



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



JONNY MELLOR
NEW ITP AMBASSADOR

The
Platelet

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

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

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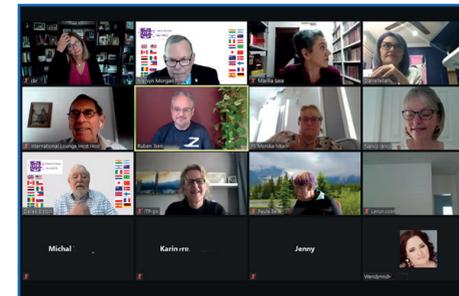


From ITP HQ

As you read this, our December edition of the Platelet Journal, you will be preparing for a quite different Christmas compared with 'normal' times. I keep asking myself where has this year gone?

This edition of the Platelet contains a report on our recent 'Virtual' Convention which took place back in October, the feedback from those who attended the event (from the comfort of their own homes) has been amazing. With over 350 people registered and more than 3000 site visits in the first month from dozens of countries it is clear that the virtual format worked. A huge thank you to all our presenters, sponsors and especially those who registered and enjoyed the event.

The day before we held our Annual Convention we also hosted (Virtually) the Annual meeting of the International ITP Alliance, this is the umbrella organisation for all the ITP Patient Groups around the world.



It was also an opportunity to recognise the contribution of two colleagues from the ITP Patient Association in the Netherlands. Theo de Wispelaere and Karin de Boer, both of whom have recently finished their terms of office on the board of their organisation. Vice Chair of the ITP Support Association Mr Derek Elston gave them the news that they were being made Hon Members of the UK ITP Support Association, special certificates have since been sent to both.

Congratulations should also go to another friend of the Association Mr Ajoy Roy who organised and hosted the first 'Virtual' ITP Meeting in India. Derek Elston and I also dialled in to give our support, well done Ajoy.

You will not be surprised, but planning is already underway for next years UK ITP Convention, given the ongoing Covid-19 issue we are playing safe and planning with two options in mind, if Covid is no longer an issues (which is very doubtful) then we still have our booking in London, however if, as seems likely the Covid restrictions are still in place then we have also have the production team from this years event on standby. We will decide which option to take early in the new year.

You will also read about our new ITP Support Association Ambassador, Mr Jonny Mellor, read more about Jonny in this issue.

From everyone at the ITP Support Association, thank you for your continued support, stay safe and enjoy the festivities of the Holiday season.

Mervyn Morgan CEO

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American Perspective

The American Perspective: "Teaching a New Dog a New Trick" Spero R. Cataland, M.D.

In recent years physicians and researchers in most fields of medicine have become increasingly specialized. Especially at university settings, physicians not only focus on one area of medicine (hematology, cardiology, etc), but also focus on one particular disease in their field of specialty. While this focus on one disease can be very productive and lead to many advances, to the outside observer it might appear to prevent people with different interests from communicating ideas and research projects. The annual American Society of Hematology (ASH) meeting will be held virtually in early December this year. Each year, hematologists from around the world get together to share information, ideas, and discuss research from within their specific field or disease of expertise. The exchange of ideas that will occur between different groups of researchers may focus on seemingly different and distinct diseases, but invariably this exchange leads to new ideas and studies that may apply to their own disease. These types of exchanges likely have contributed to the development of the three novel treatments for ITP that will be discussed in this essay that had their "start" in other diseases.

IgG antibodies bind to the platelets of ITP patients leading to their clearance and destruction, and the clinical picture of low platelet counts and bleeding that characterizes ITP. Efgartigimod (say that quickly three times) is a fragment of the human IgG antibody that binds to what is known as the FcRn receptor, leading to the premature clearance of the IgG antibodies that lead to ITP. Efgartigimod was originally studied in myasthenia gravis, another antibody-mediated disease like ITP, that can lead to severe muscle weakness. The thought behind the development of the drug is that treatment with efgartigimod will lead to



lower levels of the anti-platelet IgG antibodies and improvements in the platelet count by decreasing the amount of anti-platelet antibodies that are present to degrade or clear platelets. Indeed, the initial studies of this drug have shown a rapid reduction of these antibodies does occur after treatment, and this drop in the antibodies was accompanied by increases in the platelet count. A larger, multicenter study is presently underway to study the effectiveness and safety of this treatment in chronic ITP.

There is a relatively new class of drugs called Bruton tyrosine kinase (BTK) inhibitors that have been approved for the treatment of different forms of chronic lymphocytic leukemia (CLL) and lymphomas. This class of drugs can lead to decreased survival of malignant B cells in patients with these conditions, but may also lead to a decrease in the B cells responsible for production of anti-platelet antibodies that target platelets in ITP. At this year's upcoming ASH meeting the results of a study of the oral medication rilzabrutinib will be presented. In this study of chronic ITP (many of which that had already failed prior ITP treatments), nearly half of patients showed an improvement in

their platelet counts. While further study is needed with rilzabrutinib and other similar medications, there is hope that this medication may soon be able to help patients with chronic ITP.

The complement system is part of our normal immune system that helps to protect us from infection, inflammation, and other threat to our bodies. There are three different components of the complement system that are activated in different ways and for different reasons. These include the classical pathway, the lectin pathway, and the alternative pathway. Impaired function in any one of these components can be associated with several diseases, and there are different treatments targeted to each specific pathway. In the specific case of ITP, there has been evidence for the activation of the classical pathway of complement by platelet antibodies contributing to the destruction of platelets. Sutimlimab is an antibody that targets C1s, one of the proteins involved in the classical pathway of complement. This medication has been shown to be an effective treatment of a rare blood disease called cold agglutinin disease that leads to the immune destruction of red cells by the same classical complement pathway. At last year's annual ASH meeting sutimlimab was reported to lead to a sustained increase in the platelet count in patients with chronic ITP patients that had failed at least two prior therapies. This study provided evidence for an additional mechanism of destruction of platelets in ITP, and provides hope for new treatment options for those patients that have not responded to prior therapies for chronic ITP.

The upcoming 62nd Annual Meeting of the American Society of Hematology will without question be different this year due to the ongoing pandemic. However, the exchange of ideas among researchers that is the most important part of the meeting will remain the same. It will just happen on a computer, in a colder climate for many of us who look forward to the locations of this meeting and a little bit of sun each December.

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.



Your Questions

Q from Linda, My platelets can get into single figures and I have absolutely no symptoms, i only find out my platelets are low from the blood test or if my period arrives, does this mean I am OK to function with platelets in the single figures as I am not a bleeder? Although I am in my 40s, I play rugby, snowboard, and downhill mountain bike.

A From Dr. Cindy Neunert, we generally think adults should be maintained at a platelet level of 20-30 but recognise we don't have good information in this area and some patients may be okay at lower levels. That being said for the activities you want to enjoy a higher platelet count would be needed.

Q from Louise, Hi, are there any links between ITP and HPV, i have recently tested positive for following smear and I am intrigued if there are links, thank you .

A From Prof. Newland, HPV can reduce the platelet count but often reduces white cells as well. This is because the infection may depress the bone marrow. This is not common and will recover. ITP may be seen following HPV but again is very unusual and also transient.

Q from Gabrielle, How long is it safe to stay on the maximum dose (75mg) of eltrombopag?

A Dr. John Grainger, we have over 10 years safety data on maximum doses. More side effects may be seen at doses >75mg but very safe at "normal" doses.

Mans best friend can also have ITP

Q My dog was recently diagnosed two months ago, and I am trying to identify any research going on in dogs for better treatments? Randomly I saw a press release today from the company I work for about FDA fast track of a product for humans. Are you aware of anything in dogs?

Hopefully, this product will be approved for human use and possibly lead to something for our furry friends as well. Please let me know if you are aware of good treatment options outside of prednisone?"

Would you be able to kindly enlighten the association as to whether there is another positive treatment apart from Prednisolone?

A Andrew Kent BVSc, there are various immunosuppressive medications used for ITP alongside or instead of prednisolone although a lack of evidence to show superiority of one over another. Examples include ciclosporin and mycophenolate which are both used commonly. There are also clinical trials ongoing into platelet replacement products in dogs but no results yet to show whether these are of real benefit.

The bulk of recent questions have been regarding the possible Vaccines for Covid-19.

Editor's Note: There has been a steady stream of positive news regarding the trials of the various Covid-19 vaccines in recent weeks, this has also resulted in questions from ITP patients.

Questions such as, I have ITP, will I be able to have one of the vaccines? or Will I be limited to one particular vaccine over another? plus a number of others.

It is still early days and not all of the trial data is available, but Professor Adrian Newland has kindly given us his assessment of the current position, which for everyone, including those with ITP is looking more hopeful. as a result Professor Adrian Newland has produced this assessment of the current position (as of end of November 2020) with regards to Covid-19.

Covid-19 Vaccine Assessment

Covid-19 vaccination. By Professor Adrian Newland



There looks to be some relief on the way as we now have sight of 3 potential vaccines against Covid-19. All slightly different, which is a good thing, which means the virus will be attacked in different ways.

The data on the Oxford/Astra Zeneca vaccine looks promising but we wait more details. The pharmaceutical company, Pfizer, has also developed a vaccine that has shown to be 90% effective and we have seen more data on that. Protection is apparently achieved 28 days after the initiation of the vaccination, which consists of two doses given 21 days apart. The vaccine has already been through Pfizer's own trial and enrolled more than 40,000 people from across the world. 41 per cent of these participants are aged between 56 and 85 years old and it's really encouraging to know that the Pfizer vaccine seems to work on older people as effectively as in younger ones.

Although the full trial data has yet to be published on any of the vaccines, the companies all say that there have been no serious safety concerns.

It is natural to have questions about the safety of a vaccine produced so quickly. However, it is important to say that the vaccines will have to meet strict safety criteria in order to satisfy the MHRA, the UK's regulator of medicines and medical devices, responsible for ensuring their safety, quality and effectiveness. The MRHA will also seek advice from the Government's independent advisory body, the Commission on Human Medicines. The Commission will also critically assess the data on the vaccines before advising the UK Government on the safety and quality of this vaccine. It is important to understand that their development has been based on much work that was already underway. The speed of development and size of the trials have reflected

the enormous effort and funding that has gone into the whole process and corners have certainly not been cut.

The data on the vaccine will also be reviewed by the US Food and Drug Administration and the European Medicines Agency for approval, which are the counterpart regulatory bodies in the USA and Europe.

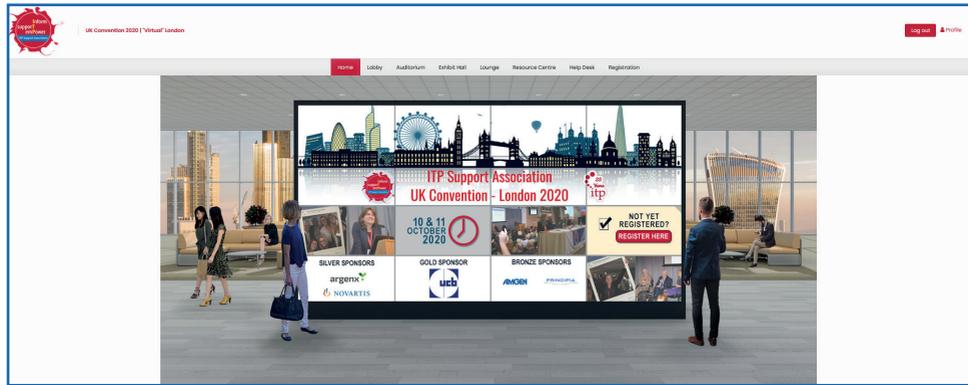
The news of this vaccine is obviously encouraging and can hopefully guide us out of this pandemic, but the full safety data of the vaccine still needs to be examined carefully by the regulatory bodies to ensure its safe for the general public and we await this news with cautious optimism. We hope that the first batches will be approved for use later in December.

We do not yet know who will be offered the vaccines in the first instance, but it is unlikely that a diagnosis of ITP alone will be sufficient. Although the intention is that as many of the population as possible will be offered one of the vaccines eventually, the early categories will be guided by age, other susceptibilities and probably to key workers. We will have to wait government guidance on this.

There is nothing to suggest, at the moment, that one will be better than another and I suspect which vaccine is used will depend on availability. The Oxford/Astra Zeneca vaccine will be cheaper and easier to handle as it does not need storage at very low temperatures. The third product, from a company called Moderna, is also on track but will probably concentrate its first launch in the USA as it was developed with support from the US Department of Health. It is also the most expensive.

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.

UK ITP Virtual Convention Report



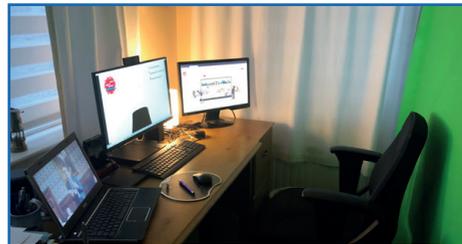
Due to the ongoing Covid-19 Pandemic which has brought a temporary halt to holding any normal style 'in-person' events we moved our Convention to the virtual environment (for the first time).

Our Convention, which was originally scheduled to take place in London back in May finally took place in October but with the famous London skyline as a backdrop.

I must add there was some nervousness and trepidation about moving such an important event to the world of the internet, but we need not have worried. Thanks to the skill and expertise of the team at Syndikast in Arizona, USA things went off without any major issues. The Associations CEO, Mervyn Morgan also had a small studio setup in his home office and took care of all the introductions and some presentations. The link between the two was, seamless.



Main Production Studio Arizona USA

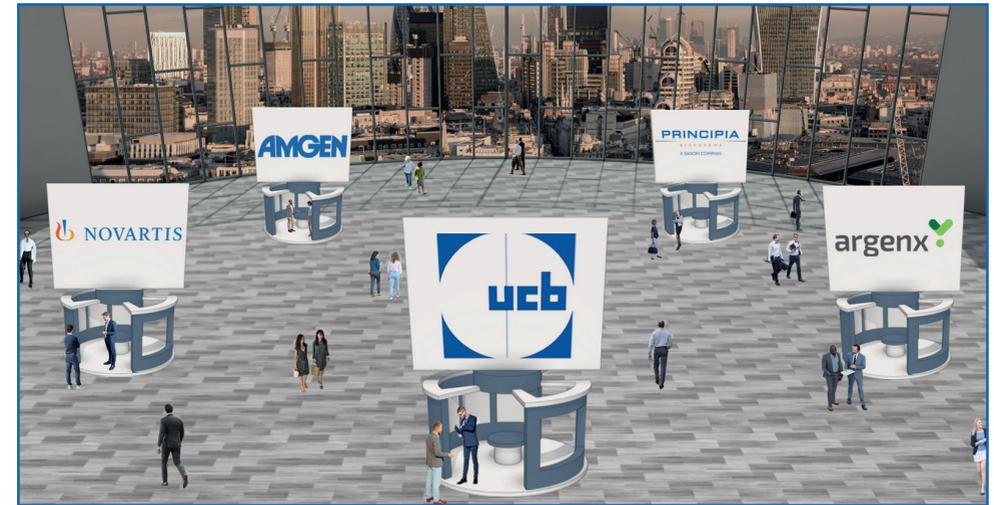


Bedfordshire, United Kingdom

With a normal 'in-person' convention in London, we can expect between 150 and 180 people, we had a feeling that a virtual event would be popular after the success of our Covid-19 Webinar back in April. However the number of attendees was mind blowing, we have over 350 people register to attend and during the month of October (the two days of the convention and the rest of the month) the Convention website attracted over 3000 visits from North and South America, Asia, Africa, Australasia and Europe, thank you to everyone who visited the Convention website.



The Convention website is still available and will be live until at least April/May 2021, if you have not registered just visit <https://www.itpconventionuk.org/registration>, enter your details and you can watch all the video presentations.



A huge thank you must go to our event sponsors; without them this event would not have been possible.

Video Presentations available on the UK Convention website at www.itpconventionuk.org include:

The New ITP Guidelines – Professor Adrian Newland

Covid-19 and ITP – Dr. Nichola Cooper

The Adults ITP Registry; Real Life Care – Dr. Vickie McDonald

What's new in Paediatric ITP; the Children's ITP Registry – Dr John Grainger

Clotting Problems in ITP – Dr. Jecko Thachil

Immune Thrombocytopenia: Looking Beyond the Platelet Count - Dr. Cindy Neunert

What's New in ITP Treatment - Dr. Drew Provan

Pregnancy and ITP - Dr. Susan Robinson

Plus, more, Q&A Webinar, Breakout Sessions, Patient Stories etc.

Don't forget the Convention website is still available and will be available until at least April/May 2021, if you have not registered just visit <https://www.itpconventionuk.org/registration>, enter your details and you can watch all the video presentations.

Local ITP Support Meetings

**ITP SUPPORT
ALL AROUND
THE GLOBE**

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

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ITP Support Association Group Meetings

Please note that in line with Government Guidelines for Coronavirus we have cancelled all in person Local ITP Group meetings and have moved to using the Zoom virtual meeting system.

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.

If you would be interested in volunteering to help organise an ITP Local Group Meeting in your area, please email mervyn@itpsupport.org.uk

Imperial Paediatric ITP Group Meeting - Next Meeting: 9th December 2020 7:00pm

England and Wales ITP Group Meeting - Next Meeting: 14th January 2021 7:00pm

Scotland ITP Group Meeting - Next Meeting: 21st January 2021 7:00pm

All-Ireland ITP Group Meeting - Next meeting: 23rd February 2021 7.00pm

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

Research Funds Appeal

It is only through the generosity of your donations and fundraising events that we have been able to fund the ITP Registries and other research projects. Please help by supporting our ITP Research Fund for future projects! You can donate by cheque, on line at www.itpsupport.org.uk or through Facebook at www.facebook.com/ITPSuppAssocor.

You can also donate by texting ITPA22 and the amount (£1 – £5 or £10) to 70070. You can also support ITP Research by holding a fundraising event!

Derek Elston EHA Appointment



EUROPEAN
HEMATOLOGY
ASSOCIATION

European Haematology Association (EHA) Appointment

We are extremely pleased and proud to announce the appointment of the ITP Support Association Trustee Mr Derek Elston to the European Haematology Associations, European Affairs Committee as the second patient representative from the Patient Organisation Workgroup. This is a three-year appointment. The committee comprises numerous eminent haematologists from all over Europe and is chaired by the President and Vice President of EHA.

The European Affairs Committee (EAC) represents and promotes the interests of haematologists and haematology by engaging with EU Institutions and other relevant stakeholders. The EAC serves as an advisory body to the EHA Board and works closely with the EHA office and other EHA Committees.

Their tasks and responsibilities are:

- Raise awareness of haematology as a distinct medical discipline with specific needs.
- Increase the visibility of EHA as a representative of all haematologists in Europe.
- Advocate key EHA positions vis-à-vis policymakers and interest groups.
- Contribute to policy debates to influence future legislation/regulation.
- Build relationships and alliances to support and strengthen EHA advocacy work.
- Represent EHA in its advocacy activities and projects.

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

Rhonda Anderson | Tel: 0208 504 2688
E-mail: rhonda.anderson@virgin.net

Derek Elston | Tel: 0151 625 8213
E-mail: derek.elston@itpsupport.org.uk

David Farrow | Tel: 01664 852218
E-mail: davidfarrow40@yahoo.co.uk

Karen Smith | Tel: 07521 279565
E-mail: k.smith01@btinternet.com

Fundraisers

Virgin Giving - £1.063 inc Gift Aid - donations during ITP Awareness Week

£432.00 raised on Facebook from the ITP Awareness Week Picture of a Purple London Eye lit up!

Atlas Trading have a collection tin and regularly send in donations - a total of £423.60 has been raised in three months!

£200.00 - Dave Bagshaw donation.

A lifelong supporter Mrs Ackerman donated £100.00

Running Bear Sport - donated £100.00

Mr Guest donated £500.00 cheque to the research fund

£162.50 was raised at a Selkirk Golf Match - in memory of Murray Cleghorn

A huge thankyou to everyone who has supported the ITP Support Association during these difficult times.



IT'S IN US ALL TO SAVE A LIFE #DonatePlasma

BLOOD IS 55% PLASMA

44% RED BLOOD CELLS

1% WHITE BLOOD CELLS & PLATELETS



WHAT IS PLASMA?

Plasma is a key element of blood (55% of the total blood volume). Plasma is the clear straw-coloured liquid portion of blood that remains after red blood cells, white blood cells, platelets and other cellular components have been removed. Plasma carries water, salts, and proteins through the body.

More and more patients across the European Union are diagnosed every year with life-threatening plasma protein-related disorders.¹ This means certain proteins in their body are missing or are deficient. In many cases, Plasma Derived Medicinal Products (PDMPs) are the only treatment option for these severe diseases.



PLASMA IS 7% PROTEINS 92% WATER 1% OTHER SOLUTIONS

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Patients across Europe rely on Plasma Derived Medicinal Products (to treat a variety of rare and chronic and/or genetic diseases and serious, often life-threatening medical conditions).



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For individuals with these conditions, Plasma Derived Medicinal Products replace their missing or deficient proteins.



It is worth noting that it takes more than 130 donations per year to treat a single patient with a primary immune deficiency.



Without these treatments, many patients would either not be able to survive or would have a substantially diminished quality of life and productivity.



Convalescent plasma and Hyper Immune plasma are plasma that is collected from patients who have recovered from an infection. Antibodies present in the plasma are proteins that might help fight the infection.



Human plasma is the unique and indispensable starting material for the manufacturing of plasma derived medicinal products.



Introducing Jonny Mellor

Introducing our new ITP Ambassador Mr Jonny Mellor

Following his amazing video at the recent UK ITP Convention we would like to introduce our new ITP Support Association Ambassador, Olympic hopeful Jonny Mellor, who recently won the British Championships at the #LondonMarathon running 2:10:38.

You can watch Jonny's video by going to our website at www.itpsupport.org.uk.

His story is an inspiration for everyone who has ITP.



Life with ITP by Rhona Bowie

More often than not, in order to reflect on something, the event or experience in question usually has to be over and your thoughts, and feelings on the matter finalised. However, I must confess that my feelings on this matter are certainly not finalised, nor am I sure they ever will be.

Immune Thrombocytopenic Purpura. By now, everybody reading this knows what ITP is. However, at sixteen years of age, when I got diagnosed, I didn't have a clue. Our bodies attack the platelets that clot our blood, meaning we bleed constantly and freely from everywhere in the body. When it's put like that it seems almost insignificant, merely a trivial cog that has become rusted in the well-oiled mechanisms of our bodies. Although, it's not quite that simple is it?

Hospitals have this unique feeling about them, as if time isn't real and nothing seems quite right. Let's be clear, no one likes spending their time in the hospital, it's eerie and too big and is riddled with sick people. And in the summer of 2019, I became one of them. After undergoing weeks of stress whilst sitting my lifeguard exam, I finally went to the doctors about

the weird rash that was covering me head to toe. Within days I lay in a hospital bed, confused and beyond exhausted, with a needle jammed in my arm ready for a blood transfusion that didn't go ahead. Instead I had to take twenty steroids a day for four days in the hopes of resetting my immune system and to stop my platelet levels dropping below ten.

The hospital practically became my holiday destination that summer and even now, not once, has that eerie feeling that something's not quite right left me every time I enter the hospital that I have become so well acquainted with. By the time that you're reading this, it will have been around a year and six months since my diagnosis. And I must admit that at the grand age of seventeen that still sounds like a tiresomely long period of time and to be truthful these past months have felt that way too. It's a hard concept to wrap your head around. That the world cannot stop and wait for you. That everyone around you will continue to move on, without you. It was a painful revelation as I lay in a stuffy hospital room with the sunlight glaring through the windows. Why did no one seem to understand that life had

thrown me this curveball when I hadn't even learnt to catch yet? My ITP diagnosis forced me to come to the realisation, one I'm certain we all have at some point in our lives: that life does not stop to wait for you and the world continues to turn.

Anger. It's a word used so frequently to describe a feeling of mild irritation that sometimes we forget how it really, truly feels. But now I can remember. How overwhelming it is. To feel anger behind everything that you do. Anger pooled in the deepest pit of my stomach, through my arms and legs, deep in my bones. First, anger at myself, at my body for letting me down at such an early stage in my life before it had truly even begun. Second, anger at the world that it kept on spinning when my own world felt like it was crashing and tail spinning into darkness. Finally, anger at everyone else. That they got to carry on, complaining about mundane everyday inconveniences. If I'm being honest, which is a challenge in itself, my view on the world changed. And not in the classic coming of age movie scene like way. I was bitter, more negative than I have ever been in my life. My patience and empathy were dwindling, things that I had always relied upon to keep me sane. Which only made me feel worse. I knew it wasn't a sound outlook to have: that I had some sort of right to feel the way I did, as though my problems were greater than everyone else's. It's challenging, to admit to yourself, let alone someone else, the selfish thoughts you have but I know that that is only part of the process. Of grieving the person, I was and accepting this new version of myself.

It doesn't take a genius to come to the conclusion that there is an endless list of issues in the world. Poverty, homelessness, murder, pollution, famine and disease. And that barely scratches the surface. So why was it okay to feel as though the world owed me something? As if having this illness deserved some sort of explanation as to why? Why me? Why this age? Why this particular disease? All the cliché questions. As though every single other person in the world was not also fighting a battle of their own, many far more extreme than mine. So, is it okay to feel so hard done by and kicked to the curb by life, when other people's problems can be considered as far worse? I struggled with this concept for so long, and this is where my earlier confession reveals itself, as I still have not discovered the answer to this question. Some days my head feels calm, the tide

is low, the waves slow and methodical and the sun shines. And on these days I feel like I don't have the right to complain at the cards I've been dealt, at the sheer idea that I've been robbed from a fuller life. Then, there are the days where the tide rises, the waves are high, crashing against the rocks and the sky turns bleak to match my outlook on the world. It feels so incredibly unfair to be stuck with this illness and to have no explanation as to why. However, I've realised as I'm sure most people do, that unfortunately, sometimes life is just unfair, and we have to learn to run with what we've got. Which is what I do. I'm hopefully to continue my studies at university in addition to carrying on my competitive swimming.

Hope. An exceedingly dangerous emotion. It can be the only thing in the world that keeps a person going, propelling them through life and without it, we are lost. It doesn't seem right that it can be stripped away in the blink of an eye. For me it was the word "chronic" being uttered from the doctor's lips. Although I must admit my hope of going into spontaneous remission was dwindling at each low blood result, it was still there, clinging to every fibre of my being. So to hear my worst fear confirmed, that in fact my ITP was here to stay, for the rest of my life, with no cure and nothing to help it was definitely a kick to the stomach. I think that maybe it's difficult to reflect upon and find the answer to my burning questions because the reality has not yet hit me. That I will have this autoimmune blood disorder for the remaining years of my life on this earth. And here comes the kicker, I still don't think I have it in me to regret my illness. Initially, as I'm sure is obvious from my diary like confessions, there was a less than positive change in myself but one that was necessary nonetheless. There is a definite process, one that after you are crushed as a person and are sitting alone questioning the meaning of life itself, one must go through. Although the thing is, this process is forever ongoing, reflections forever changing and yet the world forever turning. So, I'm certain that in another few days, few weeks, few months and most certainly few years my reflections will have shifted. But for now they are as follows; life can be unfair and the sooner we realise that the better, anger is an ugly emotion but one that is occasionally necessary to move on, good days and bad days are valid and must not be underestimated and finally, hope is an emotion that we could not, and should not, live without.

Rare Disease Day 2021



EURORDIS (Rare Diseases Europe) and 37 National Alliances around the world work together to build the annual campaign for Rare Disease Day. This is to help you in your local mission to build awareness for rare diseases and more specifically the rare disease which may affect you or your family.

For more information about Rare Disease Day 2021 visit www.rare diseaseday.org

Here we go again... By Rhonda Anderson

As I write, we are getting news of how Lockdown Number 2 will end, and we are wondering what sort of Christmas we will be having with or without our families. How many of us would love to have a magic wand to wave like a pantomime Fairy Godmother, and say good bye to all our troubles of 2020. It has been a tough year, but some interesting positives have come out of it.

We had a most successful ITP Convention, all online for the first time. More people were able to attend from various countries all over the world. This may set the pattern for future international meetings. Local support groups have successfully been meeting on Zoom.

I have had to reluctantly embrace learning new technologies and glad that I have, although the learning curve has been steep and stressful. I now voluntarily tutor the Expert Patients' Programme on Zoom with co-tutors and it has been most rewarding, helping those with long-term health conditions. Many mental and physical health conditions prevent people from leaving home to attend groups, but Zoom brings other people into your home at a safe distance, and like a miracle you can attend. Find out if this free service is available in your area, so you can benefit.

Even the humble telephone, letter or card, is a great way to keep in touch with friends and family. We send occasional letters to our grandchildren with post cards and things they like to collect such as Lego cards. We have probably become more aware of our families and some have been drawn closer together with technology assisted meetings.

During this period, you have probably been

more reliant on technology, so maybe it is time to treat yourself to some new hardware, or even online training courses and a resolution to keep in touch with friends more frequently.

I am fully supportive of having a vaccine and want to be vaccinated myself as soon as possible. I am cautiously optimistic about the various vaccines coming on stream and this is the way out of the pandemic, given time. Why do I say that? The vaccine is the answer to Covid-19, but it will take a long time to vaccinate the world. Perhaps we will have to produce proof of vaccination at the point of exit and entry to various countries like the old days' yellow card, with them all listed. These days it will be a QR code, no doubt! This might kick start the travel industry for the benefit of all. Travel is certainly one pleasure that we have had to reluctantly forego.

Uncertainties keep an underlying anxiety smouldering inside us. We need to acknowledge this and make provision for our own compassionate self-care. A new self-care category is Zoom Care! I usually walk down and up some house stairs and fit in some physical jobs in the breaks, like getting the washing on, emptying the dishwasher, making the bed and so on. It can in fact be very tiring doing a lot of things online and staring at the screen in a sedentary position, and this is no new concern. Beware of overdoing it and take regular breaks and stay hydrated.

At the end of my previous article, to be found under Bonus Articles on the website, I asked how your smile was going. I have to admit, mine has been hiding a lot of the time. Lack of social interaction has made it shy.

Lack of facial expression due to the wearing of masks, and no possibility of lip reading has made things very difficult for me, with my hearing problems, which many people share. There are some transparent masks, but not many people wear them. On the other hand, the volume on a Zoom call and YouTube can be turned up, making some entertainment, talks, courses and meetings more accessible.

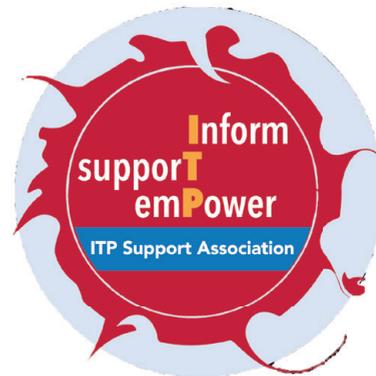
Although there are many beauties of the winter season, some people experience a drop in mood and this is called SAD, Seasonal Affective Disorder. It is linked to the lack of daylight, due to shorter days and the position of the sun in the sky. The dullness, dampness and sheer dreariness of wet days can depress mood, but take steps to lighten your thoughts and take care of your mental health. Always ask your doctor if you have cause for concern. I heard the term 'Daylight Bathing' which simply means going outside when it is daylight and enjoying the light. Sitting outside at home would do the same. Note to self, no more late night walks!

Being a volunteer has many benefits for the person volunteering. At the moment these opportunities are limited in face to face situations, but perhaps think about what you might do in the future, and making positive plans is good for your mind.

Christmas will undoubtedly be different this year and as I don't have a crystal ball, I am not going to make any predictions. However, in Australia they have a tradition of 'Christmas in July' as it is then winter, so log fires abound and restaurants, (remember them!), do traditional Christmas fare. Perhaps we could plan to have a family Christmas gathering in July with outdoor picnics in the warm sun, and the bonus will be that we have had two Christmases.

Flowers are amazing, uplifting and something to focus on. Each week I buy 3 inexpensive bunches of flowers for friends with my online supermarket order, and I know how much joy this brings to those who cannot go out, and for anyone to know a friend is thinking of them. We have had pleasure looking at the gardens we pass on our daily walk. Why not treat yourself to some blooms?

We never know what the future holds, so make every day a good one in some small way, and live in the present moment.



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.

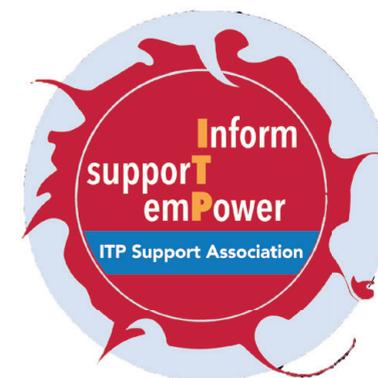
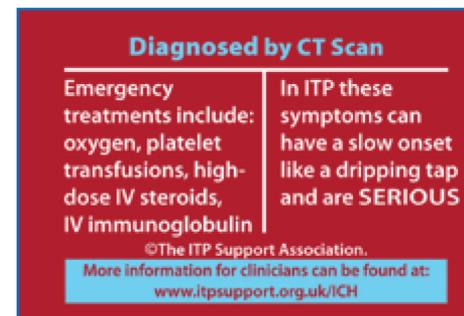
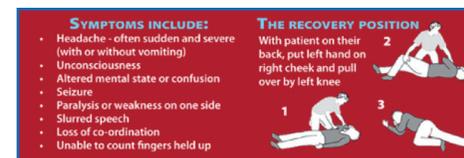
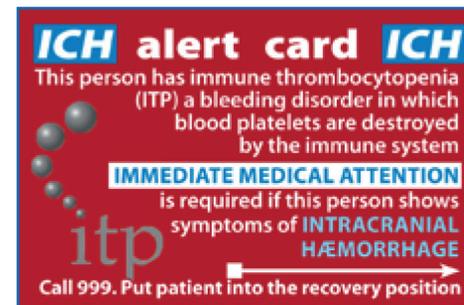
Order a free ICH alert card

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.



Getting My Teeth Into ITP

GETTING MY TEETH INTO ITP - A trip to the dentist. By Anthony Heard

For most people, the merest hint of a dental appointment usually sets the colliers wobbling. For some it's the buzzing of the drill, for others it's the whiff of the various chemicals or the sight of needles, not to mention the current Covid-19 protocols. Whatever turns us off, dental appointments are not much fun, unless of course unlimited nitrous oxide is dispensed. Ha ha ha!

Luckily, I have always had excellent treatment from my dentist and any appointment has never held any fears at all. I guess I'm lucky in this respect. But should any visit to our dentist as an ITP patient be any different to any, we may have pre purple?

Well, er, yes actually, it's very different. Obviously it is important to advise the dentist and hygienist that you have ITP and explain what treatment you have received, what drugs you are taking, what your latest platelet count is and what treatment regime you are going to continue with.

This is all detail that I know about because I have obtained a really useful leaflet from the ITP Support Association. It is quite soberly entitled... Protocol for dentists treating patients with Thrombocytopenia. A protocol... sounded like something the UN would have drawn up. But nevertheless, it is extremely helpful, and I gave a copy of it to my dentist. It is a really helpful leaflet and I fully recommend it be something ITP folk should get and share with their dentist.

It may seem obvious that our dentist needs to know our platelet count. If any treatment is needed, especially an extraction, a platelet count under 50 may preclude that treatment from being carried out. In that situation the suggested course of action would be to consult your ITP

specialist first.

Advising our dentists of what medication, we are currently taking and have taken for the last 12 months is also vital. Any drugs the dentist uses to anaesthetise us for example, may clash with any medications we have taken for our ITP or any other medical condition for that matter.

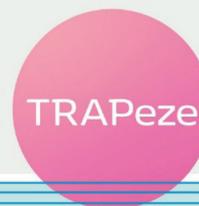
Another thing to bear in mind about dental treatment, is that should we encounter any pain following any interventions the only painkillers we can take are Paracetamol. Us ITP sufferers must avoid Aspirin or Ibuprofen. Having purple in our life gives us so many things to think about doesn't it?

The other important point to bear in mind is that because ITP is so very rare, most dentists will probably not have even heard about it. So, for our benefit it is important to make them fully aware of our enigmatic condition. It will help them, to better help us, if we educate and inform them about our ITP.

All that said, just because we have ITP it must not preclude us from getting proper, regular dental treatment as it is so important for our overall health. So many health problems may be connected to poor oral hygiene and lack of regular dental treatment, as outlined in the following link -

<https://www.nhs.uk/live-well/healthy-body/health-risks-of-gum-disease/>

So before your next visit to the dentist (whenever that might be, Covid-19 permitting), make sure you are well prepared and that your dentist and hygienist is equally aware of your ITP status. Don't just assume that they will know about ITP or that it is not important. Before you open wide make sure you open up about your ITP.



Thrombopoietin Receptor Agonist Patient experience survey

Help shape what the future of ITP treatment looks like for you

This survey is about how your ITP treatment fits into your daily life.

Understanding your needs can raise awareness for more suitable care.

This survey should take about 30 minutes. Please feel free to ask for help with completing this survey from a family member, carer or friend.

How do I participate?

Fill in the online survey at:
<https://bit.ly/33tTp7U>

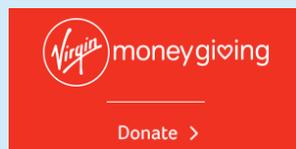


SCAN ME

Ways To Donate

Virgin Money Giving

The ITP Support Association are pleased to announce that they have joined the fundraising and donation platform #VirginMoneyGiving, this platform is more widely recognised than our previous fundraising partner 'Wonderful' which is due to cease operations at the end of March.



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/itpsupportassociation and use the links on the easyfundraising site to take you to your chosen retailer. You'll get access to hundreds of exclusive discounts and voucher codes. Join the 53 supporters who have raised almost £600 for us so far!

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

Publications List

BOOKLETS

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

