



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

www.globalITP.org

Global ITP Awareness Week

Organized by:



A global voice for immune thrombocytopenia patients.

SEPTEMBER 21-25

The
Platelet

JOURNAL OF THE ITP SUPPORT ASSOCIATION

SEPTEMBER 2020

The ITP Support Association Team

Charity Registration No. 1064480

THE ITP SUPPORT ASSOCIATION HQ

The Platelet Mission
Kimbolton Road, Bolnhurst, Beds.
MK44 2EL (UK)
Tel: 01234 376559
Web: www.itpsupport.org.uk
E-mail: info@itpsupport.org.uk
Shirley Watson MBE Founder

TRUSTEES

Professor Adrian Newland CBE (Chair)
 Derek Elston
 Xenia Norman
 Colin Williams

OFFICE

Chief Executive
 Mervyn Morgan
Office & Fundraising Administrator
 Liz Gooch

VOLUNTEERS

Social Media
 Hayley Howie
Group Liaison
 Derek Elston
Patient Mentors
 Rhonda Anderson
 Dave Farrow
 Derek Elston
 Karen Smith

MEDICAL ADVISORS (Adult ITP)

Prof. Adrian C. Newland CBE
 MA FRCP FRCPATH
 Dr. Drew Provan
 MD FRCP PRCPATH
 Dr. Jecko Thachil
 MRCP FRCPATH
 Dr. Will Lester
 MBChB(hons), BSc, MRCP, FRCPATH, PhD
 Dr. Nichola Cooper
 MA, MBBS, MD, FRCP, FRCPATH
 Dr. Gerard Crotty
 MB BCh BAO, FRCPATH, FRCPI

MEDICAL ADVISORS (Childhood ITP)

Dr. John Grainger
 MBChB MD MRCP FRCPATH
 Dr. Mike Richards
 MA BM BCh DM MRCP FRCPATH
 Dr. Cindy Neunert
 MD MSCS

AMERICAN PERSPECTIVE (Contributors)

Dr. Cindy Neunert
 MD MSCS
 Prof. Spero R. Cataland
 MA FAAP (USA)
 Dr. Adam Cuker
 MD MS
 Dr. Rachael Grace
 MD MMSc

The Platelet is the quarterly journal of The ITP Support Association. The Platelet is copyright and may not be copied, quoted or reproduced without written permission of the ITP Support Association (copyright holder). Articles in The Platelet represent the opinion of the writer, or writers, and not necessarily those of The ITP Support Association. Whilst every effort is made to ensure the accuracy of information, responsibility for omissions or errors cannot be accepted by The ITP Support Association, its personnel or medical advisors since circumstances and particulars vary from person to person. The Platelet is available free of charge to all to members of The ITP Support Association. It may not be sold.

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

If there is any positive to come out of the current Covid-19 Pandemic, I would highlight how the Association has managed to provide support for ITP Patients in spite of the lockdown and changes to the way the NHS is providing treatment for its patients. Our Local Support Group Meetings on Zoom have enjoyed the support of several Medical professionals who have given up their time to answer questions from those patients taking part in the calls, thank you to all who have supported these groups.

You would have also seen that our 2020 UK ITP Convention will now take place as a VIRTUAL EVENT over two days, Saturday 10th October, and Sunday 11th October. You will find the agenda for this event in this edition of the Platelet. By the time you receive this edition of the Platelet the Convention Registration Page should be open, please note the Virtual Convention is free to register. To register visit www.ITPConventionUK.org.

As mentioned in the last edition of the Platelet we are continuing to receive more emails and telephone calls than normal from people with worries and concerns about their own or a loved ones ITP and what Covid-19 means to those with Immune Thrombocytopenia. We have tried to answer all the questions and hope you have found this supportive during these worrying times.

The Covid-19 section of our website is updated when new information comes to hand, just visit www.itpsupport.org.uk and click the link.

Do not forget ITP Awareness Week September 21st to 25th.



www.globalITP.org

2020

SEPTEMBER 21-25

Global ITP Awareness Week

Organized by:  INTERNATIONAL ALLIANCE

A global voice for immune thrombocytopenia patients.

You can read more about ITP Awareness Week in this edition of the Platelet.

In order to keep abreast of the Covid-19 pandemic that is engulfing the planet we have also been having virtual meetings with our friends from ITP groups from around the world, who have all been pulling together in support. The ITP Support Association is proud to be part of the International ITP Alliance for more info visit www.GlobalITP.org.

We have found during the lockdown that our fundraising income has taken a huge hit, this is understandable as most of the events our supporters would use to raise fund have been cancelled or postponed, lets hope things are able to resume at some point in the not too distant future.

However, many people have decided to raise money for the ITP Support Association on the Facebook Platform, go to our ways to donate page for more details.

From everyone at the ITP Support Association, thank you for your continued support, Stay Safe, Stay Alert.

Mervyn Morgan CEO

Contents

- 3** From ITP HQ
- 4** Your Questions
- 5** Patient Mentors
- 6** The Flu vaccine and ITP
- 8** UK Virtual Convention 2020
- 10** UK ITP Registries
- 13** Local ITP Group Meetings
- 14** Fundraisers & 'In Memory Donations'
- 14** Evan's story by Caron James
- 16** I sporT purple for Platelets UK Poster
- 18** Global ITP Awareness Week
- 19** Life with ITP by Shehzma Hirani
- 21** My ITP story by Lina Moniz
- 22** Leaving a Legacy
- 23** Treatment during Covid-19
- 26** Order a free ICH alert card
- 27** New Christmas Cards
- 28** Ways to Donate
- 29** Publications List
- 32** Membership Form

Your Questions

Q **from Linda,** I am 72 and have had chronic ITP since July 2010. After many treatments without sustained improvement in November 2013 I started on Romiplostim. After many ups and downs and dose adjustments I am now stable on 250mcg every 7 days administered at home, with blood test and Haematology consultation every 8 weeks. I remain asymptomatic with a platelet count between 70 and 100 and other blood readings are normal.

My main side effect has been muscle and joint pain for a couple of days managed with paracetamol. I have developed osteoarthritis affecting my fingers, foot and hip on the right leg where I also have a total knee replacement in this leg (Since 2010) I am making an effort to lose weight, doing exercises indoors and I walk every day usually achieving 8,000 steps daily.

I do all this even if I have pain. I believe that there must be inflammation in the joints but unable to take NSAIDs because of ITP. Can you suggest any safe anti-inflammatory treatment? I would really appreciate your advice in this matter as I have found the support of the association invaluable since my diagnosis.

A **From Dr. Jecko Thachil,** Non steroidal are not ideal in patients with ITP especially if the counts are below 50. It is allowed if the count is above 50. In these cases, a COX-2 inhibitor like celecoxib is preferable.

On the other hand, taking non steroidal long-term is also associated with adverse effects on the kidney and the heart.

Ideally, the pain is dealt with definitive measures which may include physiotherapy and in rare cases, surgery.

Q **from Jo,** I was wondering if you have any information about Revolade (eltrombopag) and the effect it has on different people. I have been on 50mg since January and off the steroids for 5 months I have had a really miserable time with the side effects, a constant background headache, joints aching, not sleeping, not eating due to lack of taste, weight loss, and the most terrible fatigue which is such that I have to go to bed most afternoons. My Consultant has been very reluctant to address any of these side effects as overall my platelets are not stable but not dropping off the register. I have been told that it will settle when the steroids leave my system there is absolutely no sign that this is happening.

Prior to this I had 2 years of my platelets crashing on a regular basis and lots of A & E visits and although at times I felt very unwell never did I feel so constantly unable to cope and live a half decent life.

My choice would be to reduce to 25mg and hope my Platelets would not drop too drastically. Do you know of anybody who has suffered similarly?

A **From Prof. Newland,** Certainly all the symptoms Jo describes are all recognised side effects of eltrombopag, but she is very unlucky to get the full house. They may wear off with time, but life seems intolerable at the moment so would be worth dropping to 25mg or alternating 25 and 50 if her consultant is happy with it.

If things don't improve then reluctantly, she will need to look for an alternative. The new agent, Avatrombopag, is not licensed in the UK for ITP, although it is for liver related thrombocytopenia so her consultant may be able to get it on compassionate grounds as a one off as it would be worth trying.

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

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.



The Flu Vaccine and ITP

Please note that this general advice on the influenza vaccine has been written by one of the Association's medical advisors, Professor Adrian Newland CBE, but it does not replace any advice given to you by your consultant or GP who knows you and your ITP.

The influenza vaccine has been linked to the development of ITP in a small number of adults and may cause a temporary dip in platelet counts in children or adults receiving the vaccine. However, the risks are higher for children (or adults) who are unvaccinated and develop influenza.

There has been significant disruption created in the health service by Covid-19 this year and as the service strives to clear the backlog of patients needing NHS assessment and treatment, it must also plan for the winter ahead. Many experts have predicted the possibility of a resurgence of the Covid-19, either locally or more generally, and there is also the possibility of a flu epidemic, which we frequently see in the autumn. This poses a serious risk to health in the UK.

These new pressures are in addition to the challenge winter usually presents to the NHS, when other infectious diseases are more common and conditions such as asthma, heart attack, chronic obstructive pulmonary disease and stroke tend to worsen.

Flu vaccination is available and should be considered in addition to the other important steps that we are taking to minimise the of Covid-19. The advice on how to minimise transmission of Covid-19 in the community, will also help minimise the risks of flu as well. The health service is also working to provide Covid-19 and Covid-19-free zones, and ensuring that there is adequate PPE, testing and system-

wide infection-control measures to minimise transmission in hospitals and care homes while also working to provide healthcare for the general population.

As the symptoms of Covid-19 and Flu can be very similar guarding against the worst effects of flu with a concerted effort to get people at risk (including health and care workers) safely vaccinated in the late summer and early autumn will be a very important step.

Flu is an unpredictable virus that can be unpleasant, but if you are otherwise healthy it will usually clear up on its own in about a week. It can cause severe illness and even death among vulnerable groups, including older people, pregnant women and people with an underlying health condition. Certain people are more likely to develop potentially serious complications of flu, such as bronchitis and pneumonia.

The groups in whom the flu vaccine is recommended include:

- are 65 years old or over
- are pregnant
- have certain medical conditions that increase your susceptibility to infection (this is the same list that the Association put out for the Covid-19 risk)
- are living in a long-stay residential care home or another long-stay care facility
- receive a carer's allowance, or if you are the main carer for an elderly or disabled person whose welfare may be at risk if you fall ill
- live with someone who is at high risk of coronavirus (on the NHS shielded patient list) or you expect to be with them on most days over winter

It is likely that the flu vaccine will be extended to all 50-64-year-olds and we are expecting more information in the autumn. However, if you are aged 50-64 in an at-risk group, you should not delay having your flu vaccine.

The flu vaccine mutates its genetic make-up on a regular basis so that a previous infection may not protect from infection later. Each year the vaccines are made to cover the flu virus strains that have become prominent over the previous months. In general the vaccines are effective in up to about two-thirds of cases, when the vaccine has been matched to the circulating viruses. There is also evidence that even if the vaccine does not fully protect from getting an infection that the impact and complications are lessened by having had the vaccination. There are substantial public health and personal benefits from being vaccinated.

There are many myths regarding the flu vaccine. Two of the main ones are:

The flu vaccine can give me the flu. Fact: The injected flu vaccine contains an inactivated virus that cannot give you influenza. If you feel achy or slightly feverish, it is a normal reaction of the immune system to the vaccine, and generally lasts only a day or two.

The flu vaccine can cause severe side effects. Fact: The flu vaccine is proven to be safe. Severe side effects are extremely rare. One in a million people may get Guillain-Barré Syndrome (GBS), which cause muscle weakness and paralysis.

The vaccine has been linked to the development of ITP in a small number of adults and may cause a dip in platelet counts in children or adults receiving the vaccine. These are usually transient effects. However, the risks are higher for children (or adults) who are unvaccinated and develop influenza.

Two types of influenza vaccine are widely available: inactivated influenza vaccines and live attenuated influenza vaccines. Traditionally, influenza vaccines (both IIV and LAIV) have been produced to protect against 3 different seasonal influenza viruses (also called trivalent vaccines) but quadrivalent vaccines (against 4 types are also being produced). These are generally given as an injection into the arm. There is also a live attenuated nasal spray influenza vaccine available, for children and those who want to avoid an injection. There is no preference expressed for any one vaccine over another, all are equally effective. If you have questions about which vaccine is best for you, talk to your doctor or other health care professional. However, note the issues relating to live vaccines in the following paragraph.

Specifically in ITP for the newly diagnosed patient (within 3 months of diagnosis), who is not on treatment flu vaccine need not be given unless there are any of the risk factors previously mentioned. In the persistent or chronic ITP the flu vaccine should be considered, particularly in the patient who has required, or is on, treatment and in those who have had a splenectomy. The live vaccine should not be given to those who are on, or have recently received steroids or immune suppressive drugs, or rituximab in the past 12 months. This should be discussed with your doctor or the healthcare professional administering the vaccine.

There are on average 10,000 deaths each year in the UK from flu, although in 2017-18 it was more than double that. Many of these were in at-risk individuals so to reduce spread and the incidence of infection, vaccination should be considered by all people over the age of 6 months every year.

Professor Adrian Newland

UK ITP Virtual Convention



ITP Support Association
UK Convention - London 2020

1995 – 2020 25 Years of ITP Support

The ITP Support Association is pleased to announce that its 2020 UK ITP Convention will now take place as a VIRTUAL EVENT on Saturday 10th October and Sunday 11th October*.

***Please note the revised date for this event**

Registration for this event will be available (Free) by going to www.ITPConventionUK.org

This event is supported by:

GOLD SPONSOR



SILVER SPONSORS

BRONZE SPONSORS

Pre-recorded Sessions to View On-Demand

Agenda and speakers subject to change

Registration for this event will be available (Free) by going to www.ITPConventionUK.org

AGENDA - UK ITP Support Association - Virtual Convention October 10th and 11th 2020	
SAT 10th OCTOBER	SESSION
10:00 - 11:00am	EXHIBIT HALL, RESOURCE CENTER, and ITP LOUNGES OPEN Please visit our event partners in the exhibit hall, browse the ITPSA Resource Center, and connect with others in one of the ITP lounges.
11:00 - 11:15am	Introduction - Mervyn Morgan
11:15 - 11:45am	The new ITP Guidelines - Professor Adrian Newland
11:45 - 12:05pm	Covid 19 and ITP - Dr Nichola Cooper
12:05 - 12:30pm	Patient Discussion - Mervyn Morgan
12:30 - 1:30pm	EXHIBIT HALL, RESOURCE CENTER, and ITP LOUNGES OPEN Please visit our event partners in the exhibit hall, browse the ITPSA Resource Center, and connect with others in one of the ITP lounges.
1:30 - 1:55pm	The Adult ITP Registry; Real Life Care - Dr Vickie McDonald
1:55 - 2:20pm	What's new in Paediatric ITP; the Children's ITP Registry - Dr John Grainger
2:20 - 3:00pm	EXHIBIT HALL, RESOURCE CENTER, and ITP LOUNGES OPEN Please visit our event partners in the exhibit hall, browse the ITPSA Resource Center, and connect with others in one of the ITP lounges.
3:00 - 4:00pm	CONCURRENT – Breakout Session – Women's' issues - TBA
3:00 - 4:00pm	CONCURRENT – Breakout Session – Adults issues - TBA
3:00 - 4:00pm	CONCURRENT – Breakout Session – Children's' issues - TBA
4:00 - 4:25pm	Clotting problems in ITP - Dr Jecko Thachil
4:25 - 4:50pm	Letter from America - Dr Cindy Neunert or Dr Adam Cuker (topic to fit in with programme; bleeding, fatigue, QoL, TPOs.)
4:50 - 5:30pm	EXHIBIT HALL, RESOURCE CENTER, and ITP LOUNGES OPEN Please visit our event partners in the exhibit hall, browse the ITPSA Resource Center, and connect with others in one of the ITP lounges.
SUN 11th OCTOBER	SESSION
1:00- 1:30pm	EXHIBIT HALL, RESOURCE CENTER, and ITP LOUNGES OPEN Please visit our event partners in the exhibit hall, browse the ITPSA Resource Center, and connect with others in one of the ITP lounges.
1:30 - 1:55pm	What's new in ITP Treatment - Dr Drew Provan
1:55 - 2:20pm	Pregnancy and ITP - Dr Susan Robinson
2:20 - 2:45pm	Patient Story - Mervyn Morgan
2:45 - 3:00pm	EXHIBIT HALL, RESOURCE CENTER, and ITP LOUNGES OPEN Please visit our event partners in the exhibit hall, browse the ITPSA Resource Center, and connect with others in one of the ITP lounges.
3:00 - 4:00pm	Live Q&A Webinar • Dr Drew Provan (Chair) • Prof Adrian Newland • Dr Nichola Cooper • Dr John Grainger • Mrs Rhonda Anderson • Dr David Kuter (TBC) • Dr Waleed Ghanima (TBC)
4:00 - 4:30pm	EXHIBIT HALL, RESOURCE CENTER, and ITP LOUNGES OPEN Please visit our event partners in the exhibit hall, browse the ITPSA Resource Center, and connect with others in one of the ITP lounges.

UK ITP Registries

The ITP Support Association has been a proud supporter of the UK ITP Registries since their inception.

In 2020 we continued this support with grants of £22,000 for the Adult ITP Registry at Barts Health NHS Trust and £22,000 for the Childhood ITP Registry at the Royal Manchester Children's Hospital.

In the last five years the ITP Support Association has supporting these ITP Registries with over £200,000 of funding, which has enabled them to continue their ITP research.

If you would like to support the ITP Support Associations Research Fund you can donate by going to our website and clicking on the Virgin Money Giving Donate button. www.itpsupportorg.uk

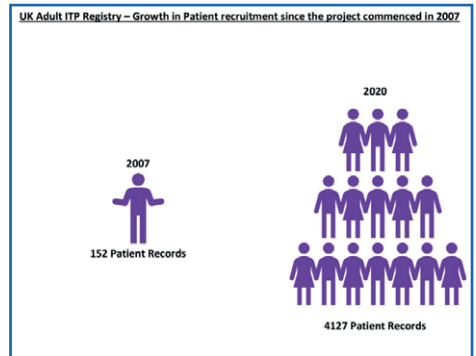
UK Adult ITP Registry Update September 2020

It has been a busy year at the UK adult ITP registry! We are delighted to let everyone know that 2019 was our best recruitment year on record since the study began in 2007 with 567 patients recruited. As of the 31st August 2020, we have recruited a total of 4127 patients, and we have over 70 active hospitals recruiting patients. The global pandemic caused by COVID-19 has inevitably had an effect on recruitment numbers in 2020 and with lockdown measures restricting movement for staff and patients alike, we have made some changes in how we see and recruit patients in the Registry. As a result, sites will be able to consent patients remotely via telephone and postal communication. Our pregnancy registry continues to recruit well under the direction of Dr Sue Robinson from Guys and St Thomas' Hospital, an update of which was prepared for the British Society for Haematology meeting.

We have continued to work on studies understanding the treatment outcomes in patients with ITP. We have looked at the outcomes after splenectomy in patients with ITP, including which patients respond and potential complications. It shows that in the UK we perform far fewer splenectomies for ITP and most patients now receive medical treatments rather than surgery. The data will be presented virtually at the

British Society for Haematology later this year. Our collaboration with Quentin Hill from Leeds Hospital is making good progress and will help us understand if there are influences on the response to treatment with IVIG or rituximab. We are looking forward to working with others.

Visit our website <https://www.qmul.ac.uk/itpregistry/> for more information, latest updates and publications. As always, we thank the patients and the ITP patient support association for their support and involvement! We look forward to updating more at the support association patient day in October.



A map to show the hospitals who are active in recruiting patients and contributing to the data in the UK Adult ITP Registry.



The list of over 70 active Hospitals who are recruiting patients and contributing to the data collection for the Adult ITP Registry	
The Royal London Hospital Hammersmith Hospital	Kettering General Hospital
University College Hospital	Ealing Hospital
Royal Victoria Infirmary	Epsom and St Helier University Hospitals
Sunderland Royal Hospital	University Hospital Southampton NHS Foundation Trust
Kent and Canterbury Hospital	King's College Hospital
Northwick Park Hospital	Derriford Hospital
Glasgow Royal Infirmary	King's Mill Hospital
The Royal Liverpool University Hospital	Worthing Hospital
Queen Alexandra Hospital	Burton Hospitals NHS Foundation Trust
Churchill Hospital	Royal Shrewsbury Hospital
Royal Cornwall Hospital	South Tyneside District Hospital
Leicester Royal Infirmary	Southmead Hospital
St James's University Hospital	Royal Derby Hospital
North Tyneside General Hospital	Medway Maritime Hospital
Princess Royal University Hospital	Birmingham Heartlands Hospital
Harrogate District Hospital	Gloucestershire Royal Hospital
Worcestershire Royal Hospital	Birmingham Women's Hospital
Nevill Hall Hospital	Kingston Hospital
University Hospital of Wales	Addenbrooke's Hospital
West Middlesex University Hospital	Warwick Hospital
Pilgrim Hospital	Chesterfield Royal Hospital
Royal Gwent Hospital	York Hospital
Guy's Hospital	Airedale General Hospital
Poole Hospital	Russell's Hall Hospital
Manchester Royal Infirmary	Wythenshawe Hospital
Bristol Haematology and Oncology Centre	Queen Elizabeth Hospital (Gateshead)
Hereford County Hospital	Nottingham City Hospital N H S
Colchester Hospital	Norfolk & Norwich University Hospital NHS Foundation Trust
Bedford Hospital: Accident & Emergency Department	Bradford Teaching Hospitals NHS Foundation Trust
Royal Devon and Exeter Hospital (Wonford)	Royal Victoria Infirmary
Basildon University Hospital Accident and Emergency	Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust
St George's Hospital A&E Department	Scarborough General Hospital
Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust	Newham University Hospital
Grantham and District Hospital	Queen's Hospital
Prince Charles Hospital	Cumberland Infirmary
St Richard's Hospital	
University Hospital Lewisham	

UK ITP Registries cont...

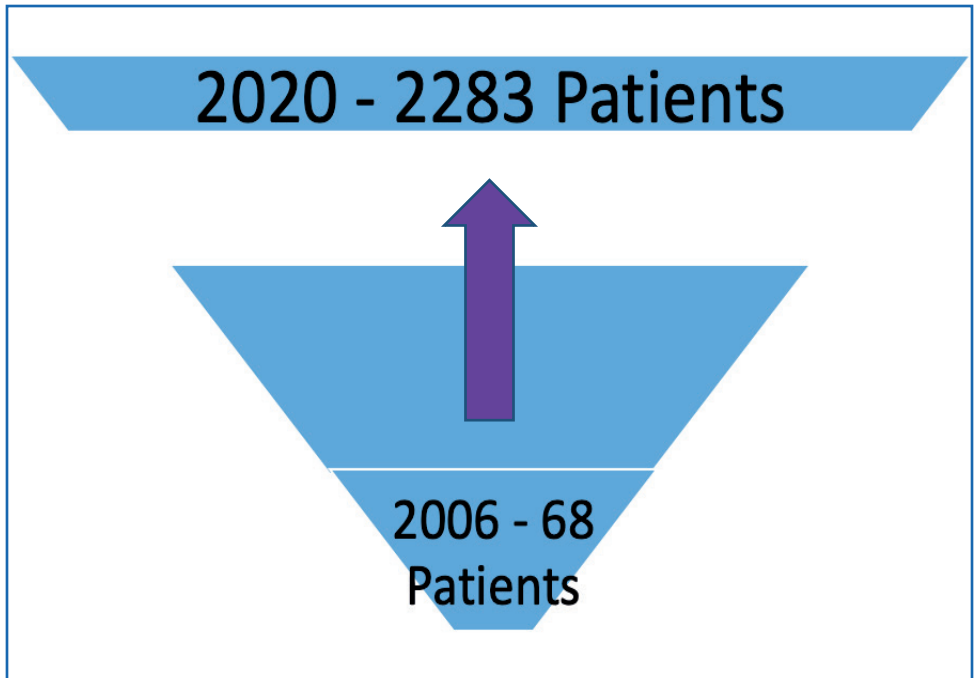
The ITP Childhood Registry

This year the ITP Childhood Registry had two abstracts accepted to BSH. The first abstract examined the impact of therapy on quality of life during the initial 6 weeks after ITP diagnosis. Results demonstrate improving HRQOL in all groups over the 6-week study period with greatest improvement in those receiving immunoglobulin. The second abstract reviews treatment trends for those children with persistent ITP after 6 months and ongoing severe thrombocytopenia, this study demonstrates a more rapid move to second line therapy and increasing uptake of TPO-RA. It does however demonstrate that the majority of children are not receiving therapy.

The planned student projects were cancelled due to COVID. It is still the intention that these projects will take place but at a later date. Project 1 will examine the outcome of children with moderate or mucosal bleeding in comparison to the TIKI (IVIG) study and project 2 will examine markers of alternative thrombocytopenia diagnosis.

Outside of the registry there are two upcoming clinical trials for children with persistent ITP, details of which will be shared once we have the relevant permissions.

UK ITP Childhood Registry – Growth in Patient recruitment since the project commenced in 2006





**ITP SUPPORT
ALL AROUND
THE GLOBE**

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

AMGEN **argenx** **GRIFOLS** **PRINCIPIA** **ub** **Omph**

ITP Local Zoom Meetings

Since the intervention of Covid-19 onto our daily lives we have been holding our Local Group Meetings using the Zoom Video Conferencing System, each one has been well received by all who have taken part. We are pleased to announce that the next meeting will be our Scotland ITP Group and we hope to have Dr Catherine Bagot, Consultant Haematologist, Glasgow Royal Infirmary joining us to answer questions from those taking part.

Planning is also underway for an All-Ireland Zoom Meeting in November, check out our website for details as plans develop.

We would like to thank our sponsors for making the use of Zoom for our Webinars and Virtual Group Meetings possible.

Scotland ITP Group Meeting

Next Meeting: Thursday 1st October 2020 7.00pm.

Online Zoom Meeting - For details email mervyn.morgan@itpsupport.org.uk

All-Ireland Group Meeting

Next meeting: November (Date to be confirmed)

Online Zoom Meeting - For details email mervyn.morgan@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!

Fundraisers

Before the Covid-19 lockdown Kidderminster Harriers Under 10's organised a Parents v Players Charity game to raise money for the ITP Support Association. A member of the team, George, has a sister who suffers with ITP, so the team wanted to come together to raise some money and promote awareness.

The game was a big success, even though they had to play through thick fog! In the end the Parents managed to sneak the victory with a 14-12 win and we managed to raise £75 on the night!

Well done to everyone involved.

There were many Fundraising events due to take place in the past few months but, understandably due to the Covid-19 pandemic these have all been put on hold. We would like to thank all our fundraisers who are eagerly awaiting a return to semi-normality so they can get back raising funds for the ITP Support Association.



Evans Story

Evans' story – by Caron James

My son Evan was an extremely boisterous 3-year-old little blondie, always on the go, always happy and loving preschool. He woke me up one night with a nosebleed, he had never had one before, so I wasn't worried, it stopped within 5 minutes, so we just carried on. A few days later, he had another nosebleed, but this time, it did not stop. I knew something was not right, so I made an emergency GP appointment, they said children's noses are extremely sensitive and prescribed some sort of cream.

We were also sent for a blood test 'just to be sure' within a couple of hours I took Evan to A&E. The consultant called us in and Evan dramatically vomited blood. The consultant pushed a button and the room was suddenly swarming with doctors, stripping Evan down to his underwear and

putting in an emergency cannula, which was very traumatic for Evan. They said it looked like leukemia and my heart stopped! He was covered in petechiae and bruises, even more so than the few I'd seen and put down to him being a clumsy boy.

His blood results came back while we were still in the emergency room. His platelets were 2. That is when I heard ITP for the first time, this complicated sounding illness, I'd never heard of. Evan was admitted to the ward and as we passed the playroom, Evan got excited and tried to run. He collapsed and I carried him to his bed. The doctor came in and explained the illness in more detail and said our GP had called in an absolute panic saying his patient has 2 platelets, the doctor said, "don't worry, he's already here". We watched Evan like a hawk and he slowly got less and less responsive. We called the nurses and again my boy was surrounded by doctors and nurses, they gave him fluids directly

into his cannula and he eventually came round. To this day that was the scariest moment of my life, it seemed as though Evan was lifeless forever. He was given a blood transfusion and platelet transfusion and we were in hospital for 3 days. We were sent home with a bag full of medication and steroids. I was still trying to process what had happened and tried to educate myself about ITP as much as I could.

We were back and forth to hospital doing regular blood test and having consultants' appointments. I was told Evan would likely recover from ITP within 3 months, he didn't, then I was told 6 months, still, he was struggling to maintain double figures and he was off and on steroids at varying doses and he had rounds of ivig. He responded well to treatments thankfully, but it was always a quick fix. He had a fall and hit his head badly and because he had single figures, he was sent for an MRI. They wanted me to leave him because of the radiation but Evan was scared so I refused to leave. I had to wear a bomb proof dress and neck guard and watch my tiny boy go into the biggest machine. He was so brave and laid perfectly still. There was no internal bleeding. Thank God.

After his 1-year diagnosis anniversary we were referred to the paediatric haematologist in Southampton hospital and Evans case was discussed with Dr Grainger in Manchester. We discussed treating Evan with either rituximab or eltrombopag. The decision was ultimately in my hands and I struggled with the decision. I did not want my child on any medication. He was frequently visiting hospital, he was quite a celebrity, he loved going to hospital, but was missing so much school and was beginning to fall behind. Turns out, the threat of treatment, made Evans immune system behave and his count began to rise. He managed to get triple figures without meds and just before Christmas when Evan was 7, we were told Evan was "likely in remission" it was literally all I had wanted to hear for the last 4 years! And we were all SO relieved. Evan's remission lasted 1 whole year, the following November, Evan came downstairs with blood blisters in his mouth. My heart sank, I could feel the weight of my boy's condition hit me again like a ton of bricks. We went to hospital and his platelet count was 2. He was given 3 different courses of steroids,

but each time he weaned off, his platelets would crash. Evan was sent for a lumbar puncture. The results confirmed ITP which was expected but it was a relief to know nothing else was lurking. Evans count remained dangerously low, then one evening, he went for a wee and his urine was pink. We rushed him to hospital. They asked for a sample and his urine was RED. It had clots in it and I somehow managed to calm Evan who was obviously shocked and worried, the nurses in turn, tried to calm me. Evan was given steroids by IV and we were admitted. The steroids gave Evan good numbers but we were back within 8 weeks with blood blisters and he was given ivig another 4 times before the consultant said "now is the time for treatment" I had to make a decision so I discussed Evans options again directly with Dr Grainger, we spoke for over an hour and between myself, Evans consultant and the specialist, we decided to put Evan on eltrombopag. Evan was upset that he would potentially not get to go to hospital so regularly, so I bribed him with a weekend at Legoland. It has been such a relief to me that Evan has taken his condition like a champ and has not felt poorly. My philosophy is, if Evan's well, I am well. He is a strong boy and I must be strong for him.

It took 3 months, but Evan reached triple figures and his dosage was reduced. I was comfortable with how things were going and so were the doctors. His liver function tests were coming back normal and he was having no side effects except for not being allowed any dairy after 5pm, this drug was magic. Things were great for 6 months, then on 23 March, days after lockdown and the added worry of this pandemic, Evan was covered in bruises. We called the community nurse for a blood test, his count had crashed to 23, he had not been unwell, there was no reason for the crash. His medication was increased, and his count is slowly rising. He currently has 58 platelets. I check the inside of his mouth daily for blood blisters and check for bruises. I am constantly aware of his ITP and know how unpredictable it can be. I've found the ITP support association a great source of information and assurance and I have become friends with some ITP mum's via Facebook pages, which has been so nice to talk to others who know exactly how you feel. The doctors are hoping that puberty might spur Evan into remission. I remain ever hopeful.

I sport **T** purple
in

insert local

#Global4ITP #ITPAware

Global ITP Aw

September 2

ITPsupport.org.uk

A global voice for Immune Thrombocy

e for **P**latelets n

ation here

#ITPAwarenessWeek2020

areness Week

21 - 25, 2020

GlobalITP.org

topenia (ITP) patients and care givers.

ITP Global Awareness Week



Global ITP Awareness Week (Scheduled 21st to 25th September) is fast approaching.

Immune Thrombocytopenia (ITP) is the most common autoimmune bleeding disorder affecting 10 times as many people as haemophilia, yet is unknown to most. Beginning September 21st ITP patient support organisations from around the world will observe the annual Global ITP Awareness Week.

During this week, thousands of individuals and families will join together to promote public awareness of this rare disorder and share their ITP Warrior stories in their fight against ITP. Global ITP Awareness Week will feature a social media-based photo-sharing campaign called, "Going #global4ITP". Participants from around the world will celebrate the power of purple as they share their photographs with sign depicting their country demonstrating how widespread ITP truly is. You can download our #global4ITP poster from our website at www.itpsupport.org.uk.

ITP is a condition in which the blood has a lower number of platelets than normal. Platelets are cells that help the blood clot. ITP is called an autoimmune disease since it is the result of the body's immune system attacking platelets as if they are foreign cells. A person with ITP is at a higher risk of bleeding. ITP is often accompanied by fatigue and sometimes depression and has a profound impact on a person's quality of life. This lack of public awareness leaves many ITP patients feeling isolated and alone and is the main reason why there is so little support for research on ITP and the lack of advancement in treatment. ITP is a growing but little understood health problem that most people (including some medical professionals) have never heard of. It affects individuals of all ages, sexes, and ethnic origins. The International ITP Alliance of patient support organizations from around the world play a vital role in education, awareness and establishing a global voice for immune thrombocytopenia patients. For more information about ITP, Global ITP Awareness Week or to find a patient support organisation, visit: www.globalITP.org.

Life with ITP

Life with ITP - By Shehzma Hirani

I have ITP.

I have lived with ITP for over twenty years, that's half my life. After receiving first class honours at my university graduation in my early twenties in 1999, I noticed an unruly spectacle of unexplained purple bruises sprawled across my body which I ignored with indifference. However, an over protective mother forced a GP appointment, revealing an over protective immune system, platelets in single figures (average being 150-450), which overnight, led to, unbeknownst to me at the time, a long term diagnosis of chronic ITP. Since then, it's been my shadow through my training and career as a teacher, walking with me through my marriage and the birth of my two beautiful daughters, and now following me into my forties with a further distinction at university.

I've had relations with a range of treatments including the dreaded steroids (a destructive relationship at an impressionable age where I became unrecognisable inside and out), a splenectomy (I heavily invested in it but it didn't work out, scarring me for life and leaving me with a lifetime of Penicillin V as a souvenir); I've toyed with IVIG, platelet transfusion, Tranexamic Acid, Anti D, Azathioprine (fear of long term commitment), Romiplostim (extremes in behaviour) and Rituximab (the one!).

It's not been an easy road relapsing often at milestones in my life; writing essays whilst on a drip when training to be a teacher; three months before my wedding day, feeling far from the blushing bride; on my thirtieth in Paris; discovering blood, blisters, blemishes and bruises and requiring treatment whilst pregnant with my second child; during my fortieth when 'life begins', or in my case, when it comes into question, yet again. Devastating but I got through it. I had to.

I have long phases of not being well, phases of

being well, and phases of somewhere in between. I've recorded every single platelet count, from 2 to 500 plus, and logged every corresponding treatment. I have journaled my journey. I am officially an ITP geek!

I don't like to be defined by my ITP but there are days when I can't see past it, I can't see beyond my own skin. Literally. When I feel low, I obsessively look in mirrors, trying to catch it, before it catches me, persistently inspecting every blemish, searching for the potential bruise from every bump, always on high alert, from when I am brushing my teeth to when I am itching my skin to inspecting red imprints of my socks on my feet. I remember as a teacher marking books and panicking when I spotted red blemishes on my hand, only to find in relief that they were the specks from my marking pen. I used to eat an abundance of beetroot (in vain that it would 'cure' me), and again being caught off guard by crimson fragments stuck in my teeth or stains on my fingers.

Although the nature of the symptoms has changed over the years with changes in my body, my age, changes in medication and so on, the bruises, the red dots (petechiae), and the bleeding (gums, heavy menstrual cycles, unstoppable blood from anonymous cuts, mouth blisters) remain a constant feature. What has worsened above the visible symptoms has been my well-being. When I feel my platelet count threatened, bone tired weariness and weakness can consume me from the inside out, and it can be a struggle to put one foot in front of the other. I can feel unbearable fatigue, a lack of drive and energy. My eyes grey and sink, giving me away; my hair thins, my body wilts. I over do the make-up to feign normal. I feel drained of everything, leading to lack of exercise, too much sleep, too little sleep, low motivation, and emotional overwhelm. I feel over sensitive, overanxious, misunderstood, breathless, nauseous in my own skin, out of control, deflated. I envy people with their soaring energy levels and strength in their eyes.

Ricocheting thoughts engulf me. Will I need treatment or will the platelet count rise without intervention? Do I carry on, battle, defy or surrender? If I need treatment, how will I manage work and childcare? Am I actually low or am I just really tired from juggling life, or is this just how it is to be getting older? I incessantly try to find patterns of why a relapse may have occurred, scrutinising my diet, any changes I may have made; locked down in complete uncertainty and paranoia.

When I do have confirmation of a relapse, once the troublesome veins allow a blood test to give the dreaded number, life becomes complicated yet so simple. I can go numb, on auto pilot, following procedure. I can slip into social hibernation opting out of life and relationships. Conversely, in moments of clarity and enlightenment, all the seemingly big things that I worry about pale into insignificance and I take the opportunity to re-centre, reprioritise, refocus on what is important, change perspective, readdress balance, embrace life, notice the sunset. I appreciate things around me that before may have passed me by. Maybe it's a good thing, bypassing some of the indulgences of the material world. All I want in times of feeling unwell, all I crave is to feel good, feel well enough to enjoy the world around me.

When I have longer phases of feeling well, it's like nothing ever happened. I can feel 'normal' tired and have the strength to carry life, to see things in perspective. My libido for life slowly resurrects itself. Internally, I allow myself to let my guard down gently.

Although I am beginning to notice timescales, behavioural patterns and internal influences now before a relapse, ITP at first, struck me out of nowhere. As a result of an unpredictable and ambiguous condition, I feel that I may have become a type of person or have developed particular tendencies. I am often scared of change, scared to take risks, to try new things, to be ambitious, to follow my truth, to make plans in case I don't feel good, in case I fail, often taking a backseat in life. I'm cautious to trust others and to

trust myself, wary of investing too much in people and relationship; scared to take knocks in more than one sense of the word, scared to say yes to life, always with one foot in, one foot out, constantly conforming and seeking external reference and affirmation; feeling defensive, protective, indecisive, fractured, compromised, lost; living in a metaphorical and physical bubble, not knowing when I will be caught off guard, overzealous, like my immune system. Is there a connection between my ITP and my emotional psyche? Which one came first? Which way round is the cause and effect? How much of my persona is due to my ITP and how much is down to my historical tapestry, my ego, my lifestyle and physical and emotional diet, is a point of reflection and awareness.

I have fought ITP as an enemy but also allied with it to achieve what to me are great things. It can be my nemesis, also my friend. I try not to become complacent or take things for granted but to use it as an opportunity to dance with life. ITP is idiopathic, no definite cause, no definite cure. Sometimes, I have to find my own inner cause, my own inner cure, my own meaning from within; to bow to my existence, handover, be kind to myself, live gently and without apology, unmask, accept, align with my voice, be happy, be me. My ITP calls me back to life.

I am grateful, grateful that since my diagnosis all those years ago, so much support from friends and families has been there, so much research has been done by experts which I participate in as much as I can, so many different treatments have been discovered, so many wonderful people have championed the cause; life-affirming professionals who support me inside and out beyond their remit, 'angels' who ensured the safe delivery of my treasured children. When I speak to the doctors and nurses, I am heard. Action is taken swiftly and I know that everything soon will be okay and I will get another chance. As I sit in the haematology department adjacent to oncology, I am humbled.

My ITP Story

My 15 year's ITP story in Portugal... and still counting by Lina Moniz



My 15 year's ITP story in Portugal... and still counting by Lina Moniz

Lina Moniz

I was first diagnosed with ITP in 2005, when I was 33 years old and 7 weeks pregnant with my first child, a baby girl. After an exceedingly difficult period in which I was put into Intensive Care and began to receive treatment with Prednisolone and intravenous immunoglobulin, with no results whatsoever, my daughter died in the womb at 32 weeks of gestation. At that time, my platelet count was 3. After that, I stopped medication, but the problem persisted, although in a less severe manner, accounting for two digits.

And, what next?

Well, I am Portuguese, living in Portugal and since the beginning, I really had some difficulties dealing with my ITP. Having a scientific education, I really felt the need of further insight on ITP, I was not always able to get to my regular doctor's appointments. However, I really felt stable over these 15 years and I have been living with a general platelet level way under 50, with some counts of one digit. Only in the last 4 years, I have developed some sporadic petechiae. Most of the time I was the one reassuring doctors that I was doing ok, they seemed to look at it with huge concern and wanted me to restart on medication, which I've been declining ever since. In the early years Splenectomy was also put on the table, but since I was feeling not well enough informed about the benefits and risks of this procedure, I also declined it. Unfortunately, I was also advised against another pregnancy.

Luckily, a Portuguese doctor passed me the contact details of Professor Adrian Newland, he has been kind enough to answer some of my doubts over the years, helping me to surpass my need for

information. Although Professor Newland reassured me it was possible to carry a successful pregnancy with ITP, I never got pregnant again. I never got the Portuguese doctor's consent, neither did I feel it was safe for me or my baby to do so, in the context of living in my homeland (Portugal).

Then, again facing single figures, I have decided to do an internet search and found the ITP Support Association in the United Kingdom!

So, so happy to have found them and to be able to join. I really found answers to many of my questions!

So happy to realise my fatigue is not just a result of an unnamed imbalance.

So happy to realise that quality of life is the major focus these days! I have been feeling like a lone fighter on that battle over the years and was really feeling I was starting to lose it...

Information and support do empower people! Thank you.

For me, one of the "good side effects" of living with ITP, has been to always have the value of life clear in your mind, and try to live it the best one can. So, I commit myself, every single day, on building a meaningful and happy life. Always looking to cut out the rubbish, really!

So, I live as happy as I possibly can, with my lovely family of four, me, my supporting husband and companion and our beloved children, our 12-year-old loving daughter and our energetic 9-year-old son. People sometimes say, "well, they are like our own children" and we always emphasize: "They are not like our own children, they are our children, period!" So happy to be able to enjoy life!

I would be incredibly happy if I were able to pass this on to our children, the value of looking for happiness and life's fulfilment. That is what really counts at the end of the day!

Let us carry on!

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.

Treatment During Covid19

We ran a Survey on Social Media asking those with ITP to answer a few questions about how they found the treatment for their ITP was managed during the lockdown, below are a few of the comments we received:

It has been excellent no complaints at all, it has been brilliant.

Hospital ward staff and consultant were extremely helpful, I could get answers to any questions or concerns when I telephoned.

I have had an ITP relapse right in the middle of Covid19, Newbury hospital have been absolutely fantastic in giving me blood appointments, if it wasn't for Newbury I would be in trouble as the Royal Berkshire Hospital in Reading have stopped all blood testing and others are having to either travel to Newbury or Bracknell.

I was diagnosed in May during lockdown, this was a telephone consultation with haematologist, which was very short with no information, was advised i would not need treatment as my Platelets are currently at 75 and if I have any concerns should get bloods checked, which i have done through my GP, I have found so much more support via the ITP Support Association. Thank you.

There was a lack of information from ITP consultant/ NHS especially at the beginning of the lockdown confusing to know if ITP patients were affected.

I had no problems. I have a telephone number for contact.

Used MyChart which was excellent. I could contact my haematologist, easier than getting blood tests at GP. I only needed monitoring for ITP, no emergencies. Addenbrookes couriered my Romiplostim.

I am simply confused as to how COVID will affect us.

Maybe not so much since we have an over reactive immune system.

It has been grand; I attend Craigavon area hospital and have a great consultant Dr Brigham who I can connect with at any time.

My hospital was very organised with an appointment system for bloods being taken, then an appointment arranged a week later for a telephone consultation with my consultant.

Had to practically beg to speak to consultant, who was unhelpful and did not know answers to basic questions?

The community nurse came less often to do blood tests and one specialist appointment was changed to a telephone consultation; we have since seen the specialist in hospital with masks on.

No real clarity about how ITP can affect Covid, nothing was said about what would happen about appointments either.

I avoided first session as I had enough Romiplostim for a couple of months. Then as per normal. This was at Bristol Haematology.

I knew I probably had a bad infection but could not get appointment with GP. Despite raising my concerns about how infections affect my platelet count I could only speak to a nurse. A few days later I was admitted to hospital for two days with severe acute parotitis and platelet count of 3. High dose antibiotics, prednisolone and increased Romiplostim dose to get me sorted. Should have kicked up more of a fuss and insisted I speak to a GP.

I have been happy with my treatment.

It has been exceptionally good at Royal United Hospital Bath.

Slight delay in commencing Eltrombopag due to

pandemic but now taking this medication, had one face to face appointment, the rest were telephone consultations and regular blood tests at hospital with opportunity to get advice from haematology nurses if required. Really pleased with my care (Doncaster Royal Infirmary).

Increased anxiety re platelet count - would it go down rapidly if I contracted Covid. Was told I would then need ivig - anxious to ensure that would not happen.

Very professionally managed although more information about Covid risks would have been useful.

I was fortunate to have prednisone on hand when I started having a flare.

It has carried on as normal except for consultation via phone. Medication was also delivered by the hospital as I was shielding.

Excellent treatment.

On the back burner, will no doubt depend on how things with Covid 19 progress in coming months.

Excellent support from my consultant via telephone and when platelets dropped suddenly, I was seen short notice for a face to face appointment. However, trying to get support and blood tests when I had bleeding symptoms from my GP surgery has been extremely difficult and exhausting not what you need when particularly fatigued and anxious!

I have had 2 blood tests during lockdown at hospital. I normally have 2 telephone consultations to 1 face to face (unless there is an anomaly) so things have continued as normal.

Nurses continued to come to our home to test monthly levels for Romiplostim dosage.

I had my blood taken at home because of shielding and my disability.

I found that my treatment happened quicker than

it would have done ordinarily. I had an abdominal scan to check my internal organs which was booked and completed within 3 hours. I also was able to start Rituximab infusions within less than 48 hours of it being presented as a treatment option. The speed of these things was phenomenal.

I was getting off promacta/eltrombopag, but one week after finishing tapering off, Covid came and I had to get back on Eltrombopag to be sure. We have waited for a while and now slowly tapering off again, though it is still a bit scary to do so. But who knows when the pandemic will be over and I don't want to wait?

To be expected. Resources were needed elsewhere. Although I have a blood test booked soon.

Slow. I have been waiting for an operation since March, delayed further because of my ITP. Contact with my haematologist has been difficult to establish and trying to get them to liaise with my surgeon nigh on impossible!

I was able to email my consultant with any medical or prescription issues. My medication was delivered to my home.

At my last face to face appointment prior to lock down they asked me how I felt about Covid, gave me a blood form & explained that I would go to phone consultations to avoid having to attend Lincoln, I would receive appointment letters with a blood form enclosed. I also left this appointment with an extra supply of Eltrombopag in case there was a delay in my next appointment date. To start with I was able to go to have blood taken at Grantham Hospital. This has changed to a clean site & consultant informed me that GPs have agreed to do blood tests. Have been able to book appointment with GP without any issues. Lincoln pharmacy have phoned me after they have received my prescription & arranged for me to collect medication from Grantham Hospital pharmacy. As this has changed to a clean site, I now must go to Lincoln Hospital to collect my medication as I am working & not at home to receive delivery via a courier.

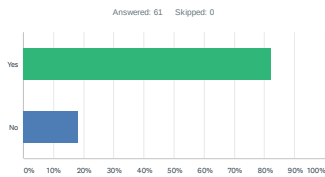
I was unwell and concerned about my count but could not get it checked anywhere. My concerns about 'my' condition was ignored and was told it was unlikely that my count would be low. I tried to explain that I am not typical in presentation to no avail.

Bloods taken by phlebotomists at temporary unit in the car park at Sheffield Arena not requiring exit from the car and at any time up to four days or so before consultation. Followed by telephone consultation

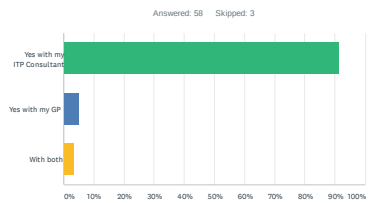
at the appointed time. This all worked well, and I consider telephone consultations to be adequate for long term patients just needing periodic checks, freeing time for new patients, and less frequent in-depth consultations for others.

Changed consultant during pandemic not happy with previous one had a face to face consultation with new one and have another face to face September.

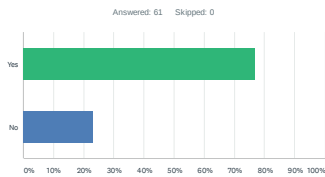
Q1 Did you carry on with your prescribed ITP treatment as normal during the Covid-19 pandemic?



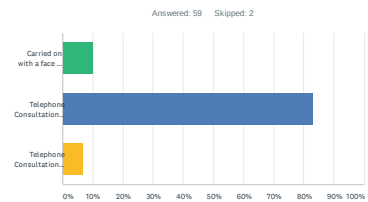
Q5 In normal times do you have a face to face consultation with your ITP Consultant or GP about your condition?



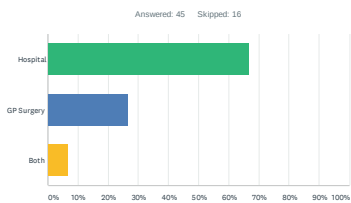
Q2 During the current pandemic have you continued to get your bloods taken to check your Platelet Levels?



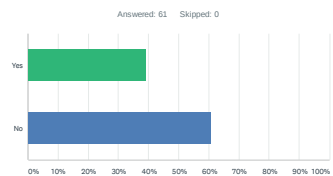
Q6 During the current pandemic many face to face consultations have been cancelled, if your consultation was cancelled did your ITP consultant and / or GP switch to a telephone consultation?



Q3 If you said yes to Q2 was your blood test taken at a hospital blood clinic as normal or at your GP surgery?

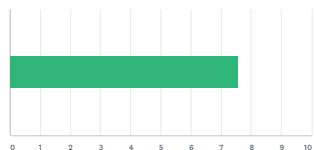


Q7 Have you avoided contacting your GP or ITP Consultant during the current Covid-19 emergency?



Q4 If you said no to Q2 what was the reason given for not having your bloods checked?

Answered: 20 Skipped: 41



Q8 Do you feel you had enough support for your ITP during the current Covid-19 emergency? Please rate the level of support on a sliding scale 0 being poor, 10 being excellent

Answered: 61 Skipped: 0

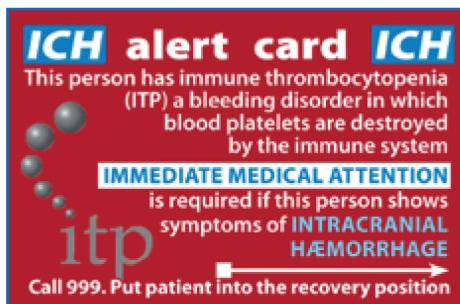
Order a free ICH alert card

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.

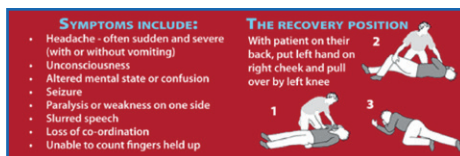


ICH alert card ICH

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



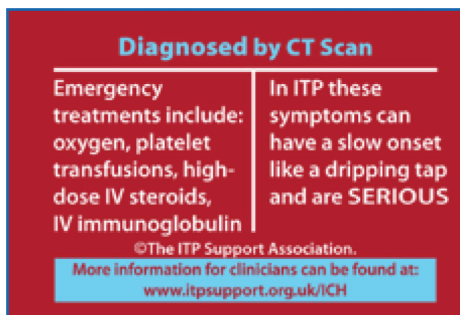
SYMPTOMS INCLUDE:

- 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
---	--

©The ITP Support Association.
More information for clinicians can be found at: www.itpsupport.org.uk/ICH



New Christmas Cards



New Christmas Cards for 2020

Our new Christmas Cards for 2020 are £3.00 for a pack of 10 cards with envelopes.

To order go to www.itpsupport.org.uk

We also have lots of ITP branded items available on our on-line shop at www.itpsupport.org.uk

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

