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ITP Support Association 2022 Annual Convention

14th & 15th May 2022



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The
Platelet

MARCH 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

Much has happened since our December edition of the Platelet Journal.

Firstly, we have held 3 regional ITP Patient Meetings, England and Wales, Scotland and All-Ireland. These meetings were supported by an ever-increasing number of patients as these meetings continue to be held in the virtual environment. If you missed any of these you can catch up by watching each meeting on our YouTube Channel. Go to our website and click on the YouTube icon in the social media panel. These 3 meetings alone have received over 500 views on YouTube.

In addition, we also organised a Covid-19 Vaccines and Boosters webinar which had more than 120 register before the event and has since received more than 200 views in just over a week. If you had a question about Covid and the Vaccines its worth watching this video, your question (and the answer) may be there.



Each of these meetings were supported by some of the top ITP specialists from the UK and Ireland, our thanks go to everyone who supported and all who took part. There were dozens of questions asked and answered, it is well worth spending some time watching the videos, your question may be there.

We also held a test in-person ITP Patient Support Group meeting with our friends from the Nottinghamshire Group, this is a small group and it worked well, thanks must go to Ronnie Bright for organising, it was good to see you all in-person once again. If any of the other groups would like to restart small in-person meetings, please let me know. In any event we will also be looking to continue with the regional virtual meetings going forward as this have such a big impact.



Whilst we are on the subject of meetings we must announce some news about our annual convention, the ITP Support Association Convention 2022 organising committee have taken the decision, after wide consultation to hold this year's Convention as a Virtual event. It will take place over the weekend of Saturday 14th and Sunday 15th May. Further details are included in this edition of the Platelet.

Covid-19 Vaccine Survey is still open

Our Covid-19 Vaccine Survey is still open, we have added some additional questions covering the Booster vaccine jab. We would also welcome any youngsters with ITP (18's and below) who have had their vaccine to complete the survey. Please go to our website at www.itpsupport.org.uk to take part. The initial survey results can also be found on our website.

For those interested in the latest findings from our Covid-19 Vaccine survey please watch the video from our recent Covid Q&A, Dr Sue Pavord presented a summary of the survey findings.



Best wishes

Mervyn Morgan CEO

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My Socks Say 'Be Kind To Yourself' by Rhonda Anderson

Surprisingly, I do have a pair of socks that say exactly that, a January birthday present from my daughter. My 'be kind to yourself' campaign started at the beginning of the year with a resolution to do more things I enjoy. I call it a campaign because it has to be worked at and planned. A conscious effort has to be made to find the time to read, watch a film on Netflix, watch a TV series, go for a walk, make a phone call, invite a friend to visit, or go visiting. Anything you want to do needs a slot.

This could be seen as selfish, but it can work the other way and make yourself a better person. If you feel better, happier, more fulfilled, you will influence others in a positive way. Like dropping a stone into a lake, the ripples fan out to touch the lives of others. Helping others is good for us. Even a very small thing, like smiling and speaking to someone very briefly, can be helpful to them. We have all missed this personal contact during the pandemic. However, a phone call to a friend you cannot visit, even if it is the next door neighbour, can lift their spirits and make them feel happier and cared for. Little inexpensive gifts of flowers from your garden, chocolate, homemade biscuits or cake, or a little note, are all mood lifters, not only for them, but also for you.

Recent knowledge to me, is that Dementia is staved off by learning something new every day. I find learning something new is a joy, no matter how small it is. I found out that the mens' hats in Durer's drawings actually have ear flaps that are tied up over the top. Nice and cosy when untied in a cold climate. I was delighted to know this as I always wondered at the shape of the hats. Also that the blue paper he drew on was made from blue rags, most probably indigo. Obvious really, but I only realised it from the exhibition at the National Gallery which I decided to brave the tube for.

Have you developed FOGO? What is that, you ask? It is Fear Of Going Out, my invention, after FOMO, which is Fear Of Missing Out. FOGO has developed in people who never had it before, as we can be anxious about mixing, even at this stage of the pandemic. Many people have lost confidence

in the things they used to do all the time. I was certainly one who abandoned tube travel. It was very restricting as I used to be in London via the tube several times a week. However, I did manage to do a lot of things at home, (no, not de-cluttering!), but lots of interesting lectures, meetings and talks on Zoom.

Recently I have decided it is safe enough for me to go on the tube. I am not entirely sure how I came to this decision, but my 'gut feeling' was that I should venture out. I went to Mile End Park to do a Park Run with my daughter, in my case a Park Walk... I did come first in my age group, which wasn't such a win, as I doubt there was anyone else in my age group there! Going on the tube with someone else gave me confidence and I went into town to see 2 exhibitions the next week on my own. Of course all sensible precautions prevail, such as using gel, wearing a mask, travelling in the less crowded periods, and so on.

Getting outdoors is something I hope you have been able to do. The first day of Spring is March 1st and the beautiful spring flowers such as daffodils, crocuses and blossom can already be seen, as we are told spring comes a whole month earlier these days. The longer days and less wintery weather will be an encouragement to walk more, and even if you can only manage a short distance, a little exercise is better than no exercise.

'Forest bathing is a mindfulness practice that involves immersing yourself in a forest setting and being totally focused on what you see, hear, smell, taste and feel,' says Gardeners' World regular, Frances Tophill in a Radio Times article. This can be done, using all your senses, even if you don't have a forest to go to. Some congenial outdoor place that pleases you is good enough, be it your own garden or some other place nearby, that you like. I have derived much pleasure from seeing the snowdrops at my front gate, and the pink camelias in my next door neighbour's garden. When you get used to looking, you can find pleasure in small things on your doorstep.

A patient mentioned skin problems as a side effect of medication, and we had a discussion about it during our Zoom meeting in January. You will probably know that the skin is the largest organ of the body and the body's first defence mechanism. We all know the discomfort of dry, irritated and broken skin. Interestingly on Woman's Hour, I heard that skin is a neglected area in the NHS, but it is very important for mental health too. Many skin conditions are visible, often on the face, so they can be disfiguring. A little bit of daily TLC, such as moisturising your skin, (ladies as well as gentlemen!), can do wonders for its condition and comfort. If you have a troubling skin condition it is wise to contact your Pharmacy for advice and also your GP. The NHS has reliable advice online. It is heartening that skin is going to get more attention, as a Member of Parliament, who lives with skin conditions, has an interest in this topic.

These days we are all victims of the air brush culture where photos look perfect and we can feel inadequate when we don't measure up. In extreme cases, people experiencing mental health issues due to feeling inadequate. A lot of skin conditions have uncertain origins, and yes, some can be autoimmune. Looking after your skin is well worth the effort.

I have covered a number of issues which I hope you will find relevant, but above all I hope you will remember, if there is only one thing you can do, make it kindness. Start with being kind to yourself, and then to others, and you will feel happier, and so will they.

With kind thoughts, Rhonda



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

1. Contact Give a Car on 020 0011 1664 or 'http://www.giveacar.co.uk/how-it-works' and say you wish to donate your scrap car in aid of ITP. It takes a couple of minutes to get your details and answer questions. Once they have your approval, a collection agent will call you in order to arrange a convenient pick-up time.
2. Your car is picked up. A tow truck usually arrives within 1 to 3 days to pick up your car, though in a few rare cases it may take up to 10 days.
3. Your car is sent to scrap or auction. Give a Car then donate all the proceeds, after administrative costs, to the ITP Support Association. Within 6 weeks you will receive a receipt for your donation, and so will we.



ITP Support Association Convention 2022



ITP Support Association Convention – London 2022

Many of you will already have seen the outline details of our next convention #ITPLondon2022 on social media and our website. The ITPSA Convention organising committee have taken the decision after wide consultation to hold this year's Convention as a Virtual event.

The event will take place on Saturday 14th and Sunday 15th May.

REGISTER NOW: You can register for access to the convention now by going to: <https://www.itpconventionuk.org/registration>

We are also planning to hold a Symposium on an issue that is very much in the minds of those with ITP, that is Fatigue, on the Sunday afternoon (15th May).

New speakers are being confirmed daily, there are many familiar names already attending:



Dr. David Kuter is Director of Clinical Hematology 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.



Dr Cindy Neunert is an Associate Professor of Paediatrics at Columbia University at CUMC, New York and an Attending Physician Paediatrics at New York Presbyterian Morgan Stanley Children's Hospital, New York.



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.

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American Perspective



Are people with ITP immunocompromised?

Many of my patients with ITP have asked if they are immunocompromised. This has become an even more frequent question given the different COVID vaccine recommendations for people who are immunocompromised. When the body receives a vaccine, the immune system will react to that vaccine and create a memory of the virus or bacteria so that next time the body sees that infection it is ready to clear it and help the body not get sick. In order to have this response, the body has to have all the right cells to recognize the vaccine, trigger an immune response and create the memory for next time they are exposed to the virus or bacteria. If an individual is immunocompromised one or more of the key steps in creating this memory response may not be completed either because certain cells are not there or because they can't work properly. Similarly, if there is a part of the immune system that is not working correctly a person may have more difficulty fighting infections.

While ITP is an immune condition, having ITP does not mean that a person is immunocompromised. ITP is an autoimmune condition that results from the immune system not acting properly. People with ITP have an immune response against something they should not, in this case their platelets. Unlike people who are immunocompromised, the body can still react properly to other things such as viruses, bacteria, and even vaccines.

There are certain patients with ITP however who may be immunocompromised because of their ITP treatment. Immunosuppressive therapies are drugs that reduce the immune system response. Several treatments for ITP are considered

immunosuppressive therapies and therefore can make a person immunocompromised. This is because many of the therapies that we use to treat ITP work by dampening the immune system and making it less reactive. While this is a good thing for the platelets, it may mean that a person will not have a proper response to certain infections or vaccines. When a person is taking immunosuppressive medications, they may be at increased risk of complications from the natural infection but also may not have as robust a response to vaccines. For these reasons, patients receiving immunosuppressive therapies may require certain vaccines prior to starting therapy, need an additional booster of vaccines during treatment, and/or should avoid live vaccines during a period surrounding treatment (usually 6 months).

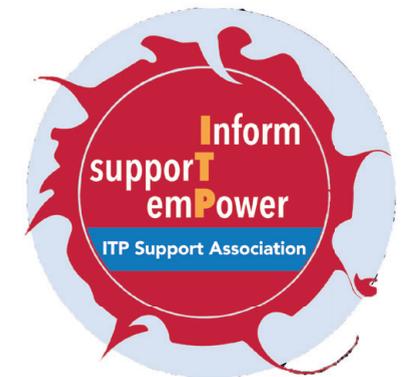
A common medication that many patients with ITP receive is corticosteroids. Long-

term treatment with corticosteroids (> 20mg prednisone or equivalent per day) can make someone immunocompromised and less likely to respond to vaccines or be able to fight infections. Another common ITP medication is rituximab. Rituximab works by reducing immune cells in the body called B cells. These cells are an important first step in creating a memory response to a vaccine. Following rituximab almost complete reduction in the B cells occurs immediately. The B cells will start to recover as early as 3 months, but it may take up to 12 months for them to completely normalize again. During this time patients remain immunocompromised. Patients with ITP who undergo splenectomy are considered immunocompromised against very specific infections. The spleen is an important organ in fighting infections with certain bacteria called encapsulated bacteria. When the spleen is removed a layer of defense against these bacteria is removed. This is why someone who undergoes splenectomy receives specific vaccines for these infections before the procedure. Following splenectomy patients are counseled to be seen anytime they have a fever to prevent and treat severe bacterial infections. Children may also be placed on daily antibiotics to prevent infections. Having the spleen removed does not affect a person's ability to fight other bacterial infections or viruses.

While this is not a comprehensive list of the treatments used in ITP and their effect on the immune system it highlights the importance of asking your doctor about the medications that you are taking and if they affect your immune system. Simply having ITP however does not make an individual immunocompromised. Before starting a new medication talk with your doctor about the effects on your immune system and if there are certain vaccines you should get before starting or boosters that are recommended. Sometimes, your doctor may

recommend checking titers, which can tell if your body has had a response to a vaccine or checking the different cells in the immune system to see if they are reduced. These can help know if a particular medication is influencing your immune system. Alternatively, it is important to know if there are certain vaccines you should avoid or special precautions to take with regards to infections.

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



Heartaches and Miracles by Greta Burroughs

Even though I didn't know it at the time, April 2005 marked the beginning of my ITP journey.

I was so tired. My brain idled in screen-saver mode while my bruised and bleeding body refused to cooperate. What was wrong with me? I definitely couldn't solve this mystery on my own, so I enlisted the aid of a specialist in women's health.

After a fruitless month of poking, prodding, and testing for any gynecological reasons responsible for my fatigue, brain fog, and never-ending menstrual bleeding, the doctor finally held the indecisive results in her hands. She shrugged her shoulders as she began her well-rehearsed generic answer, "Well, Greta, you're at that age when"

I wasn't satisfied and asked why she'd neglected to do any lab work. I'd lost a lot of blood, and purple polka dots decorated my body from head to toe.

My question and the doctor's ah-ha moment triggered the first step in my ITP adventure.

With a platelet count of 2000 upon admission in the hospital and dropping to zero a few hours later, it was a race to figure out what was wrong with me and get the bleeding under control. Finally, after being diagnosed with ITP and pumped full of IVIg, platelets, and prednisone, my platelets rose out of the single digits, and I was allowed to go home.

I was glad to be home. However, 80 mg of prednisone had me bouncing off the walls, and my muddled mind couldn't grasp the ins and outs of what I was facing. My hematologist patiently explained ITP, platelets, autoimmune diseases, and our plan of action to me. Plus, my family was behind me 100 percent. Yet, that didn't alleviate the fear, anxiety, and stress associated with having a chronic disease, relapses, different

treatment plans, side effects, and never knowing what the next day would bring.

I felt like I was the only person in the world with this wacky blood disease – all alone with no one to talk to. I had no one to tell me that they'd been there, done that, and survived.

And then, I discovered online support groups. Wow, I wasn't alone. I wasn't the only person suffering from ITP!!!

Since day one, I've kept a journal chronicling my experiences, detailing the treatments along with the mental, emotional, and psychological highs and lows associated with the successes and failures. Then, in 2010, I combined all that information into a book called Heartaches and Miracles to share with others also fighting this illness.

However, a lot has happened over the past twelve years. Advances in medications, treatments, and overall approaches to combating ITP necessitated an updated 2022 version of my book.

ITP can be a hard road filled with relapses and disappointments, but with a positive attitude and support from friends and family, there is hope. It's my wish that Heartaches and Miracles will give ITPers and their caregivers the information, encouragement, and comfort to understand and cope with this crazy autoimmune disorder.

I'm so proud to be a part of our ITP family and welcome you to join us. With support from fellow ITPers, we are in charge.

I Have ITP. It Does Not Have Me!

Universal Amazon link for H&M - viewbook.at/heartachesandmiracles



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



ITP Experiences By Patricia Conry

ITP EXPERIENCED FROM BOTH SIDES OF THE POND

When I was living in the USA during July 2010, I found that I was losing weight and losing hair. I decided to visit my local practitioner in hopes that a medical examination and blood test would provide me with some answers. The complete blood count showed that my platelets were only 61 K/mcL. Previous blood counts in the last few years showed my platelets ranged between 267– 332 K/mcL.

Why the sudden drop. How did this happen? I don't know. Does anybody know? I don't think so.

I was referred to a specialist in oncology and hematology. I asked for a reason why this happened. He guessed it must have been a virus. When I asked him to explain the ITP disease, he printed up the disease from a web site for me to read. I made three guesses of my own ideas as follows. I had recently suffered a terrible shock regarding a sudden unexpected death of my husband. I worked with radium to a small extent when working with patients at Guys Hospital in the 1960's I was suffering extreme anxiety and stress at that particular time. Looking back I realize that it was also a learning experience for my practitioner because only rare cases came on his doorstep.

Immediately, I started keeping a running chart of my platelets counts and events during the past 11 years. This has proved to be an accurate reference for me.

The doctor monitored my CBC for platelets over the next couple of years where my platelets remained mostly in the 40's and my only symptoms were some bruising and tiredness. My monoclonal were 5g/L. However in the spring of 2012, when in the USA, I had severe bleeding from my colorectal area and was placed on medication to help increase my platelets. For the next 24 days my medication included **prednisone** 60mg, which increased my platelet count, then a gradual reduction of prednisone. However I was having nasty side effects which included unsteady gait when walking, I developed myopathy, my potassium became low, I couldn't sleep at night and I was very nervous during the day

. I called my medical clinic, but the nurse denied that my side effects were caused by prednisone. She told me I may develop a moonface but that was about all. Actually the moon face suited me perfectly as it looked like I had finally gained some weight!. I was totally frustrated until I found a book via PDSA with their informational pamphlets describing ITP and treatments. This book was entitled "**Coping with Prednisone**" written by Eugenia Zukerman and Julie R Ingelfinger MD, who had herself experienced the side effects of prednisone. This book really helped my mental health and coping mechanisms with these side effects, knowing that this author had the same experience and even worse than mine which helped me to cope with all the side effects I was having. I have recommended this book to others who needed help.

In May 2013, 2 months after completing a prednisone, course, I had another episode of severe bleeding in the USA, which led to my succumbing to colorectal surgery. The surgeon stated that to proceed with surgery I needed to increase my platelets to 100ug/dl as they were only 64 K/mcL. So once again in order to have surgery, I was placed on prednisone. I continued taking prednisone after surgery, for 95 days and suffering side effects.

After recuperating from the surgery, I came home to UK to care for my mother, then in her 90's. (This November 17 2021 she turned 100yrs old). I was still taking the prednisone at that time and I checked with my local GP regarding my ITP and prednisone treatment. The blood test revealed that because of the long course of prednisone I was taking I had now developed diabetes. My doctor here in the UK immediately called my doctor in USA, alerting him and asked that I should be now be reducing and stopping the prednisone. I was so thankful to have seen my doctor at the Selsey Medical clinic in W. Sussex.

When I returned to the USA a few weeks later, I suffered nasty withdrawal symptoms. This included severe pain in my right shin started when I was in bed, and mysteriously disappeared after 4 weeks, also pain and swelling in left foot, and a pain in my trochanter hip region for 7 weeks although no injury was sustained in any of these areas.

My next adventure included the fact that I needed a meniscus repair in my knee. However my platelets were too low to enable the surgeon to perform. I thought perhaps I could heal myself instead of taking prednisone to increase my platelets. Actually my meniscus did heal without surgery.

Later in the year I had surgery to repair an abductor tendon on my Left hip. I don't know if the tendon tore because of the prednisone I had taken earlier.

A year later, once again I had severe bleeding from my colon and was hospitalized for 5 days and was diagnosed with ulcerative colitis for which I now take medication regularly. Since then to my dismay I have also developed various food allergies.

The first really positive treatment event for me was when in the UK in October 2014 when some bleeding occurred and my platelets were 26 K/mcL and I was given **Vigam immunoglobulin** IVig at Fernhurst cancer unit at **St Richards Hospital** in Chichester, W. Sussex (part of University Hospitals Sussex) The care there was **absolutely wonderful**, and beyond my expectations. Since October 2014 until now, I have received IVig periodically for my ITP which help to keep my platelets above 30. However I do endure some bleeding episodes periodically when my platelets drop below 30ug but I am able to cope successfully.

Now for the bombshell. When I was due for my IVig in August 2021, I was told that there was no IVig available in this country or any other country, because people were not donating blood now, because of the Covid 19 virus. So now the physician at the Fernhurst clinic has changed my treatment and prescribed 50mg of Eltrombopag (Revolade) daily. My platelets last week were up to 62K/mcL.

Now for something very important for all of us to know, is the existence of our support groups both in USA and UK. As a nurse when in the USA working, it came to my ears that there was a support group for patients who had ITP. In the USA this support group was founded by Caroline Kruse who, she herself suffers from ITP and she felt that there should be a means to support others who endure this rare disease. This is the Platelet Disease Support Group ie PDSA, which has a board of directors and medical advisors, headquartered in Cleveland Ohio, USA. **Dr. Bussel**, one of the medical advisors knowing that I was British and on my way back

to the UK, directed me to visit **Professor Adrian Newland** in the UK. It was a delight to meet him in his office. The PDSA has about 52 support group in different regions of USA including Canada and New Zealand. However we have now expanded to other countries around the world.

I joined the support group in Brown Deer, Wisconsin which was close to my county in USA. **This was a fantastic group where I felt quite at home sharing experiences.** I learned more from this group than reading any text book or any general practitioner (except on finding a rare ITP specialist) **Because of this experience I felt it urgent to become a support facilitator in Chichester, W. Sussex, UK**, close to my residence here. **I was encouraged by Mervyn Morgan our chief executive for The ITP Support Association headquarter in Bolnhurst, Bedfordshire.** Both the PDSA in USA and ITP Support group in UK have a magazine with tremendous articles and pamphlets which describe ITP. Both the group in USA and UK has their own annual conference once a year. Fortunately since lock down, we have been able to use Zoom for both National conferences one in USA, and one in UK. Also both countries have regional support group discussions via Zoom at present.

Now to recount my latest travel episode to USA in May 2021. I received my Covid 19 vaccination in February 2021 so decided to travel to USA in March. However my Covid PCR test showed that I was positive 3 days before I was due to travel so I postponed my trip and went instead during May 2021 for 6 weeks. There was certainly copious forms to complete to support why I needed to travel thus were only 26 passengers on that particular jumbo jet. I was certainly lucky to have had so many seats to myself.

I am careful when travelling back and forth between USA and UKI carry prednisone and Tranexamic Acid with me.

I returned to the UK at the beginning of July. In order to depart from the USA, I needed a negative PCR test within 3 days of boarding the plane and also proof that I had booked and paid a UK lab to provide Covid tests on the 2nd and 8th day of return to London and to quarantine myself for 10 days. I plan to return to USA in January and I am wondering what the rule will be then?

G'day from Australia! – Danielle Boyle

I was diagnosed in July 2015 by accident. I went to my local emergency department with chest pains, and after a full blood count and a chest x-ray, I left with an appointment with a haematologist and the possible diagnosis of ITP.

I think we can all agree that before being diagnosed, most of us hadn't heard of ITP, Idiopathic Thrombocytopenia Purpura or Immune Thrombocytopenia, let alone know how to pronounce it!

Like many ITP patients, I started on steroids, and the steroids' effects were intense. I went from being a happy and healthy woman to someone I didn't recognise. (photos from day of diagnosis to 6 weeks later on steroids).



I was lucky, though, as I was placed on a clinical trial with a treatment that worked well for nearly three years.

Before the real ITP rollercoaster hit, I was lucky to work with the team at the PDSA for the PDSA Regional Meeting held in Melbourne in March 2018. At this meeting, I meet fellow ITP patients for the first time, including the passionate and enthusiastic Dale Paynter from the PDSA from Canada. For some patients, it's decades before they meet other patients, so I made sure to relish the time I spent with everyone.



After this meeting, it was evident that we needed something here in Australia, so we pulled out all the stops and launched ITPAustralia.org.au later that year.

I then encountered my ITP rollercoaster. It included nearly every treatment available in Australia as time was limited as I headed to the UK for my daughter's wedding in 10 weeks. The decision was made that it was time for a splenectomy, so we crossed our fingers, hoping that it would work and that I'd recovered enough to fly.

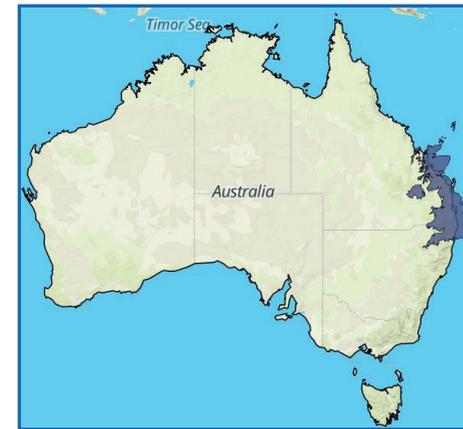
Well, of course, I made the wedding. I would have moved heaven and earth to make sure I was there. And while in the UK, I was invited to join the Global Alliance Meeting in Washington DC a few months later.

Again, just like in Melbourne, I was privileged to again meet ITP patients and ITP Patient Association leaders, from all over the world, including the ITP Support Association's very own Mervyn Morgan.



During this meeting, I realised that ITP Australia needed to be more than just a website, so I listened and learnt from everyone at the meeting and during the PDSA Patient Conference that followed.

With so many ideas running through my mind, I headed home, and we started running localised meetings, which can be tricky as Australia is 32 times larger than the UK. I travelled from the east coast to the west coast to meet with patients and



their families and learn about their ITP Journeys.

In early 2020, we'd been planning a nationwide road trip, which saw us travel to every state's capital city and several vital regional locations—all of this with an ambitious timeframe of 12 months. However, COVID-19 changed all of this, and like many other patient associations, we took things online.

So being stuck at home, I hatched a new plan—a plan that may have rustled a few feathers, but always with ITP patients in mind.

We've been involved with the recent parliamentary inquiry in Australia into improving access to novel treatments etc. for people living with Rare Diseases and worked closely with several key stakeholders to work towards moving splenectomy down the treatment protocols, with the primary objective of ITP patients receiving access to TPORAs (Eltrombopag & Romiplostim) BEFORE splenectomy ~ Unfortunately, in Australia ITP patients are still required to undergo a splenectomy before accessing these treatments and having them subsidised by our health system.

As part of this treatment change, a team of leading ITP clinicians from the Thrombosis and Haemostasis society of Australia and New Zealand (THANZ) recently published our first local treatment Guidelines for Adult patients. Previously, we've used the international consensus report, so having our guidelines has been invaluable, not just for patients but also clinicians.



We've also been spreading the word about ITP right across Australia. During ITP Awareness Week 2021, several locations and buildings turned purple of ITP, including Tasmania, Queensland, Victoria and Western Australia. In 2022 we're

hoping to get even more, so watch out for updates on our social media pages. We worked with the ITP Support Association and the PDSA on a joint webinar, and we're planning more joint activities with our patient association partners for 2022 and beyond.



It's now been nearly seven years since I was diagnosed with ITP, and I'm thankful that I was. I've found what I'm passionate about. Yes, there are good days and bad, but you can't have rainbows without the rain.

ITP Australia started a few years ago from an idea and a drive to do more. ITP Patients are at the heart of everything we do and every decision we make. We want to make sure that ITP Patients aren't just seen but heard and supported.

Many people know me mainly for my constantly changing hair colour, one day blue and the next purple, but like many Aussies, I'm loud, a bit pushy but here to make a lot of noise until all ITP Patients have their voices heard.

Spotlight - Where To Find Us

TURNING the SPOTLIGHT on where to find us

Many people on the various ITP social media forums/platforms ask questions about where to get reliable, up to date information about our rare condition and where to find the ITP Support Association.

Many people do not realise that we are available on a number of platforms so we thought that it would be a good idea in this September Awareness Month to share all of the various outlets that we can now be found on

So, the following is an up to date list of where we can be located.

The ITP Support Association - UK Registered Charity established 1995 and the first support group for ITP patients anywhere in the World....

Website -
www.itpsupport.org.uk

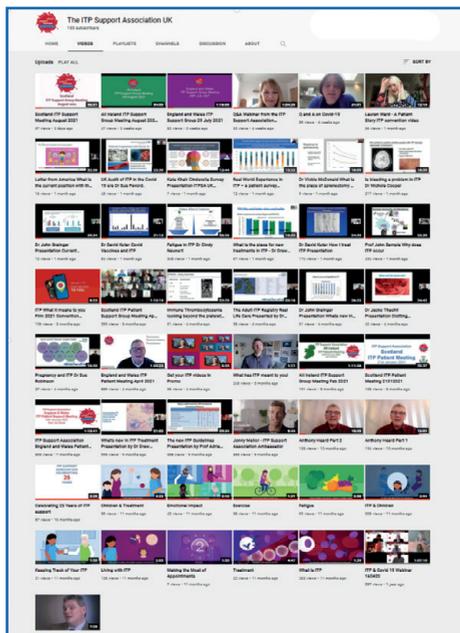
Facebook Group -
<https://www.facebook.com/ITPSuppAssoc/>

Twitter -
<https://twitter.com/ITPSupportAssoc>

HEALTHUNLOCKED forum - written by ITP sufferers for ITP sufferers.
<https://healthunlocked.com/itpsupport>

Instagram -
<https://www.instagram.com/itpsupportassoc/>

Visit the ITP Support Association YouTube Channel
You Tube Channel with numerous helpful, informative & interesting videos covering a wide range of ITP related issues - <https://www.youtube.com/channel/UCRkHWfVYAA1KKabJfI4L37g/> 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 around fifty ITP related videos available and are adding more all the time. Please subscribe to the channel.

LinkedIn - We have recently joined LinkedIn so if you have not found us yet you can do so at -
<https://www.linkedin.com/groups/1399074/>

Finally - A USEFUL REMINDER - One thing to be aware of about all of the various forums is that any content and/or suggestions or comments on any of them can never replace the relationship between you and your doctors or other healthcare professionals nor the advice you receive from them. Always consult with and discuss your case in full with your doctor/specialist or medical professional before acting on anything.

Produced by Anthony Heard

Questions

Question from Patient A - I am 79 years old, I have been advised that I need a knee replacement.

My ITP history is - my first episode was in 1997 and, until my splenectomy in 2011, I had frequent periods of extremely low (below 10) platelets which did not respond to rituximab or various other treatments. I spent a lot of time taking steroids with some ill effects. The splenectomy was successful, my platelet level since then has remained around 200 and I no longer see a haematologist. My detailed ITP history was published in 'The Platelet' of March 2021.

My knee pain is moderately bad, I manage most daily activities but cannot walk more than half a mile without feeling pain and unsteadiness. I seldom need to take painkillers but generally have quite a lot of discomfort and stiffness.

My attacks of ITP were completely random and usually didn't appear to relate to any event. As a consequence of this unpredictability, my worry is that the trauma of such radical surgery, along with the anaesthetic and the various drugs involved, will trigger a recurrence of my ITP. I would rather endure my knee problem than have a return of ITP with its attendant problems of medication, plus risk of blood clotting and consequent stroke. A stroke is the event I fear most, especially as I have already had a DVT.

I apologise for asking an impossible question. I would just value the opinion of your medical experts as I am finding it hard to make the decision.

Answer from Prof Newland - I can see this patient has been in remission and off all treatment for 11 years and is almost certainly cured of her ITP.

There is nothing particular about knee replacement or the drugs used to cover the anaesthetic or the surgery that is likely to provoke a recurrence. Obviously, the clinical team would want to know about her previous history so they can monitor her platelets before and after the operation but that is standard.

In view of the previous history on DVT they would

almost certainly want to cover the operation with heparin as the risk of clotting (although small) is higher than any risk to the platelets. Platelet counts may dip over the period of surgery but this would not be to levels that are associated with any risk and would be transient. The risks from the pain relief that I assume she has to periodically use for her knee are also something to bring into the equation in balancing risks and benefits.

I would like to strongly reassure her over the impact of the surgery and her previous ITP.

Question from the Mother of a patient - It is considered that my son developed ITP following the preschool booster vaccination and after 3 successful flu vaccines, the 4th flu vaccination knocked my son out of remission. Would it be sensible for my son to receive the Covid vaccination? He is currently 11 so hasn't been offered it yet and his consultant had said it would be a "judgement call" so I'd like to ask if you would recommend that he received it considering his history?

Answer from Dr John Grainger - In general I would consider COVID vaccine along the lines of any other important childhood vaccine. Whilst we do see occasional drops these are usually transient and probably less frequent than following actual infection. That being said if a patient was unstable and had previously had significant relapse after infection it would need discussing with the patients consultant. Provided the ITP courses had been mild, not associated with significant bleeding and patient was not refractory to therapies then I would on balance support vaccination.

Editor:

We have received many more questions however we cannot publish due to the personal content.

Please checkout our YouTube channel and the recordings from our Support Group Meetings, dozens of questions have been answered, maybe your question has already been answered?

Derek Elston interviews Maarten Van Baelen Pt.2



Derek Elston interviews Maarten Van Baelen from the PPTA – Part 2

What safeguards and regulations are there to ensure the end products used to treat patients are not contaminated with HIV, hepatitis, or any other viral infection?

The safety of PDMPs is assured by a range of complementary safety measures including donor selection and testing, as well as manufacturing steps.

Adequate selection of donors is one of the important measures for the safety of plasma derivatives, together with the virus testing of donations and pools, and the virus reduction capacities of manufacturing steps. Only healthy donors from a low-risk population are selected to donate plasma.

At every donation, each donor is requested to answer questions on history of conditions that place the donor at risk, e.g., heart disease; history of behaviours that place others at risk, e.g., IV drug use, sexual behaviour, travel, hospital admissions, etc.; uncertainties, e.g., geographical exclusions for other infections – donors from certain countries are excluded from the outset to minimize the risk; and current state of health e.g., fever, blood pressure/pulse, ('how are you feeling?').

PPTA also has a standard program in place called the 'IQPP Qualified Donor Standard,' which is part of a series of voluntary industry standards developed by PPTA [IQPP Standards Program], in addition to relevant EU (and U.S.) regulatory

requirements. The purpose of the standard is to take advantage of opportunities in the collection and processing of plasma for further manufacture into therapeutic plasma products to further reduce the risk of undetected infectious units of requiring additional testing/donations in combination with time limits to qualify these. Additionally, the QSEAL NAT Testing standard requires that QSEAL-certified manufacturers conduct Nucleic Acid Amplification Technology (NAT) Testing for HIV, HBV, and HCV at the donation (minipool) level and again at the first homogeneous plasma pool level. It also requires in-process testing for HAV and Parvovirus B19.

Manufacturing Processes

Next to donor selection and testing, the fractionation process employs a range of multiple and complimentary manufacturing steps which have a high capacity to inactivate and/or remove a wide range of pathogens which could be present in plasma. Manufacturing processes such as solvent/detergent (S/D) treatment, low pH incubation, caprylate-, pasteurization- or dry-heat treatments, nanofiltration and others are considered paramount in assuring high safety margins of PDMPs.

As a result of these complementary measures (donor selection, testing, and manufacturing steps) there have not been any documented transmissions of viruses such as HIV, HBV, and HCV through products manufactured by PPTA member companies and other recognized plasma fractionators in the past two decades with more than 35 million doses administered.

Additional requirements:

In addition, plasma is independently controlled

and released by relevant Official Medicines Control Laboratories (OMCLs) through Official Control Authority Batch Release (OCABR). These are independent national control laboratories, all of which use the same testing and assessment methods to certify the efficacy, safety, and quality of the plasma.

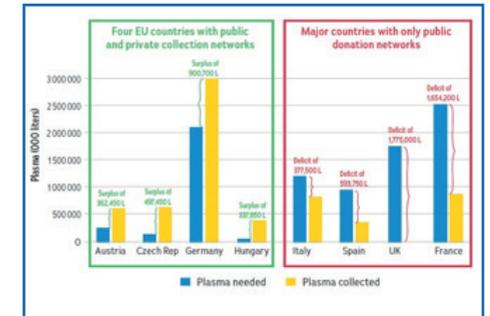
The manufacturing sites used by PPTA members to produce any plasma derivatives, regardless of whether they are located in the EU or the U.S. are regularly inspected by U.S./EU Health Authorities/Competent Authorities which are members of the Pharmaceutical Inspection Co-operation Scheme (PIC/S), an internationally recognized and independent inspection scheme. Of note is that U.S. centres which supply plasma for the European market are regularly inspected and certified by EU inspectors, in accordance with the relevant Good Manufacturing Practice (GMP) guidelines – the centres have to fulfill EU criteria in order to allow the plasma to enter the EU.

All manufacturing steps are conducted in accordance with GMP requirements, and any additional regulatory requirements. Additional legally binding requirements are Monograph O853 "Human Plasma for Fractionation" of current Ph. Eu. – and EU Directive 2002/98 EC.

Let's consider the question of donor centres. In the U.S. and many European countries, donor centres are properly regulated and controlled either because they are state operated or in some cases, commercial enterprises. Donors are often compensated for their donation. Is this practice considered ethical and safe?

Countries that have a combined public-private donation model (Austria, Czech Republic, Germany, and Hungary) contribute the most to plasma collections in Europe. In these four

countries, four times more plasma per resident is collected compared to other countries. ii These countries allow plasma collection centres to compensate plasma donors, using a fixed-rate allowance, for their expenses and inconveniences related to the donation.



Most EU countries provide some form of compensation for plasma donors. It covers expenses incurred and recognizes the inconvenience related to donating, following the principle of Voluntary Unpaid Donation (VUD). iii Some apply fixed-rate allowances, others reimburse specific expenses or compensate with time off from work, tax reductions, vouchers or by other means.

All these forms of compensation are altruistic-focused inspirations for those already motivated to donate and, in reality, all these ways of compensating donors have a monetary value. Yet compensation as a direct allowance, to compensate for expenses and inconvenience, seems to be the most efficient approach to increase plasma donations.

Living With ITP by Kavita Raina

As any 8yr old girl, I was scared when I was suddenly taken out of class at school by my mother and taken home, when I felt well. From my recollection the year was 1982. I arrived home (an apartment in London) to find our family doctor there advising my parents to take me to the hospital straight away for further tests as it was possible that I may have Leukaemia. I had symptoms of bruising and purpura (purple spots under the skin) and nose bleeds.

What followed was a physical examination for a variety of symptoms including an enlarged spleen. My spleen, at this stage appeared normal. Then there were gruelling daily/weekly blood tests. The fantastic doctors in the paediatrics department at Middlesex hospital were trying hard to give me a diagnosis. Some time had passed, then when I was 10/11 years old I was advised to have a bone marrow test. I still recall this as being the most painful procedure I have ever undergone. A sample of bone marrow was taken from my back hip bone (pelvis). I had undergone a general anaesthetic for the first time.

later I had a transfusion of a variety of blood products, platelets, immunoglobulin, blood, and plasma. This went on, intermittently, for several years. After the age of 13, I was often rushed to hospital for blood transfusions due to major blood loss through menstruating and nose bleeds. I was also put on a course of special steroid treatment (prednisolone) which made my face quite bloated and unnatural.

When I was 17/18 yrs my parents made a difficult decision to go with the advice of the haematologist and for me to have a splenectomy (surgical removal of the spleen) even though my spleen appeared normal. This decision was made as my quality of life had been severely affected. Following surgery my platelets stabilised and the condition went into remission and became more manageable. However, the splenectomy left

me more prone to overwhelming infection and resulted in my lifelong dependence on penicillin.

For many years I was able to lead a relatively normal life, I am now in my 40s and have two children aged 11yrs and 7yrs. Unfortunately, with the emergence of Covid I now have new fears to contend with regarding the vaccine and risks around clotting disorders. I had the first vaccine in March 2021 before the discovery of a link to blood clotting disorders and was extremely unwell – to such an extent I thought I would require hospitalisation. It made me very hesitant about having a second vaccine, but with the resurgence of Covid in Europe I am now reconsidering the second vaccine.

Editors note: All three vaccines will be safe for patients with ITP. None are produced from live virus so there is no risk from that point of view and there is no need to favour one over the other. All will be given by injection, and this may pose some risk of local bleeding in patients with platelet counts below 10 but we feel that, with local pressure and precautions during the vaccination, no patient should be excluded from receiving the potential benefits. Taken from the article Covid-19 vaccination assessment by Prof. Adrian Newland. The full article is available on our website at www.itpsupport.org.uk



Fundraisers & 'In Memory' Donations

Fundraisers

South Manchester Arthritis Support Group raised an impressive £1,500.00 towards the work of the association. They did not say how this was raised but a big thank you to everyone concerned!

De Facto Research Survey - £620.00. Anne Boulding was generous to donate her De Facto survey fee of £120.00.

Atlas Trading - collection tin 5 raised another £114.20 since December 2021

In memoriam

Dave Bagshaw - £659.24 – Many will remember the article written by Dave that was published in the Platelet some time ago, it is available on our website under the Patient Stories tab.

Mrs Jennifer Sutcliffe - £160.00

Wendy Tucker - £505 – Wendy was a great help in setting up one of the South Wales ITP Patient Support Groups (Pre-Covid), she was a lovely person who will be missed by all who knew her. There is a moving obituary for Wendy from her husband Robert in this edition of the Platelet.

Wendy Tucker – An Obituary

Wendy Leigh Tucker of Maesteg, South Wales passed away on 10th December 2021 of Covid-19 pneumonitis, aged 57 years. She is survived by her husband and two children.

Wendy had a wonderful life. Setting up home in rural Cornwall before living in Leicester city centre, where she worked as a nurse at Leicester Royal Infirmary, then returning to South Wales.

Wendy worked as a Behaviour Officer at Maesteg School. Wendy gave tirelessly of her time, love and patience to vulnerable children who were difficult to engage and trusted no-one other than Wendy. She was the reason that many of these children gave for completing their education or for turning up at school at all.

Wendy was diagnosed with ITP in November 2015, when her body became spontaneously covered with huge bruises over the course of a weekend. Eventually, her ITP made work impossible. Initial treatment was IVIG, (Intravenous Immunoglobulin), and prednisolone tablets. Wendy's ITP was unstable and often required hospital visits four or five times a week and numerous periods of time as a hospital inpatient. Other treatments tried included Rituximab, Eltrombopag, Romiplostim and Mycophenolate. All the treatments worked for a period of time, but Wendy's platelet levels would frequently dive close to zero and sometimes result in spontaneous bleeding. There were times when going to A & E felt like popping into our local pub because everyone knew our names. Somehow, Wendy remained happy, engaging, and uplifting throughout everything.

In recent years, during the pandemic, treatment with Mycophenolate combined with weekly injections of Romiplostim gave Wendy the most stable platelet levels and best quality of life she had achieved since diagnosis with ITP and only two hospital visits per week.



The immunosuppression from Mycophenolate was obviously a worry during the pandemic but changing treatment and the associated unstable platelet levels and increased hospital visits was also a concern. Somehow, Wendy was missed off the NHS list of immunosuppressed people and, consequently, did not receive her third Covid vaccine as early as she should have. Wendy caught Covid one week after her third vaccine.

The ITP Support Association improved the quality of Wendy's life over recent years by providing excellent information and advice about ITP. Together with Mervyn, Wendy was involved in setting up a local ITP support group in South Wales.

This moving tribute to Wendy was written by her husband Robert. Wendy was so supportive in helping to setup a local ITP Support Group in Wales and her input will be greatly missed.

The whole ITPSA family send their condolences to Wendy and all who passed during Covid. Mervyn Morgan.

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.

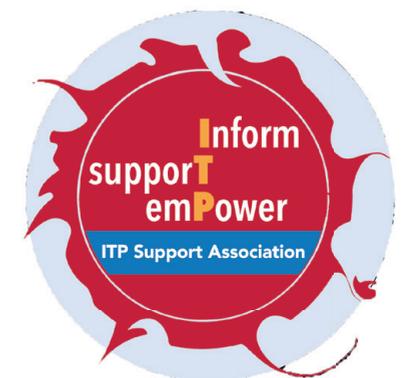
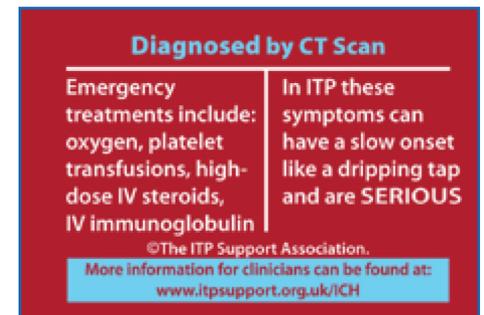
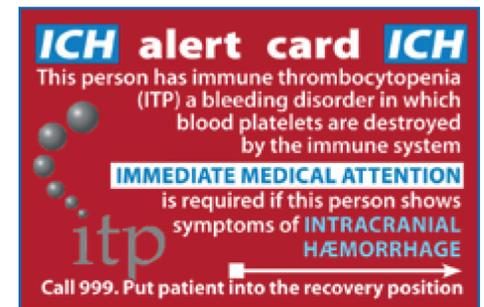
Order a free ICH alert card

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/itsupportassociation> 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 in 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/itsupportassociation 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

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

Publications List cont...

attention if the holder shows symptoms of intracranial haemorrhage (listed on the card). Also has information for medics.

FUNDRAISING & MISCELLANEOUS

Fundraising pack

suggestions for those interested in running a fundraising event

How does the Association use your donations?

an explanatory leaflet

About ITP and the Association

explanation about the condition and our work

Gift aid declaration form

tax payers can increase the value of their donations

Gift aid cards & envelopes

for donations collected at events, parties or funerals

Standing order form

for supporters wishing to make regular donations to the Association

Leaving a legacy

how to make a bequest to the ITP Support Association in your will

Collection box

rigid plastic, or pyramid foldable card, please state preference

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. The ITP pupil moving to senior school
12. Alert medical cards and jewellery
13. Healthy eating with ITP
14. H-pylori (stomach bacteria) & ITP
15. Causes of excess infections in ITP
16. A summary of low platelet disorders
17. Night calls - when to call the doctor
18. Service recruitment & ITP
19. Dentistry and ITP (questions & answers)
20. Women & ITP (questions & answers)
21. New insights on what causes ITP
22. Neonatal Thrombocytopenia
23. Post Transfusion Purpura
24. Must I mention my ITP at a job interview?
25. The 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?

Publications List cont...

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 hemorrhage in ITP

44. When bad bleeding happens

45. How often does ITP occur

46. How do hematologists 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 anesthesia, 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

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
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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

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