



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



**ITP Support Association
Annual Patient Convention 2023**
in-person event

**TICKETS
AVAILABLE**

The
Platelet

MARCH 2023

JOURNAL OF THE ITP SUPPORT ASSOCIATION

The ITP Support Association Team

Charity Registration No. 1064480

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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

We are pleased to announce that Sobi (Swedish Orphan Biovitrum) have agreed to be the 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 that support will continue for Awareness Week 2023.



We are in the final stages of planning the details of our Annual Patient Convention 2023 at the Royal College of Pathologists in London.

Events such as this cannot take place without the support of our event sponsors (Sobi, Argenx, Amgen and Sanofi, hopefully more will be added soon), a huge thank you to all our sponsors and supporters for your help.

We can also give you a glimpse of some of the speakers and their talks with this preview of the event agenda, talks and speakers include:

How do I handle the patient with ITP – Dr Drew Provan
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We will also have some breakout session during the afternoon plus a Q and A session where you can ask the experts.

Tea / Coffee and Lunch will also be provided plus there will also be an exhibition area for our sponsors.

The Convention will be taking place on Saturday 13th May from 9:30 to 17:00hrs at the Royal College of Pathologists in London (6 Alie Street, London).

Ticket prices are Members (Current members for this year) £25 and £35 for non-members.

To book go to our website at www.itpsupport.org.uk and click on the ITP Convention 2023 – Tickets link in the menu, this will take you to our Eventbrite booking page.

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.



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

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

These are perfect for Children who need to have injections. We will make our small supply available on a first come first serve basis for a small donation. You can read more about Buzzy® in this edition of The Platelet.

Mervyn Morgan CEO ITPSA

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American Perspective

Communicating about the impact of ITP on everyday quality of life – Rachael Grace, MD, MMSc

When I meet with patients and families affected by ITP, my most important questions are focused on how ITP impacts their everyday life. For newly diagnosed patients, I want to know about activities they participated in previously that they are currently avoiding and how much they worry about their low platelet count and risk of bleeding. I ask patients about how this impacts their daily routine and well-being. For patients who are on a medication treatment, I also want to know if their current treatment approach is improving their daily well-being and low platelet symptoms and, also, how their daily quality of life is being affected by how the treatment is given, tolerated, and monitored as well as its financial impact. I find that the answers to these questions are key in understanding how best to support the patient and their family and in guiding decision-making about treatment.

Although reviewing bleeding symptoms is critical at all hematology appointments, discussing the other impacts of ITP and its treatment on everyday life should not be underestimated. This includes discussions about activity restrictions, work or school related impacts, fatigue, worry, among other effects. Guidelines for the management of ITP in children direct clinicians to treat ITP based on both bleeding symptoms and the impact of ITP on health-related quality of life. Using impairment of quality of life to guide the ITP treatment approach in children is particularly important, as close observation without a medication is a common treatment approach in the absence of bleeding symptoms. Even in the absence of bleeding, observation may not be the best treatment for an individual child or adolescent depending on the impact of ITP on their daily life. In adults with ITP, the platelet count and bleeding symptoms are often the focus of the decision for treatment, but consensus guidelines also recommend consideration of quality of life and fatigue in management decisions.

In research trials, to learn about the effect of ITP and its treatment on daily quality of life, we ask patients to complete standard questionnaires that have been shown to be accurate in measuring quality of life in individuals with ITP. For children, the questionnaires



are aimed at the quality of life of the child and vary by age. Questionnaires are also completed by parents/guardians, both in terms of the impact of ITP on their child and on their own everyday well-being. The questionnaire most often used in children is called the Kids ITP Tool (KIT). In this tool, examples of questions children are asked include: how often they feel anxious or tired, how often they are bothered that they could not do things with their friends or activities that they like, or how bothered they are by their medication or having their blood taken. Other ways of evaluating the impact of ITP in children include surveys measuring fatigue. These questionnaires have shown that fatigue in children with ITP is common, similar to fatigue in adults with ITP, and may improve with ITP-directed treatments.

In research studies of adults with ITP, questionnaires are also used to evaluate the impact of ITP on everyday quality of life, including the ITP-Patient Assessment Questionnaire (ITP-PAQ). This questionnaire asks about bother from the effects of ITP and its treatment on physical health, work, social activities and exercise as well as the impact on psychological health, fatigue, and bleeding symptoms. One of the largest research studies of the impact of ITP on everyday quality of life was the ITP World Impact Survey (I-WISH) which included over 1500 adults with ITP and almost 500 physicians from across the globe. A comprehensive questionnaire

about quality of life was developed specifically for this survey study. The findings from the I-WISH study describe the extensive impact ITP has on an individual's energy and capacity to exercise as well as the limitations it causes on daily tasks. In this adult population, nearly half were considering or had already reduced their working hours and reported that ITP significantly reduced their work productivity. The physicians who also completed the survey were experienced in the treatment of ITP and reported an awareness that ITP significantly reduced patient everyday quality of life. Improving quality of life was ranked by these physicians as the second most important goal of treatment, right after reducing spontaneous bleeding symptoms. This report has helped to raise awareness more broadly in the hematology community about the importance of asking patients about the impact of ITP on their well-being beyond bleeding symptoms and platelet counts.

Currently, outside of research studies, in most hematology practices, standard questionnaires are not used for evaluating the impact of ITP and its treatment on everyday life. Clinicians who are less familiar with ITP may be unaware of the broad impact of ITP on an individual and maintain focus on bleeding and the platelet count during medical visits. As work is conducted to continue to raise awareness among clinicians, you should feel empowered to tell your physician how ITP and its treatment impacts your everyday life and find out what support is available to you and how individual treatments can be initiated or modified to help improve your quality of life. We all have the tendency to say we are "fine" or "well" when asked how we are, but you should use your appointments to talk about how your everyday life has changed since being diagnosed with ITP. You should use each visit as an opportunity to report the impact of ITP to your clinician. The UK Support Toolkit for ITP Shared Decision Making (<https://itpsupport.org.uk/index.php/en/home/shared-decision-making>), which emphasizes the impact ITP can have on daily quality of life, can help you and your clinician decide how to integrate your report of the impact of ITP into your management approach and treatment plan.

Cindy Neunert MD, Adam Cuker MD, Rachel Grace MD and Prof Spiro Cataland March 2022

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.



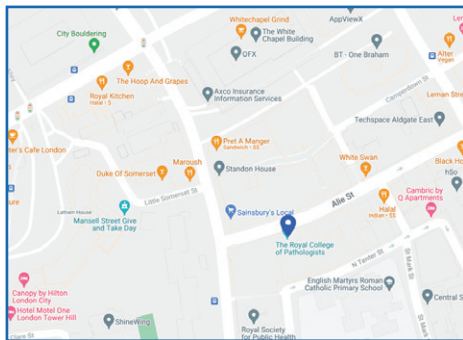
ITP Patient Convention 2023

ITP Patient Convention 2023 – Book your Tickets Now



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To book go to our website at www.itpsupport.org.uk and click on the ITP Convention 2023 – Tickets link in the menu, this will take you to our Eventbrite booking page.

You can also order by post, send your details along with your payment to our office (address on the back page), we will then send you your tickets in the post.

Just a few of the ITP experts who will be attending our 2023 Patient Convention.



Dr. David Kuter is Director of Clinical Haematology at Massachusetts General Hospital and Professor of Medicine at Harvard Medical School.



Dr Nichola Cooper trained at Cambridge University and Barts and the London School of Medicine and Dentistry. She completed her haematology training at University College Hospital and subsequently gained research experience at Cornell Medical College, New York and the Institute of Child Health, University College London.



Dr Drew Provan is currently Emeritus Reader in Autoimmune Haematology at Barts and The London School of Medicine and Dentistry. Dr Provan, along with international colleagues published the consensus guidelines for the diagnosis and management of ITP in children and adults published in Blood.



Dr Sue Pavord is a Consultant Haematologist at Oxford University Hospitals and Associate Senior Lecturer in Medicine at St Edmund Hall. Her specialist areas of interest are anaemia and iron management, immune haematology, inherited and acquired bleeding disorders, thrombosis and anticoagulation, thrombosis prevention and obstetric haematology.



Prof Adrian Newland is Professor of Haematology at Barts Health National Health Service (NHS) Trust, London, UK. He has a research department within the Medical School, where he is a former Head of the Division of Haematology. Prof Newland is also the Chair of Trustees of the ITP Support Association.



Dr Vickie McDonald is a consultant haematologist with a specialist interest in coagulation and platelet disorders at the Royal London Hospital. Dr McDonald also leads the Adult ITP Registry.



Dr Quentin Hill is a Consultant Haematologist at Leeds Teaching Hospitals and an Honorary Clinical Associate Professor at the University of Leeds. His areas of specialist interest include red cell disorders and immune haematology. Dr Hill is also the Chair of the UK ITP Forum and a board member of the ITP Support Association.

Virtual Patient Group Meetings – Announcement

ITP SUPPORT ALL AROUND THE GLOBE

THANK YOU TO ALL OF OUR ZOOM MEETING & WEBINAR SPONSORS FOR HELPING US REACH & SUPPORT A GLOBAL AUDIENCE.

AMGEN argenx GRIFOLS PRINCIPIA UCB Omph

Virtual Patient Group Meetings – Announcement

The ITPSA's Mervyn Morgan, who hosts and facilitates our ITP Patient Virtual Meetings has recently undergone surgery and will be out of action for a number of weeks. Therefore, we have decided to delay scheduling the next round of Virtual Meetings until Mervyn is back.

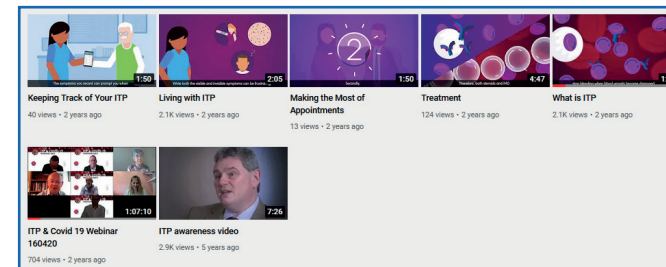
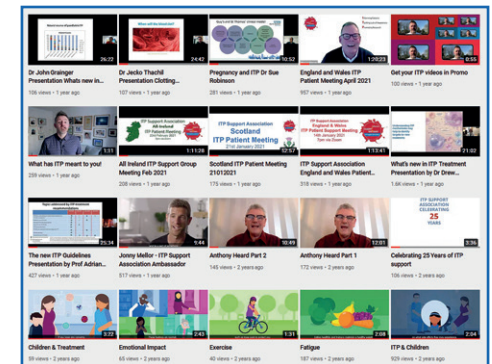
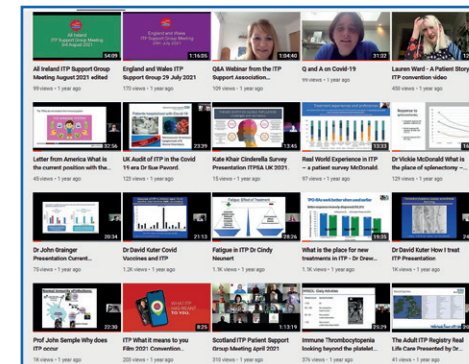
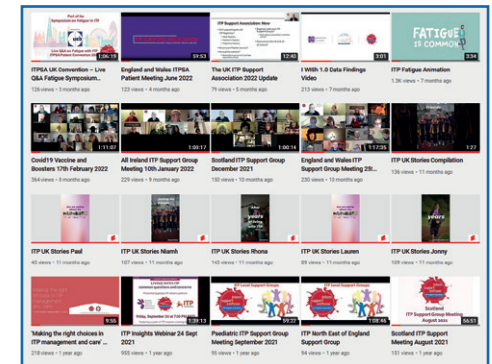
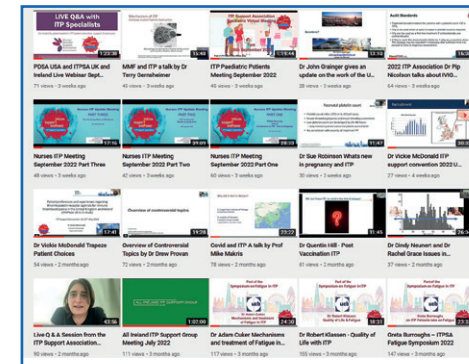
If you have an urgent question that you would like us to put to one of our medical advisors, please email info@itpsupport.org.uk.

Don't forget you can also speak with one of our patient mentors, again, just email info@itpsupport.org.uk and we will get one of them to contact you.

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/UCRkHWFVYAAIKKAbjFI4L37g/> 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.



ITP on the GOGGLEBOX - By Andrew Heard

ITP on the GOGGLEBOX

When we decided to set ourselves up on You Tube, we had a vague idea that it would be something that would prove helpful, informative and popular. Our hunch was correct.

This update is our way of saying a BIG THANK YOU to the many people who have watched our many videos and films on You Tube.

The official figures for our channel from You Tube for the period January 1st 2022 to December 1st 2022 are quite staggering -

- Views of content - 13000
- Watch time in minutes - 61700
- Likes - 265
- New Subscribers - 164
- Top viewing countries - USA- UK- India

- All time likes - 889
- All time shares - 1761
- All time Subscribers - 440
- All time views - 31184

Most active month 2022 - January
 Most popular topics 2022 - Fatigue and ITP, What is ITP?, Living with ITP

So why does all this matter ?

1. It is vital that we use every platform possible to spread awareness for our enigmatic condition
2. Education, information and help provided through as many channels as possible means that we hopefully reach as many people as we can where THEY wish to view interact with us and each other
3. The bigger the numbers of people we have interacting with our various channels enables us to present a much more attractive proposition to researchers, businesses and sponsors who may wish to engage with us.

So if you haven't seen our You Tube Channel Yet - please do check it out at the link below -

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

We have over 90 videos/films on all things ITP.

It would be greatly appreciated if when you are visiting the channel or viewing an item that you SUBSCRIBE to the channel and LIKE the item that you have viewed. The higher the numbers the better (as explained in item 3 above).

So once again THANK YOU for your support through 2022 and we look forward to even better things in 2023.

PATIENT MENTORS

Rhonda Anderson

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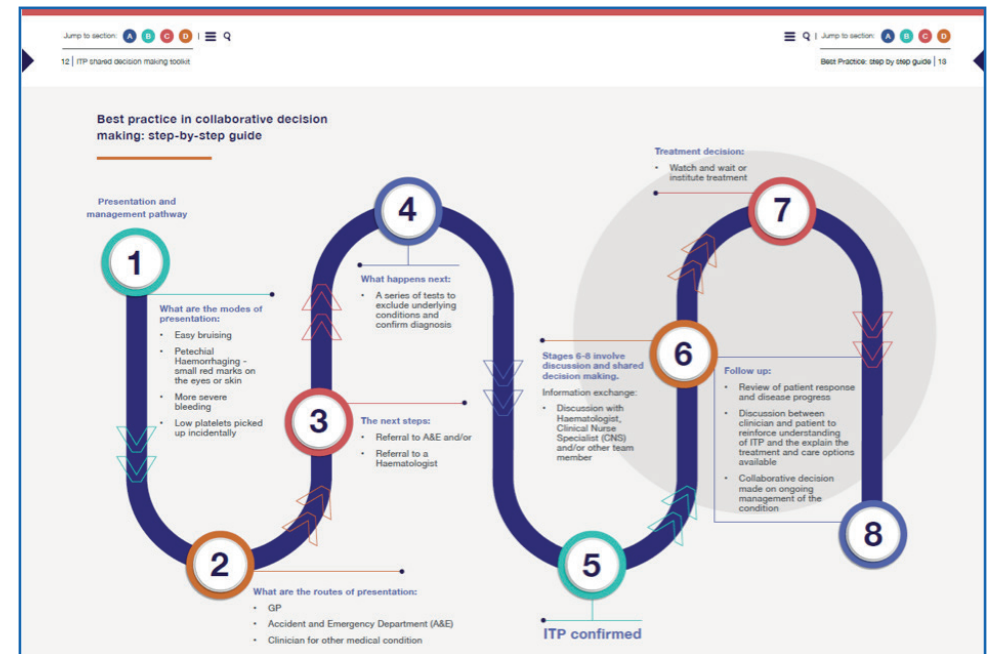
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Shared Decision Making Document available in Six Languages



'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

Healthcare Professionals Explainer

The ITP Discussion Guide

A background explainer for
healthcare professionals



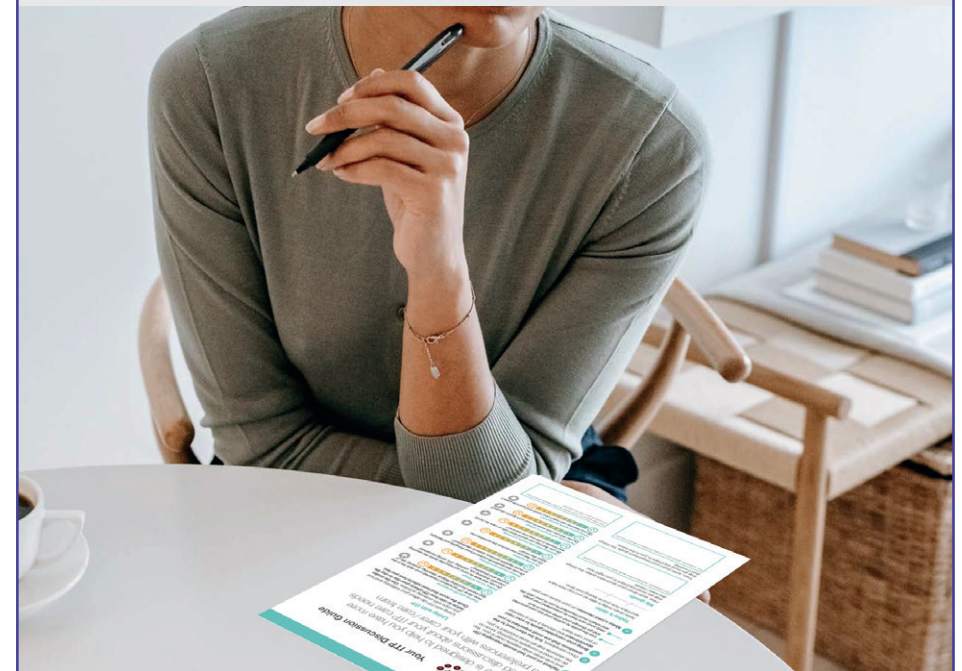
NP-23509 | Date of preparation: September 2022

Healthcare Professionals Explainer Cont...

What is the ITP Discussion Guide?

The ITP Discussion Guide is a simple and patient friendly tool that supports people living with ITP to reflect on and prioritise their ITP care goals, needs and preferences.

- Patients write down their goals and rate aspects of living with ITP, as well as their ITP management over the last month
- They then highlight their top priorities and goals based on their answers, to discuss at their next ITP consultation



NP-23509 | Date of preparation: September 2022

Healthcare Professionals Explainer Cont...

How can my patients use the tool?

Patients can use the ITP Discussion Guide either:

- Independently, before the appointment
- In a waiting room, either independently or with support from a healthcare professional

How can the ITP Discussion Guide support my consultations?

It promotes shared decision-making during consultations:

- 1 The guide helps patients to prepare for their appointment and articulate their needs, preferences, and goals more clearly to you
- 2 It sheds light on what is important for your patients
- 3 It shows how they are coping with existing treatments and if any changes to their care plan could improve their overall quality of life
- 4 It enables you and your patient to reach a joint decision about their individualised care plan, with their needs, preferences, and goals in mind

Scan the QR code to access ITP Discussion Guide

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



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.
- 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.

ITP Discussion Guide Cont...

Managing ITP effectively

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

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

☹️ 1 2 3 4 5 😊 ★

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

☹️ 1 2 3 4 5 😊 ★

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

☹️ 1 2 3 4 5 😊 ★

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

☹️ 1 2 3 4 5 😊 ★

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

☹️ 1 2 3 4 5 😊 ★

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

☹️ 1 2 3 4 5 😊 ★

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

☹️ 1 2 3 4 5 😊 ★

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

☹️ 1 2 3 4 5 😊 ★

Notes:

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

ITP treatment and your goals

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

YES NO

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

Priority discussion points for your next consultation

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

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

And finally...

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

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

SIXTEEN YEARS RARE AND STILL IN THE PURPLE

By Anthony Heard

After 16 years of living with the rare auto immune condition ITP (Immune Thrombocytopenia) I can reflect upon many incidents during that time. It has certainly been eventful, to say the least. I have jumped more fences than Red Rum and dived through more hoops than a circus performer.

It started in 2005 when I began getting random purple bruises on my arms, legs and torso. These bruises would appear without warning and often overnight I would develop them mysteriously. Some were the size of a coin and others as big as the lid of a jam jar.

I was also suffering from acute fatigue. It was beyond exhaustion. The combination of random bruises and chronic tiredness, eventually led me to report to my doctor for a check up in July 2006.

Following that meeting, a fretful dash to my local accident and emergency unit and many blood tests, it was discovered that my platelet count was a measly 4000. It took about 7 hours to diagnose my ITP, an illness that only about 5000 people suffer from in the UK at any one time.

Since then I have been on something of an ITP roller coaster, having many different treatments and suffering many wretched side effects whilst having some successes and a few failures. It hasn't been a picnic by any means. I have been through the Prednisolone ringer six times, Rituximab twice and a horrible week or so with Azathioprine (I could not tolerate it all).

I was fortunate to respond well to Prednisolone and Rituximab. With the steroid, I obtained

about 6 months remission every time that I went on it and with Rituximab, I got about 2 years 8 months remission both times that I had it, in 2010 and 2013. But in February 2016, I relapsed again.

At that point my specialist suggested that we try Mycophenolate Mofetil (MMF). He was reluctant for me to undergo a third round of Rituximab as the long-term damage it might do to my immune system was not worth risking. More stints with Prednisolone were also ruled out because of the problems that it caused when I had used it before.

MMF like Prednisolone, Rituximab and Azathioprine is an immune suppressing drug which raises the platelet count by slowing the destruction of platelets. It has the added benefit in most cases, of fewer nasty side effects.

Since February 2016 on MMF my platelets have settled at normal levels with the odd blip. I could not be more delighted.

Some ITP sufferers have had equally positive responses from MMF but as ever like with all treatments, responses vary. One important thing about MMF, is that like all immune suppressing drugs it reduces our ability to fight off infections, viruses like Covid-19, bugs, colds, flu's etc. So, we are more vulnerable. It's complicated.

Like any treatment, it is a matter of measuring risk versus reward. We have to weigh up the side effects, potential problems (short and long term) against keeping our platelet levels as high as possible at consistent levels.

I always remain positive about my debilitating condition but there is never any room for

complacency and I take nothing for granted.

In terms of the overall co-ordination of my care, I am sure that my experiences will be echoed across the rare disease community. As ITP is just so rare I have found myself spending so much of my time explaining my condition to so many people, including healthcare professionals, GP's, nurses, dentists and other practitioners. ITP is just not really known or understood by anyone who is not a specialist haematologist so it makes for a really frustrating and tiresome ordeal talking about it with anyone else.

So, it is incumbent on all of us who are able, to

tell our stories to spread awareness for our rare illness. Information and education is so important.

This is what drives me to take part every year in the Rare Disease Day campaign and to do voluntary work for the ITP Support Association where I set up and continue updating all of their social media platforms. I am now on the Board of Trustees as a Patient Observer and also contribute a quarterly article to their Platelet magazine

For those who wish to follow my ITP story, please check out my ITP blog at

<https://anthonypaulh.tumblr.com>

Fundraisers & 'In Memory' Donations

Fundraisers

The association was very grateful to be nominated for a charity donation in lieu of Christmas cards by the London Metal Exchange and received £800.00. Thanks to Sandy Elliott for the nomination.

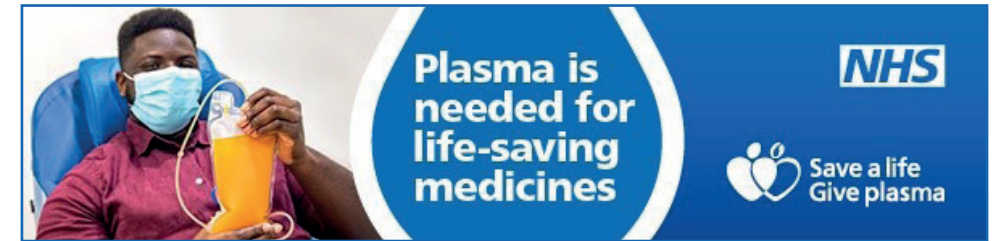
Siobhan Thornbury donated £50.00 in lieu of Christmas cards as a member of her family has ITP.

Freya Hepburn, a papercut artist, decided to donate proceeds from the sale of her own Christmas cards, 10 packs with £2 each going to The ITP Support Association. This charity was chosen because her beloved springer spaniel died of ITP. £20.00 was donated.

We would also like to thank the Warwickshire Freemasons for their generous donation, more details will follow in the June edition of the Platelet.

There are a number of wonderful people raising funds for the ITP Support Association on our JustGiving page at <https://www.justgiving.com/itpsupportassociation> Please click on the link and look for yourself.

Plasma Donation



If you received treatment with immunoglobulin, and you live in England, NHS Blood and Transplant's communication team would love to hear from you. They're seeking people who can share their personal story to help inspire members of the public to donate plasma for manufacturing into immunoglobulin. If you'd like to know more, please email stephen.bailey@nhsbt.nhs.uk



Buzzy

Information on the Buzzy® Kits for Paediatric ITP Patients.

WHAT IS BUZZY?

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

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

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



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

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

HOW DOES BUZZY WORK?

Gate Control Theory of Pain

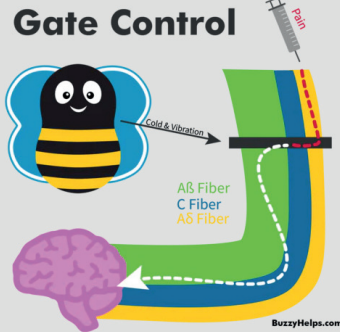
The gate control theory is the basis for the design of Buzzy®. The premise is that when nerves receive non-painful signals such as vibration or cold, the brain closes the gate on pain signals. For example, if you hit your finger with a hammer, you might instinctively begin to rub it, shake it, or run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

Descending Inhibitory Controls

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

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

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



ITPSupport.org.uk

Buzzy Cont...

Helping to take the sting out of ITP.



HOW TO USE BUZZY?

Step 1 - Freeze the Ice Wings

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

Step 2 - Attach Wings to Buzzy

Slide the ice wings through the elastic strap on the back of Buzzy.

Step 3 - Place Buzzy

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

Step 4 - Turn Buzzy On

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



WHEN CAN BUZZY BE USED?

Buzzy can help in a range of areas.

Some of these can include:

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

ABOUT THE ITP SUPPORT ASSOCIATION

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

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

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



Buzzy Cont...



ITP Buzzy Kits

Request Form

ITP Warrior Name: _____

ITP Warrior's DOB: _____

ITP Warrior's Address: _____

Parent's Name: _____

Your Name: *(if different from above)* _____

Your Address: *(if different from from above)* _____

When was your ITP Warrior diagnosed ITP? _____

Tell us about your ITP Warrior's ITP Journey

How will a Buzzy help your ITP Warrior?

What's next?

In addition to the completed Request Form, please send us a letter which includes the contact details of your healthcare professional, the child's diagnosis and date of diagnosis.

Please forward the completed form and letter to info@itpsupport.org.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.

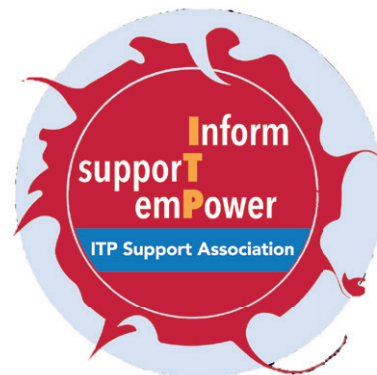
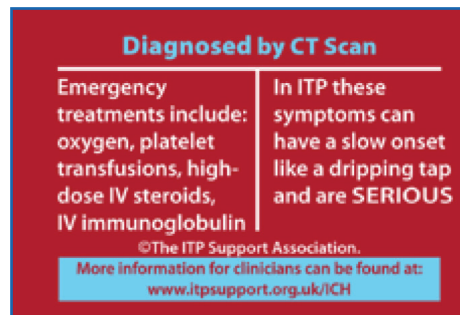
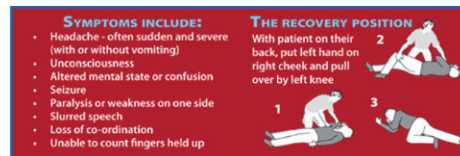
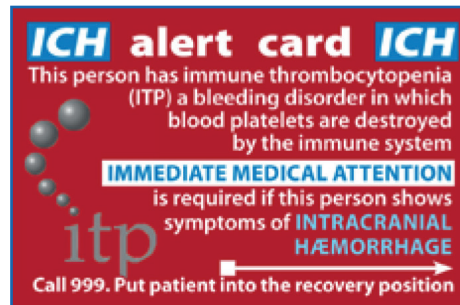
Order a free ICH alert card

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

ITP Support Association switches to JustGiving.com

ITP Support Association switches to [JustGiving.com](https://www.justgiving.com) as its default fundraising/donation partner following the announcement by Virgin Money Giving that they would be closing their site from the 30th November and will no longer be accepting donations.



Mervyn Morgan, CEO of the ITP Support Association said we joined Virgin Money Giving in early 2020 thinking like many Charities that the Virgin brand would provide a stable and long-term solution for the Charities fundraising and donation requirements. Sadly, with the news of its closing this was not the case, however we are pleased to become part of the JustGiving family and look forward to a long and fruitful future on their platform.

Please visit our page at <https://www.justgiving.com/itpsupportassociation> and make a donation.

Facebook



Towards the end of 2018 many friends of the ITP Support Association have used Facebook as a platform to help raise donations for the Association. This has raised almost £14,000 in support of the ITP Support Association is less than nine months. Facebook has 'no fees' which means 100% of the contributions are donated to the ITP Support Association.

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 and Amazon Smile a 0.5 percentage of whatever you spend comes directly to ITP at no extra cost to you.

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 53 supporters who have raised almost £600 for us so far!

Go to <https://smile.amazon.co.uk/> and enter ITP in the search box to sign up to supporting our charity whenever you shop on Amazon.

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

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

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

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

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

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

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

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

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

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

Please return this form with your cheque or standing order form to:-
The ITP Support Association, The Platelet Mission, Kimbolton Road, Bolnhurst, Beds MK44 2EL

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

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

