



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



The Platelet

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The ITP Support Association Team

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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

Since the September edition of the Platelet lots has been happening, firstly Global ITP Awareness Week – Supported by Grifols, was very busy with two well attended (Virtual) ITP Patient Support Group Meetings, the first was the launch of the Northeast of England ITP Patient Support Group with Dr Vickie McDonald from the Barts Health NHS Trust and Nurse Specialist Emily Stewart from Hexham General Hospital on hand to answer questions.



her team from Hammersmith Hospital, London on hand answering questions.



Between these patient supports meeting we also had the formal launch of the Shared Decision-Making document (detailed in this issue of the Platelet), this was launched online, on our website and by social media and email newsletters to all of our members and contacts.

To bring Awareness Week 2021 to a close we held a well-supported webinar, which brought together the ITP Patient organisations from the UK, USA and Australia for a 2-hour event. Each Association made presentations with the final part of the webinar being a Q & A with the ITPSA Chair of Trustees Prof Adrian Newland and PDSA Medical Advisor Dr James Bussell answering questions put to them by myself (Mervyn Morgan) and the PDSA CEO (Caroline Kruse). This went out across the world on social media.



Another recent highlight was getting the ITP Support Associations logo on National TV, we are pleased that one of the largest youth football clubs in England, St Albans City Youth choose to have our charities logo on some of their

teams shirts. It was pure luck but one of those teams was selected to be flag bearers on the pitch to welcome the players from St Albans City FC and Forest Green Rovers onto the pitch for their FA Cup First Round match which was being shown live on BBC2.



To make the day even better I was interviewed live on local radio before the game and had the opportunity to talk about the Association.

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.

Finally, from everyone at the ITP Support Association, the Trustees, Board members and the rest of the ITPSA team wish everyone a very Happy Christmas and a safe and prosperous New Year.

Best wishes

Mervyn Morgan CEO

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ITP Shared Decision-making Document

The ITP Roundtable project was a partnership with the ITP Clinical Forum and succeeded thanks to the help of funding support from several Pharma companies. The project stems from the results of the 2020 ITP Patient Perception Survey, the group was made up of members from the ITP Support Association and the UK ITP Clinical Forum.

The output from the project was a **'Shared Decision Making'** document entitled **'Making the right choices in ITP management and care'**. The document was officially launched during ITP Awareness Week in September 2021.

Shared Decision-Making Document Endorsements



At the launch of the document, we had endorsements from the Royal College of Pathologists, the Genetic Alliance UK, and Rare Disease UK, however we have since had further endorsements from the British Society for Haematology, the Royal College of Physicians, and the Royal College of General Practitioners. Thanks must go to Prof Adrian Newland, Dr Quentin Hill, and Dr Sue Pavord for pushing forward with the endorsement applications.

Downloads of the 'Shared Decision Making' have now topped over 4,000, this is in addition to almost 2,000 hard copies which have been sent out to ITP Specialist Centres, other Hospitals, medical staff, and patients.

We are now looking to have the 'Shared Decision Making' document translated into a number of other languages, these include Spanish,

Portuguese, German and Italian.



If you would like a hard copy of the document, please email info@itpsupport.org.uk with your address details and we will pop one in the post for you.

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."

Comments from patients

Alba said 'This is a beautiful, well made document. I fully recommend it to everyone!'

Amanda said 'SDM toolkit, which by the way looks great – congratulations.'

Karen posted 'Mine arrived in the post yesterday, it is very impressive and will be a great asset to all.'

Enormous thanks from Rhonda Anderson I have waited until the end of ITP Awareness Week to make contact.

I agree with all your previous comments on the Toolkit. The amazing response shows that this is wanted and needed. Congratulations to all the Team on the work done! Thank you for welcoming me to work with you, I feel it is a great privilege.

I don't have many medical networks but have sent it to the Patient Experience Team at Whipps Cross Hospital who will send it to all Barts PE teams. Adrian will have covered all Barts Health otherwise, I assume.

On behalf of ITP patients, I would like to extend our most sincere thanks to everyone, and especially all our Medical Advisors, who give so generously of their time, effort and expertise. This is a priceless gift to patients and their families who often have a very anxious time coming to terms with their diagnosis and treatment.

The Association has had some lovely messages of appreciation of the Zoom calls that have supported patients to an immeasurable extent.

The ways you have helped, are many and varied and cannot be listed, but you will know yourselves your commitment to the ITP Support Association and the patients.

Very many thanks to you all. With best wishes.

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 Group Meetings



ITP Support Association Group Meetings

Meetings are currently being held using the Zoom virtual meeting system.

We will be discussing future meeting options with the various Local Group organisers in the new year. If you would be interested in volunteering to help organise an ITP Local Group Meeting in your area, please email mervyn@itpsupport.org.uk.

We have several ITP Group Meetings being held around the country.

These groups are an opportunity for ITP patients, their family, and friends to meet in an informal setting giving them an opportunity to chat and talk about each other's experiences with ITP. The latest dates for our Local Group meetings are listed below.

England and Wales ITP Group Meeting - Next Meeting: 25th November 2021 7:00pm

Scotland ITP Group Meeting - Next Meeting: 14th December 2021 7:00pm

All-Ireland ITP Group Meeting - Next meeting: 10th January 2022 7.00pm

To register for any of the above meetings please go to www.itpsupport.org.uk

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. Our 2022 UK Convention will take place on 14th May 2022 (9:30am to 5:00pm) at the Royal College of Pathologists in their new headquarters building in Alie Street, London.

Tickets for the Convention will go on-sale on our website www.itpsupport.org.uk in January 2022.

Update on Patient Mentors for the ITP Support Association

This edition we welcome a new Patient Mentor to the Association, Karen Smith who lives in the beautiful county of Devon. Karen is a fellow is also the organiser of the Devon and Cornwall ITP Local Support Group.

PATIENT MENTORS

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Liam Burns' ITP Journey

Liam was diagnosed with ITP 27 years ago at the age of 50 after falling unwell. Numerous tests were done and he was referred to the Haematology Department at the Mater Hospital, Belfast where he was under the care of Professor Mary Frances McMullan. A diagnosis of leukaemia was considered until a lumbar puncture was performed, which confirmed a diagnosis of ITP.

Treatment at this time was platelet transfusions initially, however, Liam's body destroyed these platelets and therefore IGGs (Immunoglobulins) were given intravenously. These IGGs increased Liam's platelet count and his normal platelet count sat normally around 80.

Liam was a tiler by trade and had to give up this line of work. He was at high risk of bleeding and bruising. He got another job working in the Mater Hospital, Belfast as a domestic and then a driver delivering bloods to surgeries around Belfast.

As a consequence of having ITP, which is an autoimmune disorder, Liam's body then went to destroy itself further due to being immunosuppressed. He went on to develop Diabetes Type 2, Crohn's Disease, Pulmonary Fibrosis, Diverticular Disease, Haemolytic Anaemia (Evan's Syndrome) and was more prone to infection.

Due to congenital issues, he was discovered to have aortic stenosis, which required open heart surgery to insert a tissue valve as a mechanical valve was too high risk with having a low platelet count. This also meant that in the future he would have had to have open heart surgery again, as the tissue valves do not last as long as the mechanical valves.

Liam also developed bladder stones and then gallstones, both of which caused sepsis and

required procedures. What would have been a night or two in hospital, turned into a few weeks in hospital, due to low platelets. Liam had to receive transfusions, IGGs and immunosuppressant drugs such as Hydrocortisone/Prednisolone.

In October 2014, Liam's bloods were all abnormal, this included his platelet count and white blood cell count – all of which pointed to a diagnosis of lymphoma; however, further tests were performed including biopsies which ruled out lymphoma and diagnosed Crohn's Disease.

Liam was commenced on some drugs to control his Crohn's Disease a few years ago, which caused a platelet drop. This was the time he was diagnosed with Haemolytic Anaemia, as both his platelet count and haemoglobin levels were dangerously below normal. He was then commenced on steroid medication, (Prednisolone) which over time, increased both his platelet and haemoglobin count.

Since December 2019, Liam's bloods began to worsen. No one could find a cause for this, and it was just assumed that his ITP condition had worsened. In April 2020, Liam was admitted to ICU due to a small cut in his stomach, where he had internal bleeding. This was due to a very low platelet count of just 1. He was administered high dose Hydrocortisone amongst many other medications. With the help and support of Dr Benson and the Haematology Team in the Haemophilia Centre in Belfast, Liam pulled through and spent the rest of the year at home with his family, still receiving Prednisolone and two new drugs, Romiplostim (N-Plate) and Mycophenolate. The clinic in the Haemophilia Centre became like a second home to our family. In late January this year (2021), Liam's platelet count was steadily decreasing and on 15th February, he contracted sepsis and was admitted to hospital once again. This time, he had developed gallstones and cholecystitis.

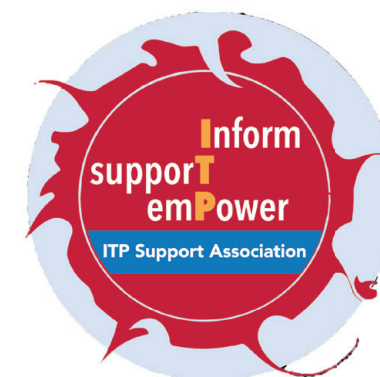
Liam did not show as having an infection previous to this as he was on immunosuppressants and this means that sometimes the patient does not always present with a temperature. During his seven weeks in hospital, Liam received platelet and haemoglobin transfusions daily. Sadly, on April 2nd 2021, he passed away. Having ITP meant Liam was not always a candidate for surgery or other interventions as he was at high risk of a bleed, even with having received platelets.

As a family, our life was not like other families we know. Liam's children spent their whole lives growing up where hospital appointments, blood transfusions, medication and taking extra precautions due to the risk of bleeding became the daily norm. Life for Liam and for us as a family was like a rollercoaster. Liam attended weekly appointments at the Haemophilia Centre, Belfast to have his bloods monitored and treatment adjusted as required. The fear we all felt as a family every week was the worst imaginable feeling ever. We were always aware that if Liam had new bruises, blood blisters/ulcers in his mouth, a petechial rash - had his platelet count dropped dramatically and was the medication no longer working? We could never travel far as Liam's platelet count could drop at any time and he had to be near a hospital. We found it very difficult to explain what ITP is and how it affects people. It is such a rare condition that most healthcare professionals that Liam came into contact with are highly unlikely to come into contact with another patient with ITP in their career. Many medics and nursing staff in the many wards in different hospitals that Liam was a patient in, did not understand ITP or how to deal with it, for example, extra care would have to be taken when manoeuvring or handling patients suffering from ITP, which many members of staff were unaware of and uneducated in.

The Haemophilia Centre did everything to give Liam the best quality of life for as long as possible. The past few years had been extremely challenging for Liam but no matter how much

pain and suffering he was dealing with he never complained and lived for every day. He is our hero and is an example to us all on how to live life to the fullest. In his darkest days he was still the one caring for others, visiting friends and relatives who were sick and always making everyone laugh with his jokes, even in times when we did not think laughing was possible. Only us, as a family, realised the implications and consequences of ITP and what Liam had to go through every day. He was so brave and did not want to trouble anyone even when he knew all his diagnoses were stacking up against him and the odds were getting shorter. We miss him immensely and our family life will never be the same.

We hope Liam's story can make a difference to other ITP patients and their families and help promote awareness of this terrible disorder.



'Chronic illness is a lonely thing' by Karen Tomkins

For the past year I religiously text my husband, Shea, every Friday afternoon. There's nothing unusual in that, but the weekly message contains just a number, no words. Triple digits and we're happy; single digits and it's time to get family in to mind the children and pack a bag for hospital.



Karen is one of around 1,000 people in Ireland with ITP

The number I text is my platelet count. I am one of approximately 1,000 people in Ireland with ITP (immune thrombocytopenia), a rare blood disorder in which the immune system mistakenly attacks its own platelets. It can occur in pregnancy, follow a virus, vaccination, or certain medications, but for most people the cause is unknown.

I learned about the importance of platelets in my first pregnancy, in 2007. As the Syntocinon drip unleashed contractions from hell on this novice labourer, I remember the midwives telling me that I only barely made the threshold for an epidural with a platelet count of 80 on the day. It meant absolutely nothing to me; I got my epidural and my baby boy, Jack, now heading for 14 years of age.

My gestational ITP was confirmed earlier on in my second pregnancy, in 2010, when my platelets fell into the 30s. A normal platelet count ranges from 150,000 to 450,000 platelets per microlitre of blood. This is usually referred to by the first three numbers 150 - 400. With ITP, a "watch and wait" approach is often adopted by haematologists when a patient's count is between 100-50 and often down to 20-30. Mild bleeding and bruising sometimes occurs when the count is less than 50.

The risk for serious bleeding doesn't occur until the count becomes very low - less than 10. Internal bleeding and a bleed on the brain are the biggest risks at this point, which can be fatal. The UK's ITP Support Association lists blood in the eyes, bleeding from the ears, blood in the urine, bleeding from the gut and a bleed into the brain (in a small number of cases) as severe symptoms of a very low count.

Thankfully, the ITP in that second pregnancy was managed with immunosuppressant Prednisolone steroids throughout. I had another epidural and another baby boy, Harry.

As predicted, the ITP went away and as predicted, it came back again on my third pregnancy, five years later. I began to take a high dose of steroids at nine weeks as my platelets were already hovering at 30.

Christmas morning

Announcing the happy news at 12 weeks was quickly met with despair.

Christmas Day 2015 at our Co Wexford home: Santa had been and gone and the boys, aged eight and five, were deep in an ambush of new Nerf guns. I smiled through their excitement but couldn't ignore the bleeding I had noticed when I went to the toilet. But what does a pregnant mother do on Christmas morning when it looks like the inevitable is happening? In between carving the turkey and greeting family, the bright red blood was hard to ignore. But it only happened when I went to the toilet and my mouth and lips were filling with black blisters. I sneaked upstairs to phone the midwives on the University Hospital Waterford labour ward. No cramping, no clotting, no blood apart from in the toilet. "Keep an eye, it could be spotting. Come straight in if it gets worse."

It's hard to find anywhere to go on St Stephen's morning when you're killing an hour waiting for the phlebotomy department to process bloods. But I didn't have to worry. We weren't far from the hospital when their number flashed up on my phone. "Are you close by? You need to get back straight away. Your platelet count is at 1 - this is really serious, Karen."



Karen recovering from spleen removal surgery at The Dunmore Wing, UHW.

Under the care of haematologist consultant Prof Ezzat Elhassadi, I was given a platelet transfusion and started what would become countless rounds of intravenous immunoglobulin (IVIg), a type of antibody treatment, extracted from the combined plasma of more than 1,000 screened blood donors. It's given intravenously over a few hours. On a non-medical note, I can tell you it comes in a cute little glass bottle. Not so cute when you need 3½ glass bottles every time, which took up to eight hours.

Dangerously low levels

My unborn baby was thriving, but my ITP was still dipping to dangerously low levels. Surgery to remove my spleen and a medical termination were mentioned as treatment options. The pregnancy was causing a risk to my life if my platelets plummeted and couldn't be feasibly increased. It is said that the eye of the storm is often the calmest place to be, and that's where I, my husband and my baby stayed. My own multidisciplinary team of family, friends, neighbours, and the parish priest were all working around the clock helping us out at home.

In March 2017 I woke up with a blinding headache, a body of bruises, a mouth full of blood blisters and a platelet count of 1

I became a regular at the oncology and haematology day ward for weekly, sometimes fortnightly rounds of IVIG along with tapering off steroids. The treatment and the prayers worked and at 36½ weeks, consultant obstetrician Dr John Bermingham persuaded my beautifully healthy little girl, Daisy, to make her appearance.

Unfortunately, my ITP journey didn't end there.

In March 2017 I woke up with a blinding headache, a body of bruises, a mouth full of blood blisters and a platelet count of 1. In the four years that followed, it was apparent that I had progressed from gestational to chronic ITP. A bone marrow biopsy didn't show anything sinister - just bad blood which I had to accept and learn to live with.

I've seen a lot of Prof Elhassadi and his team since then. We've worked through many different treatments from steroids, new high-tech drug Eltrombopag to four rounds of a biologic called Rituximab and Mycophenolate (also used to stop the body rejecting organ transplants) - some of which I lost my response to, while others caused unpleasant side-effects.

I returned to work as a news broadcaster, incorporating my haematology outpatient appointments as a way of life. When my platelets dropped, I'd go back on steroids and then taper off them slowly. The longest stint of taking them was for 10 months in which time the biggest side effect was steroid "moon face" and tighter clothes.

I'm grateful for the fact that despite having my platelets at "life-threatening" levels, I never experienced the awful stuff I find on Google at 3am when I can't sleep

Covid lockdown was worrying but my platelet level stayed above 100 without any treatment throughout. I'd like to think it was in part due to the chakra rebalancing I had done by a faith healer. I've drunk oceans of beetroot juice and papaya leaf extract, I've tried a plant-based autoimmune protocol diet, I've touched a relic of Padre Pio, I've boiled up Chinese herbs that stank the house out, I made my husband rearrange our bedroom to move us out of a geopathic stress vortex and I meditate and run every day when I'm well. And still, regardless of what I do or don't do, ITP has always found me again.

Begin treatment again

Last August, I got a phone call from the hospital just after I read the main lunchtime news on WLRfm. Not quite headline news, but my platelets were at 17 and it was time to begin treatment again. This time, I opted for N-plate - a weekly subcutaneous injection of Romiplostim administered in a day ward at UPMC Whitfield hospital in Waterford.



Karen had a splenectomy at UHW in September 2021.

For more than a year, I devoted every Friday to getting this injection, which is a two-hour round trip and a day chalked off my calendar. While Romiplostim has had varying degrees of success, I found it very inconsistent and although I can't attribute the onset of frequent ocular migraines and severe joint-pain as direct side-effects, my quality of life slowly diminished. My recent 40th birthday fell on a Friday - injection day - sweetened only by the kind gesture of chocolates from the day ward staff.

Twenty-four hours after receiving the Moderna Covid vaccine in April 2021, my platelet count was back at 1. It stubbornly rose and I let go of my stubborn refusal to consider a long talked-about second line of treatment - splenectomy. In people with ITP, the immune system treats platelets as foreign and destroys them. The spleen is responsible for removing these damaged platelets and so, in about 70 per cent of cases, removing the spleen can help to keep more platelets circulating in the body.

I'm grateful for the fact that despite having my platelets at "life-threatening" levels, I never experienced the awful stuff I find on Google at 3am when I can't sleep. However, chronic illness is a lonely thing and I'm guilty of masking my pain, fatigue and worry with fake tan, gym leggings and a smile. It forced me to give up working full-time as a news journalist, although it helped me to find my real passion as a children's creative audio writer, for which both my radio series won IMRO awards, in 2020 and 2021.

Antibiotics for life



Karen after winning an IMRO award for her work in 2020

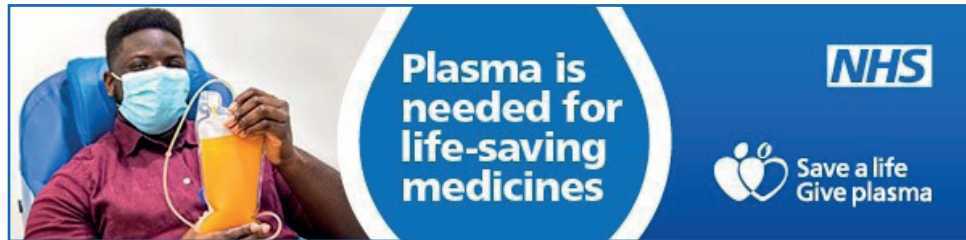
On September 9th, I took my 70 per cent chances and Prof Fiachra Cooke laparoscopically helped me bid farewell to the little organ that I might be better off without.

"It's not you, it's me," I whisper to the empty space in my upper left abdomen which used to house one of the chiefs of my immune system. In its place I've had all necessary vaccines and will have to take low-dose antibiotics for life.

One-week post-surgery saw my platelet count rise to 783. This dropped to 45 after a month, but it climbed again without any intervention and today my platelet count sits at 100. It's still early days and I have other treatment options if this doesn't work in the long term. But for now, I have high hopes, a high platelet count and no bad blood.

This article was first published in the Irish Times and has been reproduced with the kind permission of Karen Tomkins.

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



If It Sounds Too Good To Be True, It Is Too Good To Be True

By Anthony Heard

This article looks at alternative treatments, herbal and natural remedies for ITP. I have written about this very subject in the past in this very column, but I continue to get numerous questions and comments about it from many people living with ITP via our social media platforms.

So as the issue seems to keep cropping up, I thought that it would be useful to revisit the subject and explain why if an alternative remedy sounds too good to be true, then it is too good to be true.

I have never tried anything other than conventional medicines prescribed to me by my ITP specialists. I will highlight the many reasons why I personally have opted to tread this path. The drugs that I have been treated with over my ten purple years have been.....Prednisolone, Azathioprine, Rituximab and currently Mycophenolate Mofetil (MMF).

The following important factors were key in persuading me not to try any alternative treatments including things like Papaya Leaf extract and Aloe Vera juice.

1. There is no scientific evidence to confirm that any alternative, herbal or natural remedies raise the platelet count. Platelet counts may well increase in some people in the short term. But it is impossible to tell whether or not the increase is really due to the alternative remedy or just general fluctuations in our platelet count due to changes in our overall health etc.

2. No official registers are maintained anywhere to record side effects or results which may be caused by alternative, herbal or natural remedies including Aloe Vera juice and Papaya Leaf extract. With conventional ITP treatments full

records are kept and updated of any side effects encountered.

3. There hasn't been any research on the true impact of alternative, herbal or natural remedies. The bottom line is that we just don't know.

4. There are many dangers in using these types of remedies. It is virtually impossible for us as potential users to actually test/verify exactly what we are taking. We just can't really tell what is in the remedy. Is it what it says it is? With so many unscrupulous sellers especially via the Internet, it's impossible to be totally sure what we are taking.

5. There are no sure and certain guidelines as to exactly how much of these remedies we should take. Unlike conventional treatments where prescription is supervised by our specialists and our responses monitored carefully.

6. Surely if it really was possible to raise our platelet counts and control our ITP by taking a relatively simple herbal, natural or alternative concoction then why wouldn't any of the many ITP specialists I have discussed it with in my 15 purple years suggest or recommend it?

7. None of the many ITP specialists I have discussed such remedies with have had any hope that they would work. Their general reaction has been that sadly it is just wishful thinking or clutching at straws.

8. The very latest research into ITP and its' causes confirms that there is a whole host of very complicated processes going on in the immune systems of ITP sufferers. It has become increasingly apparent that ITP and the causes of it are far more complex than we have previously thought.

These are the issues that have driven my decision to stick with conventional treatments for my ITP.

I have made a conscious decision to treat my ITP with conventional medicine. I have concluded that there are no miracle cures for ITP. My thinking is driven by the opinions of the specialists that if the ITP riddle could be solved by a cocktail of herbal, natural, nutritional remedies, then they would have suggested it by now. Sadly, it is wishful thinking.

The truth is that ITP is very, very complex and because it is so rare, we simply haven't done enough research yet to really know with any certainty what such remedies can offer.

Some things that I have found helpful during my 15 ITP years have focused on trying to eat healthily and sensibly, exercise regularly and stay well hydrated. There is absolutely every reason to eat and drink healthily. By that I mean eating plenty of fresh fruit and vegetables (green vegetables especially like kale, broccoli, spinach), minimising the amount of processed foods, eating red meat in moderation, eating less or in my case no junk food, drinking more water and less caffeine and alcohol, not smoking, and getting plenty of rest/sleep. It's called common sense.

All these things will assist our overall health and well - being, including keeping our immune systems healthy and hopefully platelet production plentiful. Drinking too much alcohol for example damages the liver which is responsible for production of the substance Thrombopoietin in our systems which itself regulates the production of platelets in our bone marrow. The only other thing that I do is take a Vitamin D3 supplement every day (to see why please check out the following link - <https://www.nhs.uk/conditions/vitamins-and-minerals/vitamin-d/>).

The most important thing I will say to conclude is...

Never take anything at all without discussing it in full with your ITP specialist/doctor. In the meantime, if something sounds too good to be true then it is highly likely that it is too good to be true. Unlike Smokey Robinson, I simply cannot believe in Miracles, false promises, or so-called

magic potions.

Professor Adrian Newland has kindly written the clinicians perspective to "alternative" remedies.

Many of the drugs we use in medicine have come from herbal remedies. Often common use has brought them to attention, the active ingredients isolated, then produced in controlled environments, studied in trials and, if successful, introduced into mainstream medicine. It is the rigorous process of development that reduces the risk of taking the drug. All drugs will have side-effects and it is important not to, inadvertently, introduce more.

Herbal remedies generally come from plants that will vary depending on their growing conditions and handling and may contain contaminants and toxins and may well interact with conventional treatments in ways that may not seem obvious. For instance, the Federal Drug Administration (FDA) in the USA have found that 1 in 5 products tested may contain mercury, lead or arsenic and have banned their import into the States.

While most doctors do not object to patients taking complementary medicines it is important that they are aware what the patient is considering taking so they can advise on its suitability. The point is well made in the article that if any product had an obvious, and positive effect, on the platelet count then this would have been rapidly taken up by industry. For many years the pharmaceutical companies have been studying the South American rainforest plants for useful compounds and currently over 120 prescription drugs derived from this source have been discovered that treat many major conditions.

ITP Global News

Congratulations to ITP Australia's Danielle Boyle for turning Brisbane purple during ITP Awareness Week 2021.



During the Covid Pandemic a huge well done must go to Marilia Lia from PTI Brasil (ITP Brazil).

Marilia has carried out a number of fantastic live interviews with Doctors and specialists.

There is great work like this taking place all across the globe, this is all being carried out to support ITP patients. For more information

LIVE NO INSTAGRAM @ SETEMBRO ROXO
DIA: 09/09/2021 HORÁRIO: 19:00

NUTRIÇÃO E HÁBITOS ALIMENTARES PARA PACIENTES COM PTI

DRA. AMANDA RIMOLO
Nutricionista Clínica desde 2006
Pós-graduada em Nutrição e Dietologia
Especialista em Nutrição Enteral e Parenteral
Mestre em Gastroenterologia e Hepatologia
@nutriamandarimolo

MARILIA LIA
Paciente, Ativista e Fundadora da PTI BRASIL;
Embaixadora Brasileira International ITP Alliance;
@pti_brasil

#SEJAPROTAGONISTA



about the global effort visit the International ITP Alliance website at www.globalitp.org.

10 DE NOVEMBRO
20:00 HORAS
LIVE NA PTI BRASIL
PTI E LÚPUS

MARILIA LIA
@pti_brasil
PACIENTE, ATIVISTA E FUNDADORA DA PTI BRASIL;
EMBAIXADORA BRASILEIRA INTERNACIONAL ITP ALLIANCE;

DRA. ANA JÚLIA FURBINO DIAS BICALHO
@anajuliareumato
- REUMATOLOGISTA - GRADUAÇÃO UFMG - RESIDÊNCIA MÉDICA EM CLÍNICA E REUMATOLOGIA HOSP. DAS CLÍNICAS UFMG - TÍTULO DE REUMATOLOGISTA SOCIEDADE BRASILEIRA DE REUMATOLOGIA

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/13990747/>

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

A Question from Rebecca:

I had my spleen removed age 6 for resistant chronic ITP. Ever since I have been taking prophylaxis penicillin twice a day, as advised by my clinicians. As I am now 23, I was wondering if I still need to take the antibiotics - what are the risks / benefits? I feel like it might be affecting my gut microbiome as I get 'colds' frequently. I am aware of the risks regarding bacterial infections, and the need for antibiotics if I get a fever. I am also aware the guidelines differ in the US and Australia regarding prophylaxis antibiotics after splenectomy. So, my question is whether I should continue with the penicillin? I wonder if the risks now outweigh the benefits. Any advice on this would be greatly appreciated.

Prof Newland replied:

An interesting and difficult question.

As far as I am aware the UK is the only country that recommends life-long Penicillin in people who have had their spleen removed. This used to be three years but was changed over 20 years ago by the Chief Medical Officer at that time. There are risks of overwhelming infection when there is no spleen, and these risks are greatest in the first few years. They do not disappear completely but are very low indeed in otherwise normal individuals. In patients who have had their spleen removed for Sickle Cell Disease, Thalassaemia, malignancy or who continue to take immune suppressive drugs, including steroids, the risks remain real, and it is this group we should concentrate our energies on in persuading them the value of continued antibiotic prophylaxis.

Studies have shown that nearly 60% of patients do not take their Penicillin, and many take it intermittently. There is always an increased risk of bacterial resistance in long term prophylaxis, and this is worse in intermittent use.

Although our advice has to be to take the antibiotic, because those are the rules, there is little if any risk in not taking it after a few years administration, if you do not fall into any of the at-risk groups. We do advise keeping a supply of antibiotics at home and taking these immediately should you develop a fever or a productive chest infection, particularly if medical

advice is not available rapidly. This does not mean 'colds'.

Ultimately it has to be your decision but at nearly 20 years out from your surgery you are long passed the high-risk period. It may be worth discussing with your haematologist or GP but many do follow this route. It is worth making sure that you have had the various immunisations we recommend post splenectomy (pneumococcus, HIB and meningitis) plus the annual flu jab.

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? All patients with ITP have a good understanding of their condition and how it affects their quality of life.



Derek Elston interviews Maarten Van Baelen



This is due to the treatment they receive and, in many cases, the medication prescribed and I trust the information we provide in the platelet, at conventions and local meetings aided by our medical advisers to whom we are indebted. I have for some time thought it would be interesting to talk to people who may be concerned with enabling us to enjoy an acceptable QOL and who are concerned behind the scenes with medication manufacture, development or even in an advocacy situation. To this end I am delighted to present this interview with Maarten Van Baelen from the PPTA which I hope you will find informative and interesting.

Good morning, Maarten and may I thank you for agreeing to an interview with the ITP Support Association.

As a patient support group and a stakeholder within PPTA for many years acting in an advocate capacity, the intention of this interview is to acquaint our patient members as to the role PPTA plays in respect of plasma and production of plasma products for the treatment of many conditions.

Perhaps I could start by asking you to introduce yourself and your role within PPTA coupled with information on who PPTA are, and their global function...

The Plasma Protein Therapeutics Association (PPTA – www.pptaglobal.org), a global industry trade association, represents the private sector manufacturers of plasma-derived and recombinant analogue therapies, collectively known as plasma protein therapies, and the collectors of source plasma used for fractionation. Millions of people use these therapies worldwide to treat a variety of diseases and serious medical conditions. PPTA also administers standards and programs that help ensure the quality and safety of plasma protein therapies, donors, and patients.

As Executive Director Europe, I head the Brussels office of PPTA. I'm a pharmacist by education, but most of my career I've worked in the EU policy environment. Ensuring patient access to medicines is what drives me personally. Our mission for PPTA Europe is to create awareness about plasma and plasma-derived medicinal products (PDMPs), to increase plasma

collection in Europe, and to improve patient access to PDMPs.

For the benefit of our readers, could you briefly explain how the plasma equipment operates and who would be using this equipment?

Plasma can be obtained from whole blood donations (resulting in recovered plasma) or collected directly through a process called plasmapheresis (resulting in source plasma). Plasma donation requires commitment from the donor, as it generally takes about one hour to donate plasma and can be donated more often than whole blood. The European Commission highlights that plasma donation by plasmapheresis is more efficient, compared to recovering plasma from whole blood donations.

Direct donation by plasmapheresis is a process that removes plasma (source plasma) from the donor's blood and returns the remaining cellular components to them. This is done at a specialized plasma donation centre or blood centre. Donating plasma takes about one hour and can be done more frequently than blood donation, up to 60 times yearly in Europe, depending on national legislation. One plasma donation gives 650-880ml of plasma.

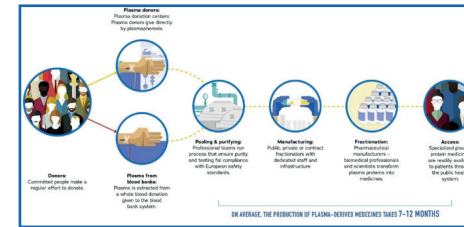
	Extraction	Donation	Frequency	Duration	Volume
SOURCE PLASMA	<p>Plasma is separated from whole blood at the donor center. Red cells are returned to the donor.</p>	<p>Plasma (plasmapheresis)</p>	<p>1 x weekly</p>	<p>90 min</p>	<p>~820ml</p>
RECOVERED PLASMA	<p>Blood is collected from the donor and processed at a specialized plasma donation center or blood center.</p>	<p>Blood donation</p>	<p>4-6 x yearly</p>	<p>30 min</p>	<p>~200ml</p>

Plasma can also be separated from whole blood through a whole blood donation at the national blood bank system. After donation, blood is separated into its different components (recovered plasma). A whole blood donation takes about 15 minutes and can be done between 4-6 times per year (depending on gender). One whole blood donation of 500ml gives 250-300ml of plasma.

Would I be right in saying, plasma collected from a donor is then treated by specialised companies and not necessarily by a donor centre?

Producing a plasma-derived medicine is a lengthy and complex process. It takes up to one year from the moment a donation is made until the therapy is ready for patients. Collected plasma is held in frozen storage for 60 days, pooled, and processed following a strict safety and purification regime.

It is then sent to a manufacturing facility that makes PDMPs. Here plasma is further tested; the manufacturing process uses fractionation to extract therapeutic proteins from the plasma. These protein fractions are further purified to extract proteins of interest, which are then cleared of potential viruses by additional steps. The purified proteins are formulated into ready-to-use medicine, tested for sterility, packaged, labelled, and distributed through public health systems.



The collected plasma is then pooled and treated. What happens to the plasma during this process of purification and the length of time it takes to reach a purified state?

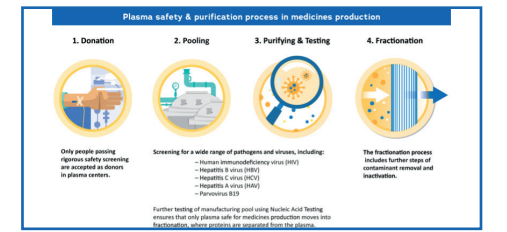
“The Power of Plasma Donation”: <https://www.youtube.com/watch?v=08Pb-UZPLiU&t=9s>

PDMPs are a unique class of biological therapies used to treat rare and severe diseases. Unlike chemically synthesised drugs or biological medicines made by recombinant cell lines, PDMPs are the only therapies solely derived from human biological material. The entire process from plasma donation to patient is considerably more complex, labour-intensive, time-consuming, and costly than that for other medicines. Furthermore, since the starting material is human plasma, the processes for plasma donation and PDMP manufacturing are separately regulated to ensure patient and donor safety.

The first of many steps in the manufacturing process is the pooling of the plasma, whereby many donations are combined into a manufacturing vessel. The plasma pool itself undergoes additional pathogen testing to give added assurance of safety. Following that, therapeutic proteins are extracted from the plasma. This process is called fractionation, and, as the term suggests, it separates the plasma into different fractions. The fractions are purified, and potential

pathogens are inactivated/ removed. Each individual manufacturer's process is different, resulting in variations between brands. For this reason, individual patient treatment relies on access to one brand. This is contrary to optimal treatment, because a patient's tolerability could differ depending on the brand of the given PDMP. Following further checks for efficacy, safety, and sterility, the batches of finished PDMP are released. The manufacturing processes require licensing by official bodies, and manufacturing sites undergo regular inspections. In addition to the abovementioned requirements, manufacturers and collectors may voluntarily adhere to industry standards such as the International Quality Plasma Program (IQPP) for plasma collection, which includes third-party evaluation of plasma donation centres, and the Quality Standards of Excellence, Assurance, and Leadership (QSEAL) program for manufacturing.

The complexity of the PDMP process impacts the time it takes from plasma donation (donor) to treatment prescription/administration (patient). Donor to patient timelines can take as much as 7-12 months. With such extensive timelines, it is critical that sufficient plasma volumes are always available for fractionation.



How many plasma donations are required to treat one patient?

It can take up to 1200 donations per year to treat one patient with haemophilia. However, the main protein that is driving the need to collect plasma is immunoglobulin. Even though it “only” requires around 130 plasma donations to treat one patient with primary immunodeficiency, to meet the clinical need for immunoglobulins in Europe we need more than 14 million litres of plasma. For the UK alone this is about 1.8 million litres.



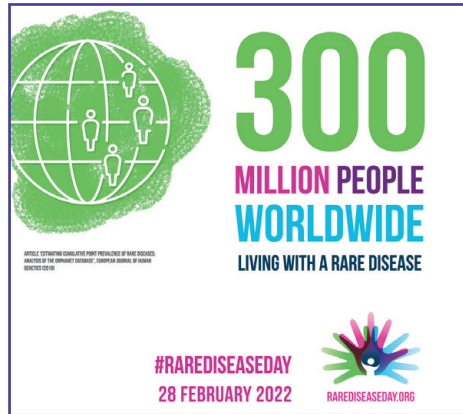
The concluding part of this interview will be included in the March 2022 edition of the Platelet.

Rare Disease Day 2022

What is rare disease day?

Rare Disease Day is the official international awareness-raising campaign for rare diseases which takes place on the last day of February each year. The main objective of the campaign is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives.

Rare Disease Day was launched by EURORDIS- Rare Diseases Europe and its Council of National Alliances in 2008.



Fundraisers & 'In Memory' Donations



Lucy McIntyre - virtually walked/ran the length of the UK from Land's End to John O' Groats starting

in January and finishing late October, raising an amazing £1,325.55 (inc Gift Aid). A tremendous effort Lucy!

Atlas Trading Limited have sent another £150.00, proceeds from collection box 5.

Sophie Booth made homemade fudge and raised £150.00.

A huge thankyou to everyone who donated via our fundraising platforms:

Virgin Giving- £784.05
Facebook Donations - £1,650.53

Please remember Virgin Money Giving is closing at the end of November and we have moved to Just Giving.

In Memory:

£40.00 was donated by friends Pat Edgar, Doris McGinnes, Brenda Darey and Maura Brown in memory of their dear friend, Mrs Doris Robinson.

Mrs Cleghorn sent a cheque for £60.00 following holding a golf competition in memory of Murray Cleghorn.



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.

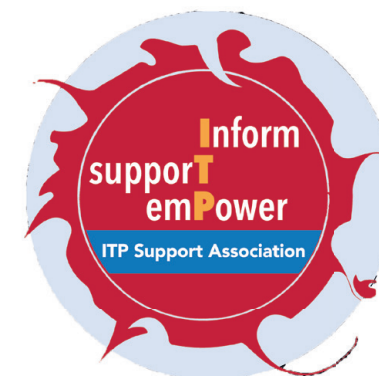
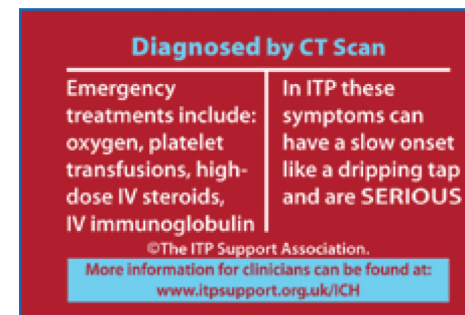
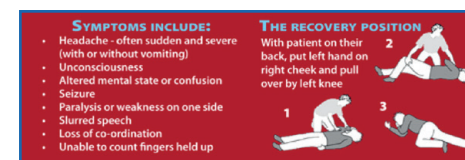
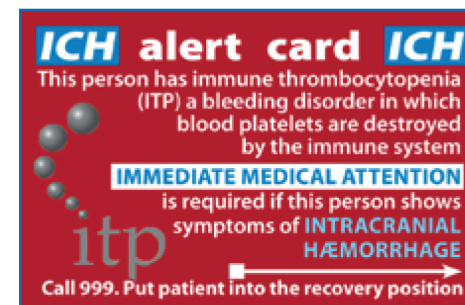
Order a free ICH alert card

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
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

