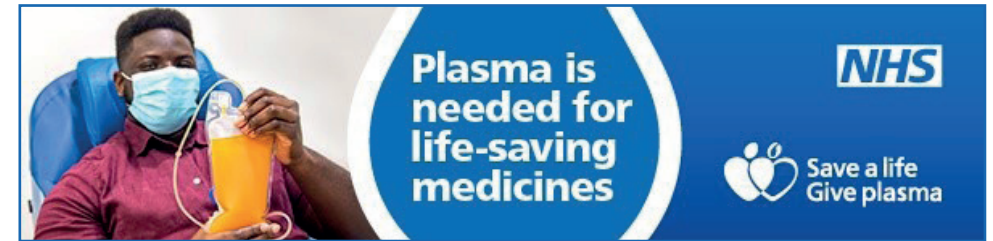
• You will receive a dedicated email address where participants can contact us directly with any skydiving questions.

• 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.

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

Plasma Donation



The NHS is getting ready for a plasma donation campaign, to hopefully help improve supplies of immunoglobulin.

If you have received immunoglobulin and you live in Greater London, the Thames Valley, or the West Midlands, you could help the campaign by sharing your story.

To find out more, email stephen.bailey@nhsbt.nhs.uk



Leaving a Legacy



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

There are 3 main types of gift you can make:

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

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

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

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

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

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

make a new will.

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

Suggested wording for making your gift to the ITP Support Association

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

Wording for a residuary gift

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

Wording for a gift of money or an item

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

Note

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

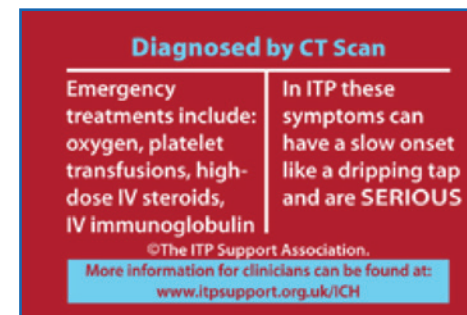
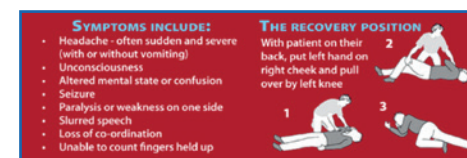
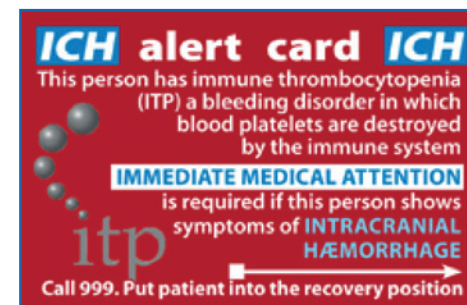
Order a free ICH alert card

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

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

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

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



Ways To Donate

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



Facebook



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

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



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

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

Thrombopoietin receptor agonists (TPO-RAs) in older patients with primary immune thrombocytopenia (ITP): effective and safe? Real World Data from the UK Adult ITP Registry

F. Rahevi¹, H. Marsh², A. Mash¹, L. Taylor¹, T. Biss³, Gillian Evans⁴, Marie Scully⁵, J. Hermans⁶, S. Marshall⁷, M. Kibber⁸, R. Rayment⁹, L. Robinson¹⁰, S. Johns¹¹, C. Ronalds¹², H. Jackson¹³, S. Ackroyd¹⁴, Adrian Newland¹⁵, Drew Proven¹, Nicola Cooper¹, Nicola McCordall¹ on behalf of the UK Adult ITP registry

1. Barts Health NHS Trust, The Royal London Hospital, 2. Queen Mary University London, 3. Royal Victoria Infirmary, Newcastle, 4. East Kent Hospitals University NHS Foundation Trust, 5. University College London Hospitals NHS Foundation Trust, 6. Nottingham University Hospitals NHS Trust, 7. Sunderland Royal Hospital, 8. Northumbria Healthcare NHS Foundation Trust, 9. University Hospital of Wales, 10. Gloucestershire Hospitals NHS Trust, 11. Royal Cornwall Hospital, 12. United Lincolnshire Hospitals NHS Trust, 13. Anuram Bevan University Health Board, Wales, 14. Bradford Teaching Hospitals NHS Foundation Trust, 15. Imperial College Healthcare NHS Trust.

INTRODUCTION

Primary immune thrombocytopenia (ITP) is a rare acquired immune-mediated disorder. The prevalence of ITP increases over the age of 60y. In older patients it may have a more aggressive course and management is often more complex due to co-morbidities, polypharmacy and possible drug interactions.

Thrombopoietin receptor agonists (TPO-RAs) induce megakaryopoiesis and have reported overall response rates of 50-90% in ITP¹. There is limited data on response rates to treatment and events of special interest whilst on therapy, specifically in elderly patients.

The UK Adult primary ITP registry is a large multicentre registry started in 2007, recruiting from 91 sites. Data is collected on: demographics; clinical features; co-morbidities; treatments and events of special interest (including bleeding and thrombosis).

Data is captured on REDCap database through an eCRF.

RESULTS: PLATELET COUNTS AND BLEEDING

The median platelet count up to two weeks before starting TPO-RA was 25 x10⁹/L and rose to 94 x10⁹/L by 4 weeks, 97 x10⁹/L by 4 months, 100 x10⁹/L by 7 months and 121 x10⁹/L between 12-24 months after treatment. There was no significant difference between eltrombopag and romiplostim (fig 1). The overall response rate was 88% by 3-4 months, 88% by 6-7 months and 93% by 2 years (table 2)

Figure 1: Platelet counts after TPO-RA treatment

Table 2: Responses after TPO-RA treatment

| Time since starting TPO-RA | Partial response | Complete response | Overall response |
|----------------------------|------------------|-------------------|------------------|
| 3-4 months | 39.65% | 48.34% | 88.19% |
| 6-7 months | 37.87% | 49.79% | 87.66% |
| 12-24 months | 31.91% | 60.97% | 92.88% |

AIM

Aim: assess outcomes after TPO-RA treatment in patients with primary ITP over the age of 60.

RESULTS: BLEEDING

In this age group, 59% patients had a skin bleed before TPO-RA, 40% had mucosal bleeding, 26.5% had organ bleeding and 10.7% had other bleeds. Use of TPO-RA was associated with a reduction in bleeds for all bleed types.

METHOD

All patients >60 years old entered into the primary ITP registry between January 2007 and December 2022 who had received TPO-RA therapy were included.

Data was analysed using R analytics for epidemiology, response based on platelet count and bleeding, significant events and co-morbidities.

Response definitions using standard international criteria² were used:

- Partial response (PR) platelet count 30-100x10⁹/L and twice the baseline platelet count.
- Complete response (CR) platelet count >100x10⁹/L.
- Overall response (OR) : PR+CR.

RESULTS: THROMBOSIS

66% patients had at least one risk factor for thrombosis and 38% patients had 2 or more factors. (table 3). The most common factors are shown in figure 3. Of all patients treated with TPO-RA, 77 patients had an arterial event and 41 a venous event. The majority of events were before TPO-RA therapy. Only 3% of patients had an arterial event and 3% a venous event after TPO-RA treatment.

Figure 3: Most frequent risk factors for thrombosis

Table 3: Number of risk factors for thrombosis

| Number of risk factors | % of Patients |
|------------------------|---------------|
| 0 | 34% |
| 1 | 28% |
| 2 | 19% |
| 3 | 12% |
| 4 | 5% |
| 5 | 2% |

RESULTS: DEMOGRAPHICS AND TREATMENTS

569 patients (296 Male and 273 female) were included in the analysis; 307 patients (54%) had received Eltrombopag group and 262 (46%) had received Romiplostim.

The median age at first TPO-RA therapy was 73.1 (67.4-79.3) (Table 1) and median time to first TPO-RA was 1.74 years, with a median of 3 lines of treatment prior to TPO-RA.

There was an overall increase in median platelet count from baseline to 3-4 months after treatment which was maintained at 1-2 years.

Table 1: Demographics and treatments

| | Overall (n=569) | Eltrombopag (n=307) | Romiplostim (n=262) |
|--|--------------------|---------------------|---------------------|
| Male/ Female (n) | 296/273 | 153/154 | 143/119 |
| Median age (y) at first TPO-RA (IQR) | 73.1 (67.4 - 79.3) | 72.9 (67.5-79.5) | 73.1 (67.1-77.9) |
| Median time (y) from diagnosis to first TPO-RA (IQR) | 1.7 (0.3-7.2) | 1.6 (0.2-6.5) | 1.9 (0.4-7.7) |
| Median treatment lines before TPO-RA (IQR) | 3 (2-4) | 3 (2-4) | 3 (2-4) |
| Splenectomy prior to TPO-RA (n) | 42 | 13 | 29 |

Concomitant Treatments at first TPO-RA

| | n (%) | n (%) | n (%) |
|--------------------|-------------|-----------|------------|
| Prednisolone | 129 (22.67) | 74 (24.1) | 55 (20.99) |
| Dexamethasone | 17 (2.98) | 11 (3.58) | 6 (2.29) |
| Methylprednisolone | 13 (2.28) | 7 (2.28) | 6 (2.29) |
| IgG | 60 (10.54) | 27 (8.79) | 33 (12.59) |
| Rituximab | 23 (4.04) | 13 (4.23) | 10 (3.81) |
| MMF | 42 (7.38) | 25 (8.14) | 17 (6.48) |
| Azathioprine | 16 (2.81) | 7 (2.28) | 9 (3.43) |
| Other Treatments | 18 (3.16) | 8 (2.6) | 10 (3.81) |

REFERENCES

1. Provan et al Blood Adv (2019) 3 (2): 3780-3817
 2. Rodeghiero Blood 2009 Mar 12; 113(11):2386-93

CONCLUSION

This data shows comparable response rates to TPO-RA in patients >60y compared to <60y from the literature based on platelet count response. This is associated with a reduction of bleeding events after treatment in this group of patients, although some bleeding persists. Despite the presence of risk factors for thrombosis, there does not appear to be an increase in reported thrombotic events after therapy in this group.

ACKNOWLEDGEMENTS

We thank all the PIs, their teams and the patients who contribute to the UK ITP registry. Please see our website for full list of PIs: <https://www.qmul.ac.uk/itp/>. In addition, we would like to thank the ITP support association, Gilead and Novartis for providing funding support for the ITP registry.

Your voice matters: navigating immune thrombocytopenia (ITP) healthcare decisions through Shared Decision-Making

A webinar for people living with ITP and their caregivers

Engaging talks led by ITP experts exploring Shared Decision Making best practice in ITP care, including personal tips and experiences.

We are pleased to invite you to the upcoming ITP Shared Decision-Making webinar on **Tuesday 26th September, 16:30 - 17:30 BST**

| Topic | Presenter |
|---|---|
| Welcome and introductions | Mervyn Morgan , Chief Executive Officer, ITP Support Association & Caroline Kruse , President and Chief Executive Officer, The Platelet Disorder Support Association (PDSA) |
| Introduction to Shared Decision-Making | Dr Cindy Neunert , Paediatric Haematologist-Oncologist, New York-Presbyterian Hospital-Columbia and Cornell |
| A HCP perspective of Shared Decision-Making | Dr Nichola Cooper , Consultant Haematologist and Senior Lecturer, Imperial College London |
| A patient perspective of Shared Decision-Making | Barbara Lovrencic , President, Italian Association Immune Thrombocytopenic Purpura (AIPIT) & Danielle Boyle , Chief Executive Officer, ITP Australia |
| Q&A session | Mervyn Morgan , Chief Executive Officer, ITP Support Association, Caroline Kruse , President and Chief Executive Officer, The PDSA & Dr Nichola Cooper , Consultant Haematologist and Senior Lecturer, Imperial College London |
| Summary and close | Mervyn Morgan , Chief Executive Officer, ITP Support Association & Caroline Kruse , President and Chief Executive Officer, PDSA |



Please visit: bit.ly/3PsqVol to access the webinar through Zoom.



This webinar has been co-created by the UK ITP Support Association, the Platelet Disorder Support Association and Sobi and supported by Sobi.
Date of preparation: August 2023 | NP-29089



Webinar Speakers



Mervyn Morgan
Chief Executive Officer,
ITP Support Association

Mervyn Morgan has worked for the ITP support association since August 2016 and became CEO in 2017, reporting to the charity's Chair of Trustees. As part of the ITP Support Association, Mervyn collaborates with medical professionals to advance the knowledge and treatment of ITP. This is achieved by funding research and salaries to pilot new ITP projects, running surveys, and providing feedback on patient concerns to specialists and drug companies. He is also involved in medical seminars for haematologists, paediatricians, and other healthcare professionals.



Danielle Boyle
Chief Executive Officer, ITP Australia

Danielle was diagnosed with ITP in 2015. Through her ongoing journey, she identified an unmet need for Australian-based information and launched ITP Australia at the PDSA Regional Meeting in 2018 in Melbourne, Victoria. As CEO, she regularly advocates with regulatory bodies and key stakeholders to improve treatment access and protocols, provides support, and is the leading source for Australian ITP information for carers and ITP patients.



Caroline Kruse
President and Chief Executive Officer,
PDSA

Caroline Kruse is the CEO of the PDSA. As part of her role, she has developed new relationships for the PDSA with key disease stakeholders and government agencies while strengthening existing relationships with partners and supporters. Her focus is to place a greater emphasis on advocacy, expanding programmes for children, teens, and families affected by the disease, increasing education initiatives, and advancing research to improve the quality of life for those living with ITP, and other platelet disorders.



Barbara Lovrencic
President, AIPIT

Barbara is the President of AIPIT, a charity for adults and the parents of children with ITP. AIPIT supports patients by providing information and resources on its website, alongside running a closed Facebook group with the aim of creating a community where ITP journeys can be shared. AIPIT has also played an active role in writing the National Plan for rare disease.



Dr Nichola Cooper
Consultant Haematologist and Senior Lecturer, Imperial College London,
Medical Advisor for the ITPSA and PDSA

Dr Nichola Cooper runs a research programme investigating the causes of haematological autoimmunity at Imperial College, with an emphasis on ITP. She is a consultant haematologist, who was trained at Cambridge University, Barts, and the London School of Medicine and Dentistry. She completed her haematology training at University College Hospital and gained research experience at Cornell Medical College, New York, and the Institute of Child Health, University College London. Her team's work has been published in international, peer-reviewed journals, including Nature Immunology, Blood, and the British Journal of Haematology.



Dr Cindy Neunert
Paediatric Hematologist-Oncologist, New York-Presbyterian Hospital-Columbia and Cornell, Medical Advisor for the ITPSA

Dr. Cindy E. Neunert is a paediatric haematologist-oncologist in New York, and is affiliated with multiple hospitals in the area, including the New York-Presbyterian Hospital-Columbia, in addition to Cornell and NYC Health and Hospitals-Coney Island. She received her medical degree from Eastern Virginia Medical School and has been in practice for more than 20 years.



This webinar has been co-created by the UK ITP Support Association, the Platelet Disorder Support Association and Sobi and supported by Sobi.
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Publications List

BOOKLETS

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

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

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

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

Know about ITP – core information booklet.

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

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

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

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

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

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

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

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

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

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

Choosing your sport – which sports are safe with ITP?

James/Jessica tells his/her story – a book about ITP

for newly diagnosed children.

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

FACTSHEETS

Treatment table – a list of drugs used to treat ITP and their possible side effects.

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.

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

ALERT CARDS

ITP Emergency card £5.00 – personalised with your essential details for emergency use. Credit card size, laminated in plastic. Request an order form from headquarters.

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

ARTICLES PUBLISHED IN PREVIOUS ISSUES OF THE PLATELET

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

Publications List cont...

21. New insights on what causes ITP
22. Neonatal – thrombocytopenia
23. Post Transfusion Purpura
24. Must I mention my ITP at a job interview?
25. – e versatility of platelets
26. How is ITP diagnosed?
27. ITP – in dogs!
28. Complications of ITP
29. Flying & ITP
30. Who needs Vitamin D supplements
31. Why don't we see an immunologist
32. What does the ITP Support Association do?
33. Sustained responses with TPO drugs
34. Is splenectomy still a valid treatment today?
35. Where are we with ITP today?
36. Are young platelets better?

AMERICAN PERSPECTIVES

1. A history of ITP
2. ITP in pregnancy
3. What is a platelet?
4. How is ITP diagnosed?
5. Non-intervention in childhood ITP
6. Activity restrictions in ITP children
7. How many platelets are enough?
8. Splenectomy and ITP
9. Can I die from ITP
10. – The child newly diagnosed with ITP
11. Surgery in the patient with ITP
12. Are alternative & herbal remedies safe?
13. Use of steroids – a boon and a bane
14. Immunoglobulin – good and bad news
15. Intravenous Anti-D – another treatment
16. Chronic ITP – disease or risk factor?
17. Platelet counts – how useful are they?
18. ITP, sports, and sports injuries
19. After failure of splenectomy & steroids
20. ITP in the elderly
21. Rituximab for ITP
22. ITP and tiredness
23. Viruses and childhood ITP
24. Increasing platelet production
25. What happens to adults with ITP
26. ITP and 'cure'
27. What is a clinical trial?
28. – The relationship between ITP and lupus
29. ITP in adolescents
30. – The development of new ITP drugs
31. Menstrual periods in women with ITP
32. Coping with prednisolone – book review
33. Assessment of bleeding severity in ITP
34. Steroid side effects
35. Splenectomy for children with ITP?
36. What happens after a child recovers?
37. Prevention of infections in asplenic

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

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

MEMBERSHIP SUBSCRIPTION FORM:

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

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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

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- Family member of someone with ITP Friend or other Health Professional

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