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

The
Platelet

DECEMBER 2022

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

Welcome to the December edition of the Platelet Journal, where has 2022 gone, more to the point due to the cycle of lockdowns recent years appear to have become truncated or merged into one.

In this edition of the Platelet, I will be talking about the exciting news concerning our first 'in-person' Patient Convention since before Covid, but more about that later.



Since our last edition there has been so much going on, we had ITP Awareness Week, thanks must go to Sobi Pharma for supporting our ITP Awareness Week Activities, this year we kicked off with a virtual Nurses ITP update meeting, a special thank you must go to ITPSA Medical Advisor Nurse Consultant

Louise Taylor for supporting the event and also thanks to the tremendous turnout from everyone who took part.

During ITP Awareness Week we also launched the ITP Discussion Guide, which was a collaborative venture with Sobi Pharma, details of the discussion guide can be found in this edition of the Platelet, it can also be downloaded from our website, however if you would like a hard copy, please email us your postal details and we will send you a copy in the post (free to members).



ITPSA Medical Advisor Dr John Grainger was also on hand during Awareness Week to lead our Virtual Paediatric Meeting, this meeting was an opportunity for parents of children with ITP to ask questions and get advice about the condition.

On the Friday of ITP Awareness Week, I took part in a Q and A session with around 185 attendees from Sobi Pharma to talk about the work of the ITP Support Association.

We rounded off ITP Awareness Week with a joint webinar with our friends and colleagues from the Platelet Disorder Support Association (PDSA) in the USA. Remember all of the videos from ITP Awareness Week are available to view on our YouTube channel.

This edition of the Platelet also includes a further update from our latest Patient Perception Survey, if you have not already done so, please take the time to complete, all of your inputs goes towards helping us map out our plans for the future benefit of ITP Patients, remember the last survey resulted in the publication of our Shared Decision Making Booklet called 'Making the right choices in

ITP Management and Care', this document has seen 1200 hard copies posted out and over 6,000 digital downloads since its publication 12 months ago.

I must also give a huge thank you to our Board, Medical Advisors and in particular Liz in the office for all of their work behind the scenes.

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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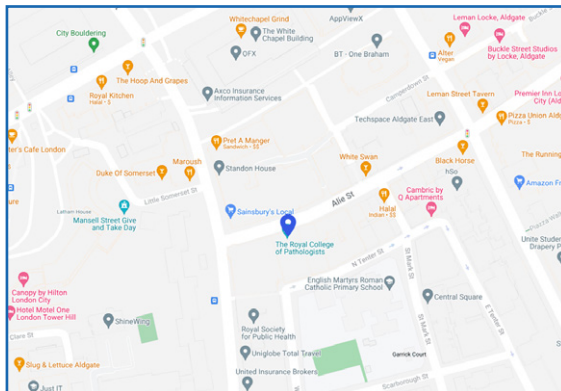
ITP Patient Convention 2023

ITP Patient Convention 2023 – Book your Tickets Now



We have started advertising the draft details of our first 'in-person' ITP Patient Convention Post-Covid. For those who purchased tickets for our cancelled event in 2020 you would have received an email with details of your new tickets for the 2023 event.

With almost 50% of the tickets carryovers from 2020 it would be a good idea to book your ticket now to be sure of a place.



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.

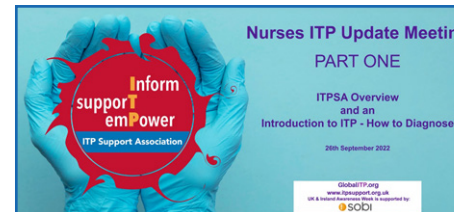
You can also order by post, send your details along with your payment to our office (address on the back page), we will then send you your tickets in the post.

ITP Awareness Week

A look back at ITP Awareness Week 2022



As we mentioned in our intro ITP Awareness Week (Supported by Sobi) during September was extremely busy. We started the week with a virtual Nurses ITP update meeting, this was organised by the ITP Support Association in conjunction with ITPSA Medical Advisor and Nurse Consultant Louise Taylor. We had a tremendous turnout with some great interaction and questions from all taking part. You can watch the Virtual Nurses meeting, just go over to our YouTube channel, and watch the videos, there are three separate videos to choose from.



We also held what has become a fixture during ITP Awareness Week, a Virtual Paediatric Meeting, this meeting was an opportunity for parents of children with ITP to ask questions and get advice about the condition. ITPSA Medical Advisor Dr John Grainger was on hand to answer questions from parents.



We rounded off ITP Awareness Week with a joint webinar with our friends and colleagues from the Platelet Disorder Support Association (PDSA) in the USA. I (Mervyn Morgan) and Caroline Kruse CEO PDSA were joined PDSA Medical Advisor Dr James Bussel from the Cornell University, New York and ITPSA Medical Advisor Dr Vicky McDonald from the Royal London Hospital, Dr McDonald is also the Director of the UK Adult ITP Registry. Remember all of the videos from ITP Awareness Week are available to view on our YouTube channel.



On the Friday of ITP Awareness Week, I (Mervyn Morgan) took part in a Q and A session with around 185 staff members from Sobi Pharma to talk about the work of the ITP Support Association and the impact ITP has on a patient's life.

During ITP Awareness Week we also launched the ITP Discussion Guide, which was a collaborative venture with Sobi Pharma, details of the discussion guide can be found in this edition of the Platelet, it can also be downloaded from our website, the ITP Discussion Guide is an addendum to our Shared Decision-Making Booklet 'Making the right choices in ITP management and care'. Hundreds of copies of the discussion guide have already been sent out to a number of Hospitals around the country.

If you would like a hard copy, please email us your postal details and we will send you a copy in the post (free to members).

A Return To A More Conventional Convention

A RETURN to a more CONVENTIONAL CONVENTION by Anthony Heard

Since the turmoil that Covid -19 inflicted on each and every one of us, we have all had to do so many things differently. It is clear that life has changed in so many ways and we have all come to do things in new ways. Adapt, evolve, survive seems to cover it.

We have, of course here at The ITP Support Association, not been immune to the challenges and demands for change that the pandemic has inflicted. So many people, reading this article will know that we have been running regular online local support groups via the ZOOM facility, to combat some of the difficulties that the pandemic threw our way.

In addition to the local support groups, we have also been obliged to hold the last three annual conventions online too. The 2020, 2021 and 2022 conventions were switched to an online basis to ensure that we kept safe and secure away from the ravages of Covid.

It has to be said that the virtual conventions were hugely successful and were attended by record numbers of people online from all across the globe. But even so, we have had many requests from our members and followers to get back to more face to face events.

In my experience of attending the face to face annual conventions in the past, I can only say that they are tremendously

informative, inspiring and helpful. There is just no substitute for being in the moment with other people who are going through the same trials and tribulations.

I have been living with ITP for over 16 years now and I can still remember attending my first annual convention. It just felt so reassuring to be able to talk to other people who had themselves been through some of the things that I had encountered. It made me feel more confident about living better with my illness and gave both me and my wife and family a huge boost.

The events have also introduced me to fellow ITP patients from across the globe who I am in regular contact with to this day. It reinforces for me the fact that we are all fighting our own individual battles with this enigmatic condition wherever we may be from BUT we are stronger together by sharing knowledge, information and supporting each other.

The convention always brings together some of the leading medical professionals in ITP but perhaps more importantly it also provides a platform for us ITP patients to talk to each other, swap our experiences and encourage each other. No man is an island and all that!

It is wonderful to know that in 2023 we will be able to get back to a more conventional Convention, but we also appreciate that some of our members and followers prefer a non-face to face way of keeping in touch. For that reason, we are continuing our programme of online local support

groups via Zoom, and it is also why we are available on the many social media platforms.

Of course, we also have this quarterly magazine as another way of communicating between us ITP folk.

Our aim at the ITP Support Association is to be available wherever people want to connect with us. As ever it is different things for different people, and we try to cover as many bases as we can.

We can be found on the following social media platforms -

LinkedIn, TWITTER, Facebook, Instagram, You Tube, which can all be accessed via the main ITP Support Association website -

<https://www.itpsupport.org.uk/index.php/en/>

Our local support groups online are listed at the following link -

<https://www.itpsupport.org.uk/index.php/en/itp-local-group-meetings>

Tickets for the 2023 Annual Convention are available via the following link -

<https://www.eventbrite.co.uk/e/itp-support-association-annual-patient-convention-2023-tickets-438996338867>

Wherever and whenever you wish to connect with us, we hopefully have an outlet for everyone.

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 International Spotlight

The following article has been written by a lady who is one of the most powerful advocates for ITP in Europe, my friend Barbara Lovrencic (President of the Aipit in Italy). During ITP Awareness Week Barbara had what I can only describe as the adventure of a lifetime and all under the sail of ITP, read on. Mervyn Morgan

ITP-In viaggio con Werlhof – living with ITP pushing the boundaries



The title could already be a story "ITP- in viaggio con Werlhof" in English "ITP- a journey with Werlhof" is an awareness campaign promoted by Sobi Italia with Aipit aps Onlus support. Aipit aps Onlus is Italian non-profit association of ITP patients and caregivers established in 2010. Sobi Italia is Italian branch of Sobi - Swedish Orphan Biovitrum AB pharmaceutical company specialized in rare disease drugs. Not all ITP patients know that Mr. Paul Gottlieb Werlhof, who was German physician and poet, was the

first physician who supplied the clinical description of ITP in far 1735. In a way our entire life with ITP could be considered as a journey with Werlhof.



Surveys about quality of life of the patients with ITP had shown that sport activities are the most affected by ITP.

The general public and also some healthcare providers are not familiar with ITP and its real impact in life of patients with ITP.

For many years there were few treatment options for patients with ITP, immunosuppressants, IVIG and splenectomy but 10 years ago TPO mimetics arrived giving us opportunity to get better care and improve our life with ITP.

The aim of "ITP- il viaggio con Werlhof" campaign is to bring awareness about ITP to the public and also to celebrate research progress that provides better treatment options for the patients with ITP. Research has made it possible that many ITP patients can live more fulfilling and free life.

Ambassador of the campaign is Mr. Mauro Pelaschier – well known professional sailor who won numerous gold medals in the Olympics and winner of Americas cup with "Azzurra".

For the first time in a history, thanks to Mr. Pelaschier's experience, five patients with ITP, Barbara, Cecilia, Gabriela, Simone e Maurizio were part of the crew of the sailing boat that participated in historical regatta "Mille vele" in Genoa that was held on 24th September 2022.



Patients with ITP often describe their life with ITP as a storm. ITP-in viaggio con Werlhof 2022 experience was a perfect reflection of our life with ITP. During the preparation day's the crew had beautiful weather with sun, calm sea, and wind just enough to offer a perfect sailing experience for inexperienced sailors.

On the day of the regatta itself the weather conditions were rain, gusts of wind over 20 knots and rough sea, so bad that one of the sailing boats that took part of regatta sank. Barbara Lovrencic, President of Aipit aps Onlus and a member of the crew comments: "Just as it happens in our life with ITP, under expert guidance, we made it! And we made it well! Thanks to

Mr. Pelaschier's spotless guidance of the entire crew we made it to 4th place in our category and 12th place in general ranking of 228 sailing boats. It was experience of the lifetime and bad conditions made it even more special!"

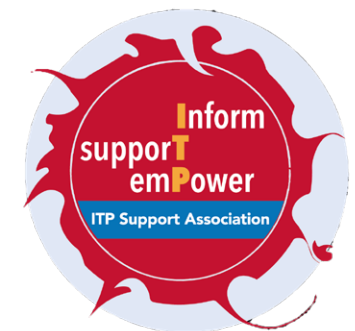
ITP- in viaggio con Werlhof 2022 pushed the boundaries so hard that the most important information agencies of the country passed the news and the rest of the media followed.

ITP has a lot of secrets to be revealed by research so rising awareness about ITP is fundamental goal of all of us. Joining our forces, we can do more!

For more information about this fantastic journey visit <https://www.itpinviaggioconwerlhof.it/>

For more information about AIPIT Onlus please visit <https://www.aipit.com/>

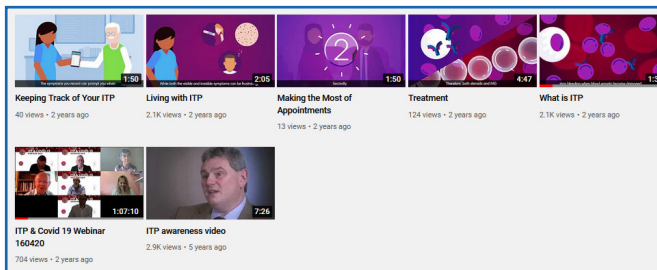
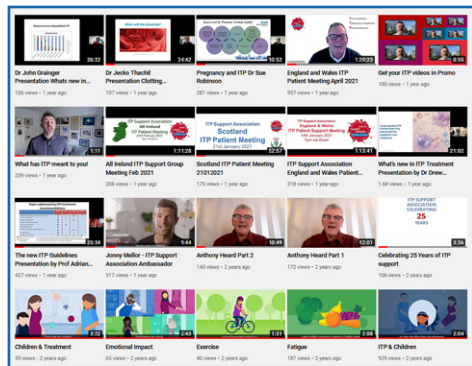
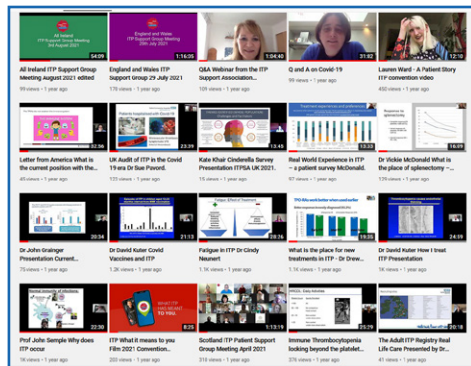
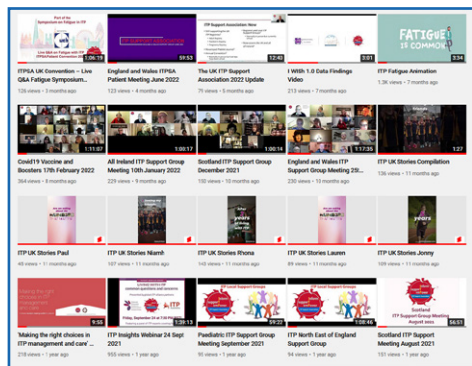
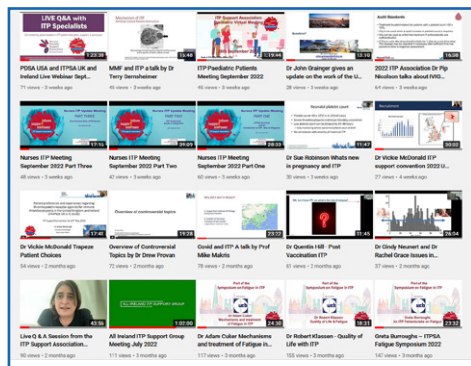
AIPIT is proud to be a member of the ITP International Alliance www.globalITP.org



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/UCRkHWFVYAIAIKKAbjF14L37g/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.



Questions

Information for patients with Immune Thrombocytopenia (ITP) scheduled for Covid-19 vaccination. (Published 27th January 2022 but still current as of October 2022)

Q I have ITP. Can I receive the Covid-19 vaccine?

A Yes. ITP is not a contra-indication to the Covid-19 vaccine.

Q Is it correct that thrombocytopenia can develop following Covid-19 vaccine?

A In one study, it was estimated that approximately one new case of ITP occurred for every 100,000 doses of first AstraZeneca vaccine. The association was not observed with first Pfizer vaccine. Furthermore, there is no indication yet that thrombocytopenia following Covid-19 vaccine is any more common than after Covid-19 infection itself.

Another rare complication observed following the AstraZeneca vaccine was vaccine-induced immune thrombotic thrombocytopenia (VITT). This condition leads to blood clotting and low platelets, typically presenting 5-30 days post-vaccine. ITP was not identified as a risk factor for VITT, and VITT was almost exclusively reported after adenoviral vectors (AstraZeneca, Johnson & Johnson), rather than the mRNA vaccines (Pfizer, Moderna) now being offered in the UK.

Q If I have ITP, could my platelet count fall after the Covid-19 vaccine?

A Some people with ITP will have a significant fall in platelet count after the vaccine (studies suggest about 1 in 15). In most cases, this will either resolve without treatment or respond to standard treatment. This effect does not appear to be specific to one particular type of Covid-19 vaccine and no other risk factors have been identified.

Q I am receiving immune suppression for my ITP, should I still have the vaccine?

A Yes. The vaccine may give you less protection if your immune system is weakened by treatments such as rituximab, steroids or mycophenolate. For this reason, a 3rd Covid-19 vaccine has been offered, at least 8 weeks after the second, to those on such treatments, and subsequently a booster (4th) vaccine, from 3 months after the 3rd dose.

Q Can I prepare for my vaccine?

A Yes. It is now recommended that your platelet count is checked 2-5 days after vaccination. Once you know your vaccination date, book a full blood count (FBC) check through your haematology department or GP. An additional FBC may be required if the platelet count is falling or bleeding symptoms develop. If you

choose not to check the platelet count at 2-5 days, observe for unusual or increased bruising or bleeding and have your platelet count checked if this occurs.

If your platelet count is likely to be less than 50, ask for a thin needle (23 or 25 gauge) and press firmly at the injection site for 2 minutes without rubbing to reduce the chance of a bruised muscle.

Q My ITP presented or relapsed after Covid-19 vaccine. Can I have further Covid-19 vaccines?

A The risk of a further platelet count drop appears higher in these circumstances, but the platelet count still does not fall in the majority of cases. You can have further Covid-19 vaccines, however discuss your individual circumstances with your haematologist first, and your post-vaccine platelet count should be monitored.

Patient information on behalf of the UK ITP Forum. Version 1 (27th January 2022). Authors: Drs Q Hill, V McDonald, N Cooper, S Pavord.

Q Can someone with ITP have both the Covid Booster and the Flu vaccines at the same time?

A The administration of both vaccinations together is recommended for logistical reasons (i.e. Making sure they are both given) and there is no evidence that side effects are any worse. About 1 in 10 will get fatigue, headaches, and muscle pains but these are transient and no worse than when they are given separately. There is no suggestion that there is an increase in low platelets if given together.

They can be given separately but there is no advice on the gap between injections. The important point is that both should be given as the problems related to either infection are significantly worse than any side effects from the vaccines which are virtually always transient.

Q Can taking Statins make your Platelet count drop?

A Statins may be associated with a fall in platelets, and this is most commonly seen with Atorvastatin. The fall is usually early, within 7-14 days, and usually improves once the drug is stopped. Often requiring no treatment. I can find no reported cases in patients with underlying ITP although I am sure that is just because they haven't been reported.

To confuse the issue one of our American advisors, Adam Cuker, has reviewed the use of statins in patients with severe refractory ITP, as there is some evidence that the drug has an impact on the megakaryocyte which produces platelets in the bone marrow. He found that in nearly two thirds the platelet count increased. Despite that it is important that any patient who starts a statin should be alert to the problem (albeit very, very small) and if they have an increase in bruising or petechiae (small blood spots) they present for a rapid blood count.

ITP Patient Perception Survey 2022

ITP Patient Perception Survey 2022 – Closes on 23rd December 2022.

Our Patient Perception Survey has now been open since June this year and well over 300 people have taken part, thank you. If you have not yet completed the survey please be aware that it will be closing on 23rd December 2022 so you only have a few more weeks left to take part.

The survey results are proving to be as emulating as our previous survey, we are aiming to publish the draft findings early in the new year.

This is your opportunity to help shape the work of the UK and Ireland ITP Support Association for the years ahead. We are inviting feedback from ITP Patients about the level of care received and perception of how ITP affects daily life. Your answers will be kept confidential – only the result summaries will be published.

The survey covers all things ITP including questions on availability issues in some areas for some NICE approved second line treatments PO/RA (such as Romiplostim, Eltrombopag etc.) This survey has been sponsored by Sobi. Sobi had no editorial control of the preparation of this material, and the content, views and opinions expressed herein remain those of the authors.

Please take the time to complete the survey, our last survey in 2020 resulted in the publication of our shared-decision making documents called 'Making the right choices in ITP management and care'. This is available to download from our website or you can email us with your address, and we will send you a hard copy.

To complete the survey please click on the following link:
<https://www.surveymonkey.co.uk/r/ITPSAPPS2022>

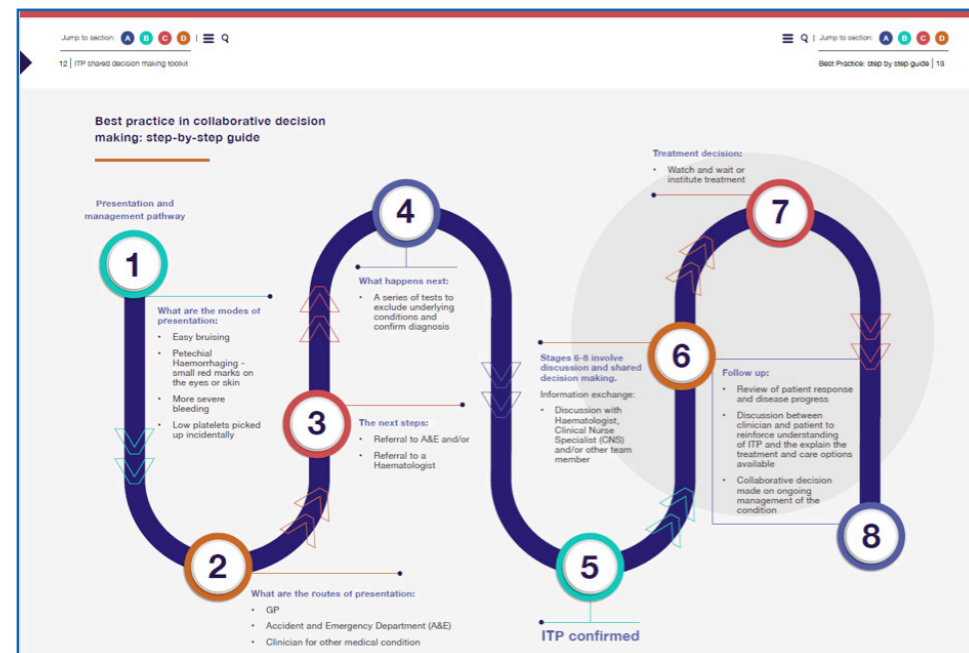
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Shared Decision Making Document available in Six Languages



'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

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

Fundraisers & In Memoriam

Rob Clark and Family



Rob Clarke with his family and the 100 DVD's to sell.



A Wrexham business owner was overwhelmed when he received a message on Twitter from Ryan Reynolds, which led to an extraordinary gesture by the actor and his wife Blake Lively.

Rob Clarke, who runs Mad4Movies in Wrexham Butcher's Market, was checking his social media when he spotted a message from the Wrexham AFC co-owner.

"I'm still figuring out Twitter, but last week I got an inbox off none other than Ryan Reynolds!

"I called Carrie over to double check it was actually him messaging me, it was, and he told me that he and Blake were having a clear out of their office and came across multiple DVD/Blu-ray copies of some of their films.

"He proceeded to tell me that they have signed every one of them and are sending them to me! Anyway, today they arrived – a box of over 100!!"

Rob continued to explain what he would be doing with the surprise shipment – and how it could

help his eldest son Charlie, who lives with a blood disorder (ITP).

Rob raised an incredible £2,440.00 through the sale of these DVD's. An amazing story!



Poppy Sharp

Poppy Sharps aged 11 decided to skip for 5 minutes every day in the summer holidays to raise funds for the ITP Support Association (as her older sister has ITP). She raised £430.00 - Well done Poppy!

TK Maxx – Homesense Foundation

We would like to thank the TKMaxx and Homesense Foundation (an independent charity) for the cheque donation of £1,500. Also thank you to the employee who nominated the association.



Yvonne Hudson

Yvonne Hudson a long-standing supporter of the charity recently celebrated her 80th Birthday. Yvonne's ballroom, sequence and line dancing friends all made donations to The ITP Support Association. Thank you, Yvonne, for the £60.00 cheque being donations in lieu of presents.

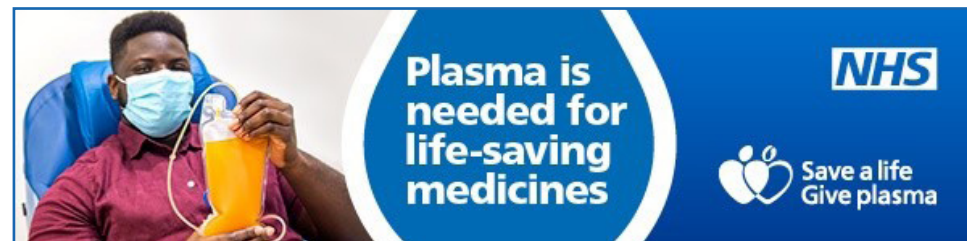
Other fundraising:

- JustGiving: £282.50
- Facebook Donations: £844.24
- PayPal Giving Fund: £1,230.84 (total for year to date)
- Atlas Trading Ltd collection box - £80.00
- Charities Trust - £22.00

In Memory:

We have received £490.00 in the loving memory of Vic Barfoot. The association sends its sincere condolences to the family and friends of Vic.

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

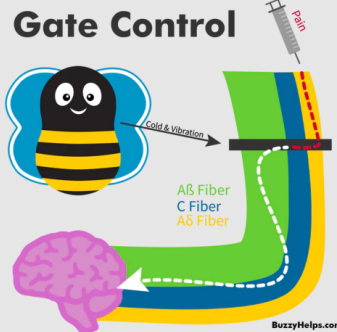
The gate control theory is the basis for the design of Buzzy®. The premise is that when nerves receive non-painful signals such as vibration or cold, the brain closes the gate on pain signals. For example, if you hit your finger with a hammer, you might instinctively begin to rub it, shake it, or run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



Invitation To Participate

Seeking individuals diagnosed with one of the following conditions

- Myasthenia Gravis (MG)
- Pemphigus Vulgaris (PV)
- Dermato- or polymyositis
- Bullous Pemphigoid (BP)
- Chronic Inflammatory Demyelinating Polyradiculoneuropathy (CIDP)
- Immune Thrombocytopenia (ITP)

Receive £150 (~€170) for participating in a simulated use product evaluation session of an injection device.

Location: London or Stockport

Dates: Late November – early December

Length: 90 minutes

Details: You will not inject into yourself or anyone else. Nor will you be asked to change your treatment.

Interested? Please call 0161 242 5225, ask to speak with Vicki, or email vicki.moran@acumenfieldwork.com

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.

Christmas Cards

ITP Support Association Christmas Cards Your last chance to order.

Go to www.itpsupport.org.uk and click on the Shop link in the menu.
A pack of 10 cards for £3.50 plus postage.



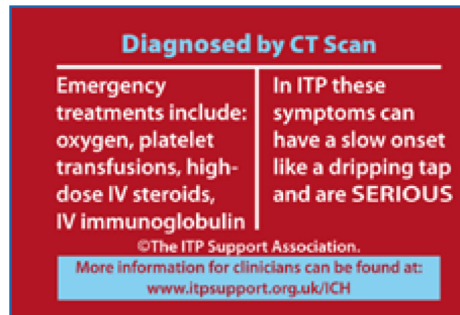
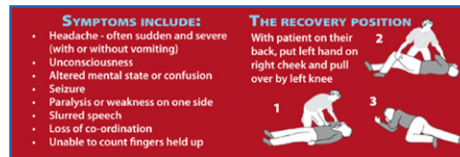
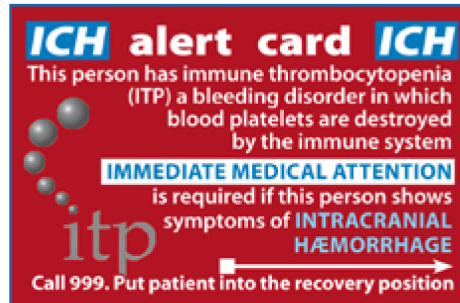
Order a free ICH alert card

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

