

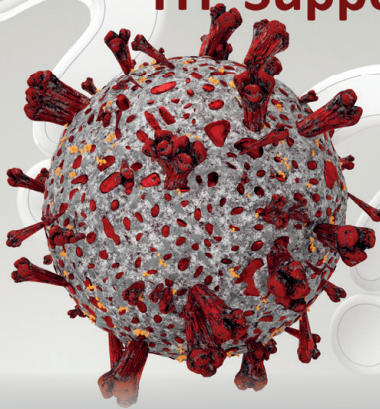


ITP news, patient stories, advice & more...



ITP Support Association

Covid Vaccine Survey



The
Platelet

JUNE 2021

JOURNAL OF THE ITP SUPPORT ASSOCIATION

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Charity Registration No. 1064480

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

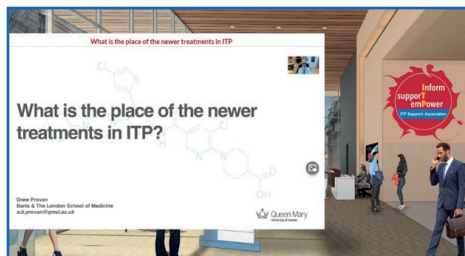
The ITP Support Association is non profit-making and relies upon subscriptions, donations, bequests and fundraising by friends of the Association to enable its operation and to fund vital research into ITP. All donations are gratefully received and acknowledged.

The ITP Support Association acknowledges its gratitude to ARGENX for grants to assist with the printing and distribution costs of The Platelet.



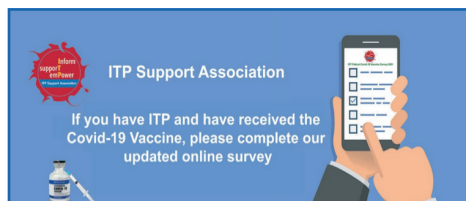
From ITP HQ

Welcome to the June edition of the Platelet, in this edition we have a report covering our recent ITP Convention which, due to Covid, was held in the virtual environment. We are pleased to report we had over 500 people register for the event from over 30 countries, the global reach of the ITP Support Association gets ever wider. Remember you can still catch up with all the presentations from both days of our Convention by going to www.itpconventionuk.org to register (its free). All the presentations will be available for at least six months, so please go to the Convention website and check it out.



As Covid-19 is still front and centre of everyone's thinking there are three videos that will be of interest, Dr. David Kuter talks about 'Covid, Vaccines and ITP', Dr. Sue Pavord presents the 'UK Audit of ITP in the Covid-19 era' and we have a 'Q&A on Covid-19' with Prof. Adrian Newland, Dr. David Kuter, Dr. Nichola Cooper and Dr. Sue Pavord.

Don't forget you can still take part in our Covid-19 – Vaccine Survey, please go to our website at www.itpsupport.org.uk to take part. Some of the surveys initial results are included in this edition of the Platelet.



Just prior to our Convention we held our latest round of ITP Support Group Meetings, what a great turnout, thank you everyone, we had people taking part not only from the Home Nations and Ireland but also Europe, USA, India and Australia.

As always, a big thankyou to everyone for your continued support during these difficult times, stay safe and we hope to see you all at our next support group meetings later in the Summer.

One final thank you to the Argenx our Platelet sponsor, who have agreed to sponsor this journal for a further year.

Best wishes

Mervyn Morgan CEO

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American Perspective

The American Perspective: Participating in Research in ITP - Rachael Grace, MD

When I first meet with patients and families affected by ITP, I tell them all of the information that we know about ITP. As part of this conversation, I also always point out the many important questions about ITP that we cannot answer. Why do certain people develop ITP while others do not? How can we predict if there will be bleeding in the future? Will the ITP resolve on its own and, if so, when? If treatment is needed, which medicine will be most likely to improve their daily quality life? When I raise these questions, I acknowledge how frustrating it is that we do not have answers to these and other questions. These unanswered important questions are the reason that there is so much active research in ITP.

Because ITP is a rare condition, it takes many patients and researchers working together to answer these key questions. For this reason, your physician may offer you a chance to participate in research studies. Medical research can lead to a better understanding of how genetics and environmental factors lead to the development of ITP and how ITP and its treatment affect everyday life. Research studies can also help us to know which medications will work best for which types of patients. Participation in research is always voluntary and those who participate in research do so because they want to and have the choice to change their mind at any time. In order to make a decision about being part of a research study, it's important to understand the type of study being offered, what is needed to participate, and what is the potential for both harm and benefit. Sometimes, there may not be any benefit to you directly but the study will help us to learn more about ITP that may help others in the future. Before participating, the clinician leading the research must carefully explain the details of the individual study to you. An informed consent document is a written explanation of the study and the risks and benefits. When patients sign an informed consent form, it means that the clinician has carefully explained the study in detail and the



patient has agreed to participate. Even though you sign this document, you can still choose not to continue to be part of the research study at any time. What are the different types of studies that a person with ITP might participate in?

Survey studies: Individuals answer questions about how they feel. These may be administered once or on a regular basis or at the time of new symptoms or treatments. Surveys are often included in drug studies to help determine if the drug helped patients with ITP to feel better.

Biology sample studies: Extra tubes of blood (or other types of body fluid, such as urine, saliva, or bone marrow) are collected, often when these are also being collected for your routine visit. Some samples are looked at right away while others are collected and stored in a biobank. A biobank stores information and samples and can be accessed by researchers who have important questions that can be answered using these samples in the future. The researchers may analyze these samples in different ways including through genetic testing.

Observational studies: Information about an individual's symptoms, laboratory studies, and/

or treatments are captured in a database. Observational studies sometimes also include surveys and sample studies. Sometimes the information is collected only once, and, other times, it may be collected at several different times to look for changes.

Clinical trials (drug testing/interventional studies): In clinical trials, individuals receive a research medication or treatment to determine whether it is safe and/or effective for ITP. There are several types of clinical trials. The goal of a phase I trial is to find the right (and safest) dose of a new treatment. A phase II trial evaluates whether a treatment is effective to treat ITP. A phase III trial compares the treatment to another treatment, standard of care, or to a placebo (a product that looks like the drug but has no drug effect).

These types of studies are all needed to answer important questions about ITP that we currently cannot answer. Since ITP is rare, investigators often work together in collaboration on research. Samples may be sent to a central repository, and a single clinical trial may be conducted at multiple centers across the globe. While participating in a study, an individual is assigned a study identification number so that his or her privacy is maintained and research teams at other hospitals cannot identify participants individually. The time and involvement needed to participate in research varies greatly between studies.

It can be frustrating for patients, families, and clinicians that important questions in ITP are currently inadequately answered. Offering participation in research is a vital part of addressing this lack of knowledge and providing hope that researchers can answer these questions in the future. Although many patients are offered participation in research, taking part in a research study does not make sense for everyone. Although research is offered, participation never impacts the clinical care that is provided.

If you are interested in learning more about participating in ITP research, please ask your health care provider which studies are open at your hospital or medical center.

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 Convention 2021



The weekend of the 8th and 9th May 2021 saw more than 500 people from over 30 countries take part in our Annual Convention, which, for the second year was held in the virtual environment.

Every one of the presentations were recorded and can be viewed for the next six months on our Convention website at www.itpconventionuk.org, you just need to register (its free) in order to view any of the videos from our superb experts.

The following presentations are available to view:

How I treat ITP in 2021 - Dr. David Kuter
Is bleeding a problem in ITP - Dr. Nichola Cooper

Fatigue in ITP - Dr. Cindy Neunert

Covid, Vaccines and ITP - Dr. David Kuter

UK Audit of ITP in the Covid-19 era - Dr. Sue Pavord

Q&A on Covid-19 - Chair: Prof Adrian Newland, Dr. David Kuter, Dr. Nichola Cooper, Dr. Sue Pavord

Women's Issues - Dr. Sue Robinson, Dr. Catherine Bagot

Adults' Issues - Dr. Vickie McDonald

Children's Issues - Dr. John Grainger

Why does ITP occur? - Professor John Semple

Letter from America: What is the current position with the thrombopoietins? - Dr. Adam Cuker

Cinderella Study - Dr. Kate Khair

What is the place of splenectomy – the Adult Registry - Dr. Vickie Macdonald

Current treatment in Paediatric ITP - Dr. John Grainger

What is the place of the newer treatments in ITP - Dr. Drew Provan

Patient Story - Lauren Ward

Real World Experience in ITP – a patient survey - Dr. Vickie Macdonald

Q&A Webinar Recording – with Prof. Adrian Newland (Chair), Dr. Drew Provan, Dr. Sue Pavord, Dr. Nichola Cooper, Dr. Quentin Hill, Dr. John Grainger, Mrs. Rhonda Anderson, Dr. Cindy Neunert, Professor John Semple.

Plus, we also have a bundle of additional on-demand ITP related videos on the Convention website at www.itpconventionuk.org.

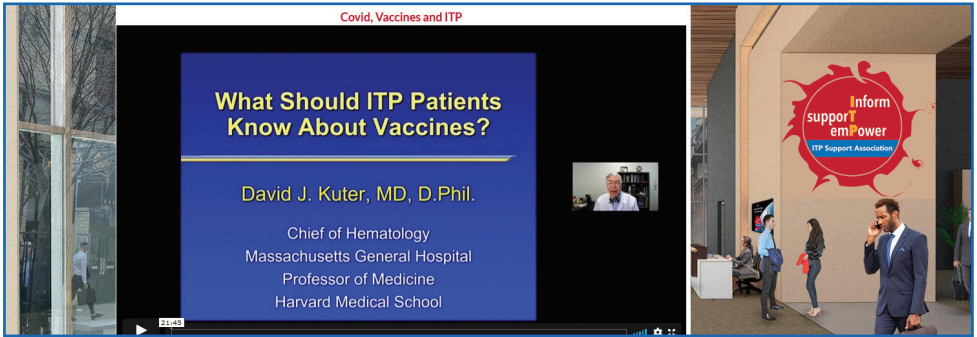
A huge thank you to each of our 2021 Convention Sponsors, we would not be able to do what we do without your support. The sponsors booths also contain lots of additional ITP related content, when you are visiting the convention website just click on the sponsors logos and take a look around.

Covid, Vaccines and ITP

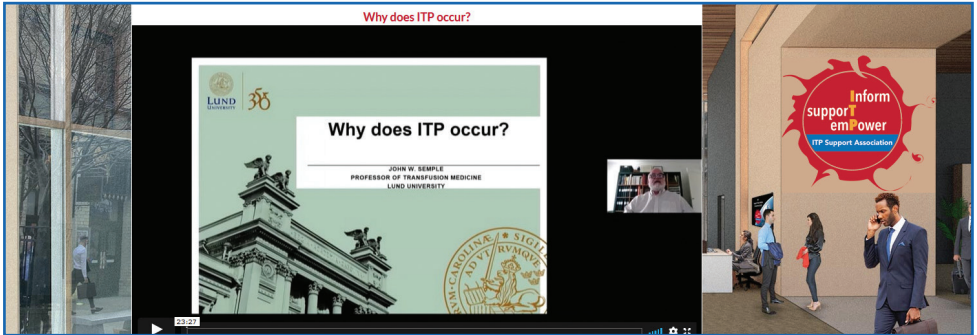
What Should ITP Patients Know About Vaccines?

David J. Kuter, MD, D.Phil.

Chief of Hematology
Massachusetts General Hospital
Professor of Medicine
Harvard Medical School

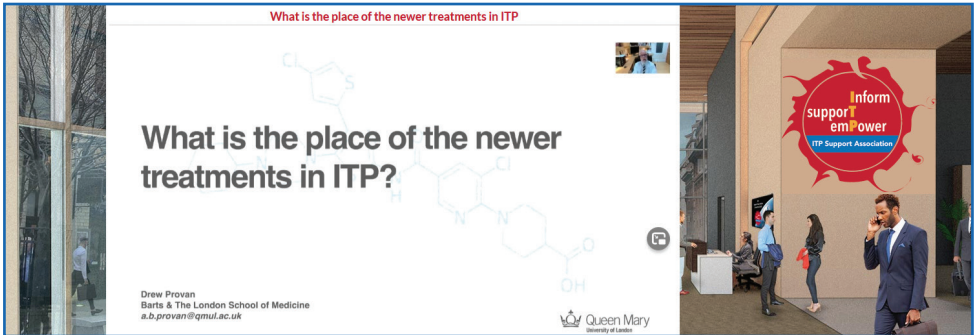


Why does ITP occur?



What is the place of the newer treatments in ITP?

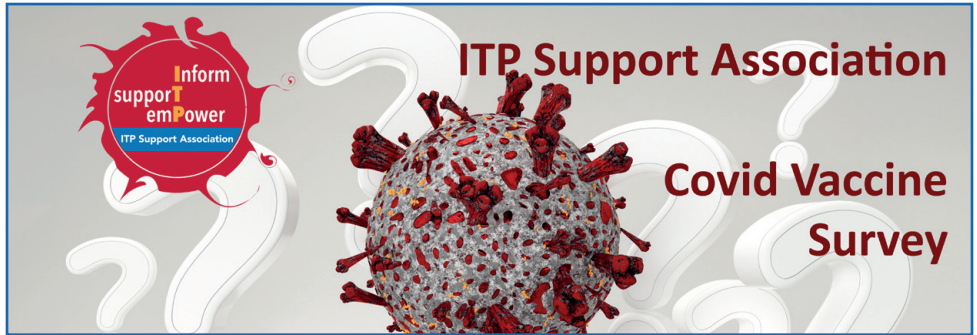
Draw Provan
Barts & The London School of Medicine
a.d.provan@qmul.ac.uk



Q&A Webinar



Covid-19 Vaccine Patient Survey



ITP Patient Covid-19 Vaccine Survey - Updated Spring 2021 – Initial Findings (1)

This paper reports on some initial findings from the ITP Support Association ITP Patient Covid-19 Vaccine Survey which was updated in February 2021.

Did having the Covid-19 Vaccine have an effect on Platelet Counts?

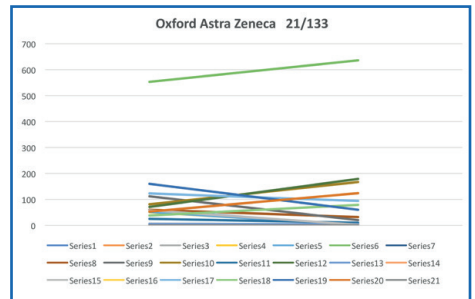
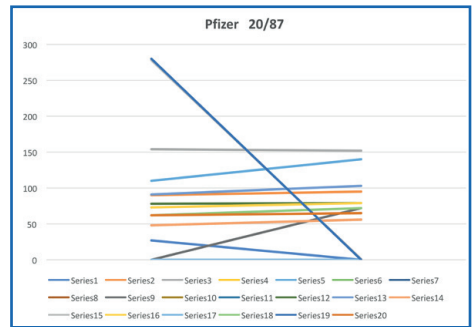
Probably one of the most asked questions since the rollout of the Covid Vaccine commenced in December 2020 was how it will affect my ITP and in particular my Platelet Count. Hence, we asked people, if they had a platelet count taken before and after their vaccination to let us know the numbers, please note we did not tell people that they must have a count taken, that would have created an issue for the Hospitals, this was for those who already had counts scheduled. observation.

The update covers the 220 people who completed the survey from the end of February 2021 to 12th May 2021. Of that total 41 ITP Patients received a pre and post vaccine Platelet Count, split almost 50/50 between Pfizer and Oxford Astra Zeneca.

The graphs on the right show the results of this information.

With the Pfizer vaccine, of the 87 ITP patients who received the vaccine up to 12th May 2021, 20 patients had a pre and post Platelet Count taken. Only two patients (160 – 60, 123 – 4) showed a drop

in the Platelet level whilst the rest maintained a stable count.



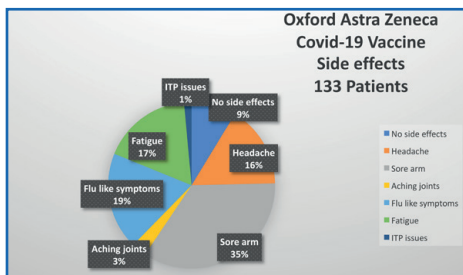
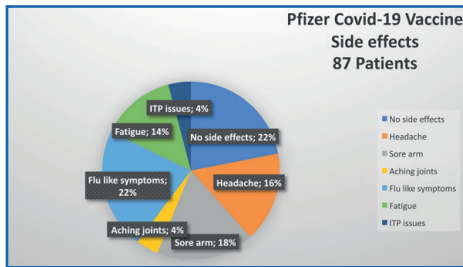
With the Oxford Astra Zeneca vaccine, of the 133 ITP patients who received the vaccine up to 12th May 2021, 21 patients had a pre and post Platelet Count taken. In contrast to the Pfizer vaccine results, there was a 50/50 split in Platelet Counts going up and down after the first dose of vaccine with 7 patients showing a drop and 7 patients showing an increase in their Platelet Count. We have classed a significant rise or fall as > than 30.

We do have some results for the Moderna vaccine, but the numbers are currently too small (4 with no before and after counts) to enable any meaningful comparison.

Have you ever tested positive for Covid-19?

A small number of ITP patients in the survey reported that they had tested positive for Covid-19, 2 patients reported that their Platelet level went up after testing positive and 2 patients reported a drop with 1 patient reporting their platelet level remained the same, none of these patients required hospital treatment.

Reported Side effects after the first dose of Covid-19 vaccine.



Other interesting data from the survey highlighted the variation of side effects reported by patients after receiving their Covid-19 vaccination.

One difference was 22% of patients who received the Pfizer vaccine reported no side effects against only 9% of patients who had the Oxford Astra Zeneca vaccine.

Both vaccines showed a similar percentage of patients reports Flu like symptoms, Fatigue, Headache and Joint pain. There was one side effect with a marked variation "Sore arm", 18% of patients reported this with the Pfizer vaccine as against 35% for the Oxford Astra Zeneca vaccine.

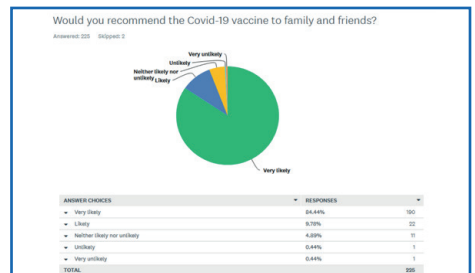
As we pointed out earlier with regards to patient

concerns and their Platelet Counts following their first dose of the Covid-19 vaccine, one of the main questions during the early rollout of the vaccine programme was how will the vaccine effect my ITP? Thankfully, the number of patients who reported an issue with their ITP after their Covid-19 vaccine was exceedingly small, only 1% Pfizer patients and 4% Oxford Astra Zeneca. They reported ITP issues such as bruising, petechiae or having a heavier than normal period after receiving their vaccine. None of these patients required any Hospital treatment.

One patient who did not take part in the survey but contacted the Association by email reported a drop in her Platelet Count with the first vaccine dose but a rise in her count with the second dose.

In a similar study from the USA of 52 consecutive patients 15% had no worsening of ITP symptoms but no count measured; 73% had no new symptoms and no change in platelet count. However, 12% had a drop in the platelet count but all either bounced back or responded to treatment and the majority were above 30 x10⁹ /L within 3 days. The changes in platelet count occurred independent of remission status, concurrent ITP treatment or vaccine type. (2)

Would you recommend having the vaccine to family and friends?



The results of this question are very encouraging with over 90% saying they would be very likely or likely to recommend having the Covid-19 vaccine to their family and friends.

*The patients who took part in this survey self-reported and did so anonymously.

You can still take part in our Covid Vaccine Survey, visit www.itpsupport.org.uk

References: (1) Mervyn Morgan, Prof Adrian Newland – ITPSA Survey (2) Dr David Kuter USA Study.

Regional ITP Group 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.








Although at the time of writing this article the Government plan is to lift Covid restrictions around 21st June, there is still some uncertainty on the level of easing that will take place. Therefore, our current plan (subject to change as rules allow) is for a phased return to group meetings as laid out below:

Phase 1, We will be looking to resume our regional Zoom meetings in July, please check our website for details.

Phase 2, Date to be advised, we will be trialing a hybrid ITP Group meeting with the Southwest of England Support Group (formerly known as the ITP Support Group Devon). For those of you who wish to attend in person the meeting will take place at the usual venue in Ashburton, however given the experiences of many over the past eighteen months I know some people will be uneasy about meeting in person so soon, therefore we will also have the option of joining the meeting via Zoom. Full details will be available once dates are confirmed. Please see the item below from the Southwest Group organiser Karen Smith.

Phase 3, we will review how Phase 2 has worked and if successful will publish dates for the resumption of the remaining support groups.

ITP Support Group Southwest

It has been decided to extend the ITP Support Group Devon (ably started by Sally and Michelle) to include Cornwall and Somerset, and to rename the group as the ITP Support Group South West.

All ITP patients, their families, carers and friends from these counties are welcome and the aim is to offer support either by email, on our Facebook page or by phone.

When Covid-19 restrictions are lifted to allow us to hold meetings together we will continue to use Ashburton as our venue. For those unable to travel we hope to include a Zoom call so that as many as possible can attend, even if virtually rather than in person.

For further information please email **Karen Smith**, k.smith01@btinternet.com or visit our Facebook page ITP Support Group Southwest.



The ITP Support Association would like to take this opportunity to thank everyone who has taken part in our many virtual meetings since the Covid Pandemic crashed into our lives in early 2020.

Like many patient support organisations, we have learned to adapt our services quickly, sometimes overnight. The reach of these virtual meetings has exceeded all our expectations so thank you all.

Update on Patient Mentors for the ITP Support Association

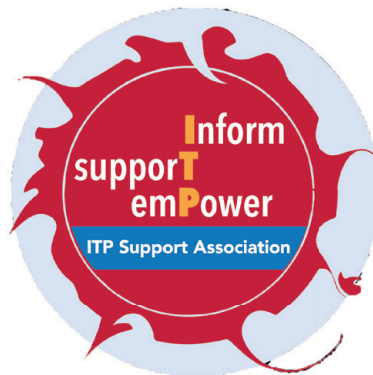
This edition we welcome a new Patient Mentor to the Association, Karen Smith who lives in the beautiful county of Devon. Karen is a fellow is also the organiser of the Devon and Cornwall ITP Local Support Group.

PATIENT MENTORS

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On The Right Track - Anthony Heard

Happy to be on Board

I start this update by taking the opportunity to say a big thank to Professor Adrian Newland CBE Chairman of the Board of Trustees of the ITP Support Association.

I was very proud to have received an invitation from Professor Newland at the end of February to join the Board of Trustees as a Patient Observer and I am delighted to have accepted.

For anyone who hasn't read this column before, I have been working as a volunteer for the ITP Support Association since 2010. I set up and continue to contribute to our various social media platforms and take part in our local support groups & the Annual Convention.

I will of course continue to play my part in the same ways as before but will also take up my new role with energy, positivity, and enthusiasm. I am ready to help in any way I can to add value to the charity and I know that I will learn a great deal from the experience too.

So I am pleased, proud and happy to be on Board.

My Very Own Platelet TRACK and TRACE

The last 12 months have thankfully seen my platelet count at normal levels. Since February 13th 2020 my counts have consistently been good and I am eternally grateful for this. My latest count was 214 on April 26th.

I have always kept a written journal record of my platelet count as well as any symptoms, side effects and medications. I also keep a food &

drink diary and have been recording everything on my ITP Pocket Log (more of which later).

This all takes time but I believe it is time well spent. I have a close eye on all of the elements that matter so much in keeping my health on the right track or at least on the best possible track that it can be on. I am doing my bit, hopefully the drugs will continue to play their part & we can all live with my ITP in some degree of comfort.

It is so important to have key information to hand, especially when we need to discuss our health with our ITP specialists on a regular basis. From the perspective of our medical advisors, it also helps them to better help us. If they know that we have taken the trouble to keep proper records they will appreciate that we are trying to take ownership of the management of our condition.

My Thanks to MMF

In early February 2020 I suffered a relapse completely out of the blue. In mid January 2020 my platelet count was a solid 132, but by February 8th it had plummeted to just 8. Even now we don't really know why this happened, albeit the suspicion is that I must have picked up a cold or virus (not Covid-19 related thankfully).

So back in mid February 2020 it came as a nasty shock to have yet another relapse after having been lucky enough to have enjoyed pretty much normal platelet counts since April 2016. I had been on 750 mg of Mycophenolate Mofetil (MMF) per day and that seemed to be holding my platelet count well.

I can only compare a sudden relapse to one of

those glass snow globe ornaments where during the ordinary course of events the contents contained inside are completely still, stable and calm . Suddenly someone shakes the globe vigorously and sends everything into a state of utter chaos and confusion. Eventually everything settles down again but for a while all seems out of control.

That scenario was the one that greeted me when I had a dramatic fall in my count to 8 in early February 2020. I was put back onto the dreaded Prednisolone for a 3 month period accompanied by an increased dosage of 2 times 500 mg of MMF. Gradually control was regained & stability with some degree of calm continues to reign.

This treatment regime worked, albeit not without the nasty Prednisolone side effects. After 3 months of the steroid, I was tapered off it and since May 2020 I have been left on just the 2 x 500mg per day of MMF. Thank goodness, my counts have been stable and normal ever since. The snow globe seems to have settled and everything has gone back to where it should be !

What it goes to show, is that we ITP folk can never completely relax our guard. Especially during these Covid-19 times we have to be ever more careful. Extra attention is needed if, like me you are on immune suppressing drugs like Prednisolone, Rituximab, Mycophenolate Mofetil or Azathioprine. Following a very strict hygiene regime is par for the course for us ITP folk anyway and especially so during this Covid-19 pandemic.

The ITP Pocket Log - A Shameless Plug

As well as keeping a written record of all my major ITP related numbers, I also use the ITP Pocket Log developed by the ITP Support

Association and Novartis. It really is an excellent tool and a very useful addition to the valuable resources we have available to assist us on our ITP journey.

The ITP Pocket Log enables the user to record appointments, log and track all blood test results and it can produce a printable graph representation of those results .

The ITP Pocket Log allows the user to keep in one place, all the important contact details for specialists, nurses, doctors, pharmacies, etc as well as lists of symptoms, medications and treatments. It also has great information on ITP including direct links to the ITP Support Association.

To learn more about the ITP Pocket Log and download it if you wish, please take a look at the following link - <https://www.novartis.co.uk/itp-patient-resources> or you can download the app, just search for "ITP Pocket Log" in the Google Play or Apple Stores.

The ITP Pocket Log is available for anyone to download and is FREE so I would urge folk to make use of it. It is very straightforward and it means that you have a wealth of your most important ITP information all kept in one place. Your data will not be captured or shared with anyone else.

Finally - please do take part in our Global ITP September Awareness Campaign. This is something that we have been actively involved with since 2011 and we have some wonderful news coming soon about this years event. So please do watch for details on our website www.itsupport.org.uk and our social media platforms TWITTER @ITPSupportAssoc and Facebook - <https://www.facebook.com/ITPSuppAssoc>

Fundraisers & 'In Memory' Donations

Fundraising

Atlas Trading: A total of £164.00 has been raised via the ITP collection box since March 2021. We would like to thank Atlas Trading Limited for their continued support.

The charity is immensely grateful to Major, Lindsey and Africa for nominating us to receive a grand total of £1,806.10 in lieu of Christmas cards 2020. Very sadly, one of their employees lost a young child due to ITP, earlier last year.

Facebook Fundraisers: A total of £826.90 has been raised since March 2021. Thank you to everyone who decides to ask for donations via Facebook instead of birthday presents.

Give a Car Scheme: Catherine O'Malley scrapped her car and the proceeds of which were donated to the association, total £106.88.

Betty Alder scrapped her car and the as a result £78.40 was donated to the Association.

Virgin Giving: £1,587.52 in donations has been received.

A huge thank you to everyone for their support with fundraising during these difficult times.

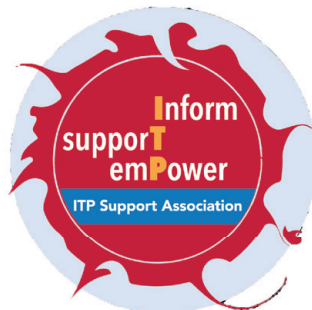
Did you know?

Virgin Giving Brighter Money Bundle offer: The new brighter money bundle from Virgin Money includes a £50.00 donation made to any charity registered with Virgin Money Giving - when you switch current account to Virgin Money.

The ITP Support Association has just received its first £50.00 donation so thank you to the person who nominated us!

In Memoriam Donations

£565.36 was received in donations in memory of the late Mr Martin Connolly. The association passes on its condolences to the family and friends of Martin Connolly.



The Joy of the Jab and Fatigue - Rhonda Anderson



These two subjects do not seem to immediately go together, but they are buzzing in my brain.

Have you felt the Joy of the Jab? Some people definitely have, but some less so, especially if they experienced unwelcome side effects. You may not have felt that joyful, but I am sure most people felt some satisfaction ticking off the event as a positive milestone. I certainly feel more secure, but my Zoom Cocoon will be hard to come out of, and the Lockdown Routine is one I don't necessarily want to give up. Seeing a few friends recently has been..., I don't know what really. Great to catch up and chat face to face, mostly with a feeling of some liberation as well as trepidation.

If you were able to be virtually present at the 2021 ITP Convention, online again this year, I hope you found lots of helpful information about the jab, as well as the usual topics. You can still access the Convention online through the ITP website.

Fatigue is always discussed at Conventions as a now recognised symptom of ITP. It was not always so, and the sharing of patient experiences bought this symptom to the fore. Since that exposure it has been recognised by medics as a real symptom of ITP. Several surveys have been done which have been of some comfort to those who experience it as they realise they are not alone. This of course is the whole reason for the founding and continuing existence of the ITP Support Association.

Fatigue is a symptom of many ailments, if you experience it you will probably say, Thank you very much for telling me that, I already know because I live with it every day, but how do I deal with it? There is no easy answer, and for everyone it will be different. Hopefully the following may give you some ideas on how to tackle your fatigue. These are my own ideas from my own experience. I must come out and say that I do not generally experience fatigue, but have looked into ways to combat it as my husband has had it for many years. Realistically, sometimes there is nothing you can do about it, just go with the flow and stop everything and rest. Consult your health care professional to rule out any pathology.

If you were normally fatigued and feeling tired, what would you do? Rest and sleep are the obvious answers. So how do we rest and sleep? It is always worth looking at your sleep environment. There is such a thing as 'sleep hygiene'! This is keeping your sleeping area purely for sleeping and intimacy. This place will usually be the bedroom in your abode. Make it a haven of sleep. Take away all distractions such as TV and devices. Only have sleep related things around you. Start with the bed. Make sure it is comfortable. You may even decide a new bed is in order. If you like satin sheets for a good night's sleep, invest in some. 100% cotton sheets are comfortable, choose the colour and style that suits you. Amazing how new bed linen can make sleep and bedtime more attractive and comfortable. Change your bed linen at least once a week. Wash with detergent that doesn't irritate your skin. If you have dry skin that itches in bed, use a moisturiser every day as this usually helps. Check your night wear for comfort. I like

The Joy of the Jab and Fatigue - Rhonda Anderson

my old, well worn, raggy nightdresses, one of which famously got left behind, at an 'in person' ITP Convention, which feels like 100 years ago...I did get it back and then lost it in a hotel in New Zealand! I hasten to add, I do not usually go shedding my raggy nightwear all over the world! Of course some people prefer to wear nothing in bed. Make sure you feel comfortable and not too hot or cold. A bedroom that is a little cooler is better than too hot. Turn off your radiator. Some people find having the window open a little helps sleep and feeling more refreshed on waking.

Bedtime routines can help. Everyone seems to have one, from minimal to complicated. If yours entails taking medication, removing makeup and contact lenses, and checking on pets and children, you may like to start a little earlier. See what can be done after dinner and only leave the things that have to be done late, to the last minute, before you slip between the covers. Note to self: That is a very good idea! (Always getting into trouble for coming to bed too late!)

Have a wind down routine, so that devices and screens are not used about one hour before bedtime. Do relaxing things before bed. Over stimulation can make it hard to get off to sleep as the mind races and blood pressure can be raised. Likewise avoid serious family discussions at bed time, or in bed! Avoid controversial subjects and heated exchanges.

Do you worry about the next day as soon as your head touches the pillow? Before getting into bed make a list of the things you want to remember for tomorrow, put the list by your bedside with a pen, in case you need to add to the list the very thing that is swirling in your

mind, stopping you from sleeping.

Make sure there are no noises to disturb you, and if there are, then ear plugs may be useful, although not usually very acceptable. May be needed as a last resort.

Are you getting enough time in bed to get your full sleep? Go to bed at the same time and get up at the same time every day of the week. Calculate if you need to spend more time asleep and so go to bed earlier if necessary. Adults usually need 7-8 hours' sleep every night. Many people just need to have the opportunity to sleep more hours. An afternoon nap can help. Give in to tiredness if you can, and rest and sleep when needed. Naps of no more than 90 minutes can be refreshing.

Look at what you are eating and drinking. Some foods have been found to make people tired. If you have an intolerance to wheat, for example, this can tire you. Some years ago I gave up alcohol, tea and coffee and rarely eat chocolate. I found I woke up more alert and energised than when I had these things.

Eating late at night and drinking alcohol can interfere with sleep. Also trips to the toilet may be more frequent if you drink liquids, in any form, near bedtime. Some people have a cut off time for liquids in the evening and also caffeine. Drink normally during the day to avoid dehydration. Caffeine is in many things and if you are sensitive to it, then do check labels. I have even seen caffeinated water! The old fashioned story is that cheese makes you sleepless. Test out what may keep you awake.

There are many websites about sleep as well

as books that you can get from the library or buy online. The above are general ideas for everyone. If you experience severe fatigue, the following may help.

If you are tired and fatigued it is tempting to sit still and let it wash over you. No matter how hard you try it is unappealing to move and do any exercise. Try small amounts of exercise, even sitting in your chair. Move arms and legs and do not sit still for too long. We are all doing this now with Zoom and so on, fatigued or not, we sit still for long periods. This is not good for us. Get up and move around, go up and down some stairs. Gentle exercise also helps night time sleeping. As you get used to doing a little exercise, build it up inside the house, and then venture out. Little by little you will be able to go further and feel better. Having someone to do this with is helpful and social, as we are now allowed to mix in some places, but check the regulations in your area.

It can be exhausting doing simple tasks, so break them up into smaller bite sized pieces. It is not necessary to have a bath or shower every day if this exhausts you. Plan a routine with help, if necessary. A long towelling bath robe can save you some of the effort of drying yourself. Rest after washing if necessary. Then plan the next activity and the time it is going to take you. Maybe a few minutes is all you can manage, so just do that.

To save time and energy, I make up batches of food and freeze some, so on a few days I have home cooked food from the freezer. This is a great time and energy saver. I always get my husband to help me and it takes half the time.

Calculate the amount of energy you have to expend every day. Some people calculate this as spoonfuls of energy or how much one task or one thing uses energy, or The Spoon Theory invented by Christine Miserandino. On a good

day you may feel you have 10 spoonfuls of energy at your disposal. How are you going to allocate the spoons? If you want to go out, that may take 3 spoons, meaning you have 7 left. What will you use those 7 on? Perhaps getting showered, dressed, having breakfast and doing a little tidying may take another 4. Now you have 3. Walking around with your friend may take 2. Then one is left for the rest of the day when you get home, so a rest may be needed. If you were intending to make a long phone call that evening it may be best to defer it to the next day, so you will not get too exhausted.

The ideas above come under the general heading of Pacing. People do this instinctively, allocating their time and energy to tasks and events. You will be able to decide what pacing activities and energy allocations you need to make in your own life. Jotting it down on a piece of paper can help. Make a diary of events and how you feel after doing them. Activity will often give you more energy and interest in yourself and others.

Some medicines can cause fatigue. Read the leaflet, talk to your pharmacist and doctor, they may be able to prescribe an alternative. Some medicines you have been taking for a long time may be tapered off, but only with medical supervision.

Of course smoking cessation is recommended, together with a healthy food intake and balanced weight.

Look long and hard at your lifestyle and see where the fatigue triggers are. Always consult your health care professionals if you plan to make changes in your lifestyle, unless you are sure they are not too radical.

Fatigue is a major symptom of depression. Talk to your GP if you are stressed, anxious or experiencing difficult emotions. Find out what

you can about support groups and information from family and friends, and reliable NHS sources on the internet.

Hopefully we will experience the full joy of the job when we can freely take up our lives again, but I suspect nothing will feel quite the same, but humans are very adaptable and I am sure we will cope. We are seeing our two grandsons soon, so that will be lovely.

Enjoy every day, find something that gives you joy, a flower, the sunshine, a satisfying activity, a smile from and to a dear one, and look forward to better things to come.

Rhonda Anderson - May 2021

A few of the things that have kept me occupied during lockdown.

Just finished the quilt last week! For a little sick baby born before his time, called Arthur. Grandson of a friend of ours. Heard yesterday that he is improving at GOSH.

Cushion for Howard made with hexagons his mother started a long time ago. I found them in our cellar and decided to use them. He asked for the cushion. It has been a long time in the making, getting motivated has not been easy! Also working out exactly how to do it. It looks OK finished.



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.

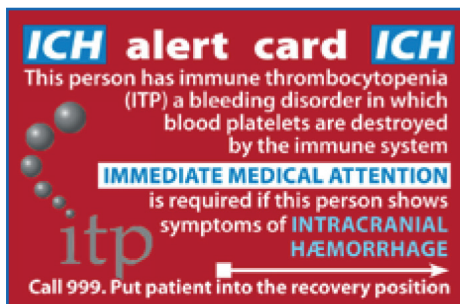
Order a free ICH alert card

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.

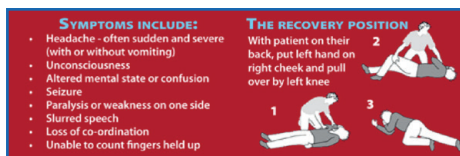


ICH alert card ICH

This person has immune thrombocytopenia (ITP) a bleeding disorder in which blood platelets are destroyed by the immune system

IMMEDIATE MEDICAL ATTENTION is required if this person shows symptoms of **INTRACRANIAL HÆMORRHAGE**

Call 999. Put patient into the recovery position



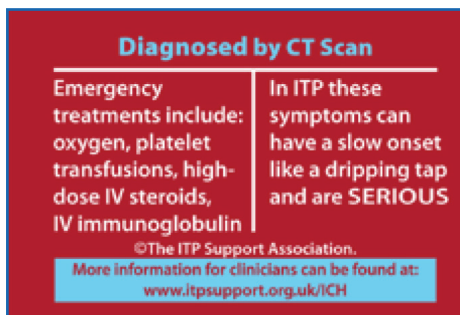
SYMPTOMS INCLUDE:

- Headache - often sudden and severe (with or without vomiting)
- Unconsciousness
- Altered mental state or confusion
- Seizure
- Paralysis or weakness on one side
- Slurred speech
- Loss of co-ordination
- Unable to count fingers held up

THE RECOVERY POSITION

With patient on their back, put left hand on right cheek and pull over by left knee

1 2 3



Diagnosed by CT Scan

Emergency treatments include: oxygen, platelet transfusions, high-dose IV steroids, IV immunoglobulin	In ITP these symptoms can have a slow onset like a dripping tap and are SERIOUS
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©The ITP Support Association.
More information for clinicians can be found at: www.itpsupport.org.uk/ICH



ITP Awareness Campaign

ITP September Awareness Campaign

It may seem a long way off but we are already planning our activity for the 2021 ITP September Awareness Campaign and in the following article I look at why it is so important that we should all make an effort to get involved. Please keep checking the ITP Support Association website at www.itpsupport.org.uk for further announcements about the campaign.

WHY IS SEPTEMBER AWARENESS MONTH IMPORTANT?

One of the main lessons that I have taken from my ITP journey is that we all need to make more people aware of this very little known, enigmatic illness. Like most ITP sufferers, before I was diagnosed with it, I had never heard of it and I really couldn't believe that I had it.

I had been experiencing ITP symptoms for at least a year before I went to the doctor to get checked out. These symptoms were mysterious, unprovoked, random bruising and terrible bouts of tiredness. I wish that I had recognised these symptoms earlier and got them checked. This is why we need to make other people aware of what to look out for.

After my diagnosis of ITP, I just couldn't really believe that I had anything as serious as that. I thought that the hospital had made a mistake. Maybe they had confused my blood test results with somebody else. Once it became clear that I really did have ITP, then I got angry.

Why me, how can I have ITP? I had never been ill

before, never smoked, never taken any drugs and always drank alcohol at sensible levels. I had lived my first 46 years without ever being in a hospital for anything other than a few stitches from football/soccer related injuries.

Well, so what? ITP does not care much about who it chooses and when. Unfortunately it can develop in anyone at anytime at any age and of any ethnicity, although we do know that it occurs more in women than men. In short, ITP is not terribly fussy, it can choose anyone, we are all fair game.

In adults it is usually more stubborn than in children. It tends to disappear (often without treatment) in many children, as suddenly as it turns up. In adults it is rarer to see it go into spontaneous remission. But it doesn't mean that we cannot live very full and positive lives. ITP is manageable in most cases and not as threatening as many other conditions.

SPREADING AWARENESS ACTUALLY GETS RESULTS

There are certainly plenty of grounds for optimism and it is clear that our ITP Awareness campaigns have borne fruit. When the annual September campaign started back in 2010 things on the purple front were very, very different.

In fact when I think back to 2006 and my diagnosis there were far fewer treatments available for ITP (For example - TPO drugs had not been rolled out) very few support groups, and certainly very limited numbers of things like blogs, social media groups, vlogs, let alone research on the scale we have now.

Things have improved dramatically and as

evidence of this I would urge anyone living with ITP to watch two video films on the ITP Support Association You Tube Channel which explain the many treatment options now available to us.

The links are set out below and I am encouraged myself when I watch them to know how many more treatment options we now have compared to when I started out, as a wet behind the purple ears person.

Link number 1 - Dr Drew Provan - What's new in ITP Treatment - <https://youtu.be/lcC329pd-fY>

Link number 2 - Professor Adrian Newland - The new ITP Guidelines - https://youtu.be/nd9FPx_hANM

The whole approach to ITP is so much more positive, more patient focused and inclusive. It is just so much more optimistic and encouraging.

Making an effort to spread awareness has undoubtedly played a big part in moving research, treatments & knowledge further forward. There is no better reason to get involved this September than knowing any contribution we make is improving things for us living with ITP now, and helping those who may follow in our footsteps in years ahead.

However, we cannot be complacent, it is up to us to keep making others aware of our condition. We know what it is like to live with it day to day and it is we who can tell others what to expect. If we don't inform people about ITP, then who will ?

So please do help in this September Awareness campaign, try to get involved even if it is to take just one or two small actions.

SIMPLE THINGS WE CAN ALL DO in the ITP September Awareness Campaign

1 Join us at the ITP Support Association in our September Awareness Online Event (Full details will shortly be available via www.itpsupport.org.uk).

2 Engage with the daily social media postings that we will be making throughout September highlighting ITP. We will be using the hashtags #ITPAware and #global4ITP

3 Retweet and/or LIKE any TWEETS we put out & in doing so this spreads visibility of the campaign

4 Try posting out a few TWEETS or Facebook messages yourself - here are a few that you may wish to use -

A) ITP is a RARE DISEASE and is just one of over 6000 RARE DISEASES

B) ITP is an AUTOIMMUNE disease, of which there are over 80 including multiple sclerosis, pernicious anaemia, type 1 diabetes, Lupus & rheumatoid arthritis

C) About 5,000 people in the UK are living with ITP at any one time, the figure in the USA is between 60,000 & 100,000

D) In ITP the immune system mistakes platelets as being foreign & destroys them. It can follow a virus, vaccination or some medications, but often the cause is unknown.

E) There is no cure for ITP but there are many treatments which are used to raise the platelet count.

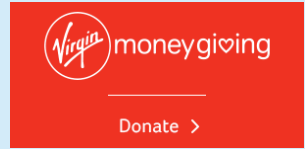
Anthony Heard
March 2021



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

