



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

ITP SUPPORT
ASSOCIATION
ANNUAL CONVENTION

8 & 9
MAY
2021



[REGISTER HERE](#)

The Platelet

JOURNAL OF THE ITP SUPPORT ASSOCIATION

MARCH 2021

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

Anthony Heard (Patient Observer)

OFFICE

Chief Executive

Mervyn Morgan

Office & Fundraising Administrator

Liz Gooch

VOLUNTEERS

Social Media

Anthony Heard

Mervyn Morgan

Group Liaison

Derek Elston

Patient Mentors

Rhonda Anderson

Derek Elston

Karen Smith

Website

Mervyn Morgan

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, FRCP

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.

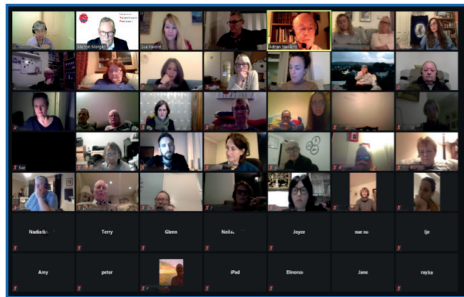


From ITP HQ

Welcome to the March edition of the Platelet, by the time you are reading this spring will be in the air (I hope) and Children will be back (or almost) at School following the latest lockdown.

With Covid-19 still front and center of everyone's thinking, in particular the rollout of the Covid-19 vaccines, we have been inundated with calls and messages from ITP Patients from around the world asking is it safe for those with ITP to have the vaccine. Can we ask that if you are worried please read the Vaccine Assessment written by Professor Adrian Newland which is available on our website.

In this issue you will find a number of patients ITP stories which I hope you will find both helpful and informative in their content, it is always good to receive these stories and share the experiences of ITP patients, if you would like to share your ITP story please email info@itpsupport.org.uk.



Our Support Group Meetings have been extremely well received during the pandemic, the decision to switch the meetings to the virtual environment has been an enabler in encouraging more ITP patients and their family members to take part from the safety of their own homes. We are pleased to say that recordings of our last three support group meetings (England and Wales, Scotland and All-Ireland) are available on our website, YouTube, and Social Media Channels.

You will also find in this issue details of our next ITP Support Group meetings that are scheduled for April.

Other exciting news is the announcement that the ITP

Support Association Annual Convention will be taking place over the weekend of the 8th and 9th May, just like last year in the virtual environment. You will find further details including how to register and the draft agenda in this issue of the Platelet.

We are also pleased to announce a new addition to the ITP Board, Mr Anthony Heard will be joining the board as a Patient Observer, many of you will know Anthony for his Social media work for the Association plus his many interesting articles for this journal. Welcome Anthony.

As always, a big thank you 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 in April or at our Convention in May. Best wishes

Mervyn Morgan CEO

Contents

- 3** From ITP HQ
- 4** The American Perspective
- 6** Your Questions - FAQs ITP and Covid-19 vaccinations
- 8** UK and Ireland Virtual Convention 2021
- 10** Regional ITP Group Meetings
- 11** Patient Mentors
- 11** Fundraisers & 'In Memory Donations'
- 12** Angela Smith - My ITP Journey
- 13** Humans of Scotland - Linda MacMillan
- 14** My ITP Journey by Paul Stacey
- 15** My ITP Story by Dale Gregory
- 16** Bereavement, Loss and Healing - By Rhonda Anderson
- 19** Leaving a Legacy
- 20** Order a free ICH alert card
- 21** The MIND really MATTERS by Anthony Heard
- 24** Ways to Donate
- 25** Publications List
- 28** Membership Form

American Perspective

COVID-19 Vaccination: What you Need to Know by Cindy Neunert MD

In a previous issue of the American Perspective, we discussed the risks of the COVID-19 virus in patients with ITP. In just a short time since that article, we have learned so much more about COVID-19 and now are entering into a new time when vaccines are becoming available. It is exciting to think that we may be able to protect ourselves against the virus but at the same time it can be overwhelming to keep up with all the new information that is coming out. In this article we will provide an overview of the different vaccines, their safety and considerations for patients with ITP.

There are currently 3 vaccines available in the UK: Moderna, Pfizer, and AstraZeneca. The Moderna vaccine and Pfizer vaccines require 2 doses, given 4 and 3 weeks (ED note: In the UK this interval has been extended to 10-12 weeks) apart respectively. They are mRNA vaccines. We have been working to develop mRNA vaccines for decades even though they seem very new. Most other vaccines work by placing a small amount of the weakened or inactivated germ into our bodies. mRNA vaccines, however, do something a little bit different. These vaccines teach our bodies how to make a specific protein, causing our bodies to react and form an immune response to that protein. This results in us making antibodies and protects us from getting sick if the real virus enters our bodies. In the case of the COVID-19 mRNA vaccines these are giving our bodies the instructions needed to make a harmless piece of the surface of the COVID-19 virus called the "spike protein." After it makes this protein our bodies eventually break down the instructions and get rid of them. However, our cells now have this protein and the immune system will recognize it as a "foreign" protein and begin to make antibodies. These antibodies are what will protect us if the real COVID-19 virus enters our system. The AstraZeneca vaccine works a little different and the doses are given further apart (up to 12 weeks). This vaccine uses a version of the common cold virus that is harmless to humans and has been changed so that it has the "spike protein" on its surface. Once this enters the body this triggers the immune system to



begin to make antibodies against the spike protein so that if we get COVID-19 the immune system will recognize it and fight it. Regardless of which vaccine you receive, they all result in the immune system making antibodies which will protect you against the COVID-19 virus.

After receiving the vaccine it takes several weeks for the body to begin making antibodies. Following the second dose about 80-95% of people will have antibodies. The safety of the vaccines is being tracked. Mild side effects are common including discomfort at the site of the vaccine, mild fever or chills, and feeling achy. These may be slightly worse after the second dose of the vaccine. These side effects actually tell us that the vaccine is working and the body is responding to the vaccine. A few people have had an allergic reaction to the vaccine and so this is why you should be watched for a few minutes after getting the vaccine. Even after getting the vaccine it is important to still continue to practice safety measures with masks, hand washing, and social distancing.

Of particular interest, are the reports of ITP which developed after the vaccine. We still do not have evidence that the vaccine and ITP are linked for a few reasons. First, we don't have enough information on all the patients who developed thrombocytopenia to

ensure that they are all truly cases of ITP. Second, ITP is fairly common, about 6 cases per 100,000 adults per year. Here in the US about 33 million adults have received at least one dose of the COVID-19 vaccination. We would therefore naturally expect that over the 2 month period that the vaccine has been given about 330 of these 33 million adults would be diagnosed with ITP. So it is possible that the 36 patients reported to have gotten ITP following the vaccine were going to do so even in the absence of the vaccine. The timing of their ITP diagnosis to COVID vaccination therefore maybe coincidence and we cannot yet say that the vaccine caused their ITP. Lastly, ITP caused by a drug or vaccine usually happens a few weeks after the patient is treated, because as mentioned above it takes several weeks to develop the antibodies that would cause ITP. For some of the cases the timing was too soon to be due to vaccine antibody production. The risk of getting very sick from COVID-19 far outweighs the potential risk of ITP and these small number of cases of ITP should, in no way, be a deterrent to vaccination.

There are some other considerations for patients with ITP. Patients should seek medical attention immediately if they notice increased bleeding or bruising following vaccination and in some cases it may be appropriate to obtain baseline and post vaccination platelet counts if you have ongoing thrombocytopenia, a history of unstable platelet counts, or history of significant bleeding. Some patients with ITP may be on treatment that makes their immune system less responsive to vaccines. You can ask your doctor if you are on one of these types of medications. We still recommend that patients on these medications receive the vaccine but it may be good to check for the COVID-19 antibodies afterwards to know if the immune system was strong enough to respond. If you are planning on undergoing splenectomy or starting a new medication that would reduce your immune system, it is recommended that you receive the vaccination at least 2-4 weeks before.

We are hopeful that having a vaccine available will slow the spread of the virus and begin to protect us all. Getting the vaccine is an important way to protect yourself and others against the serious disease of COVID-19 and we support all patients with ITP receiving the vaccine after discussion with their ITP physician.

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

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



Your Questions

FAQs; ITP and Covid-19 vaccination

Q 1. ITP and the Covid-19 Vaccine – Would having ITP be classed as an underlying condition and help push you up the priority list?

A There is no evidence that ITP alone increases the risks of catching Covid-19 and would not be considered an underlying condition. However, when taking into account other risk factors such as age, any ongoing treatment (such as steroids at higher doses (greater than 20mg), or immunosuppressive drugs) or other health conditions it would be part of the equation in considering priority.

In ITP COVID-19 infection, like all viral infections, may cause a relapse often with a rapid fall in the platelet count. It is important to be aware of this and know who to contact if there is any suggestion that the platelet count has dropped or if there is any excessive bleeding or unusual bruising.

Q 2. Could ITP affect the immunity which a Covid vaccine is supposed to provide?

A Someone with ITP will react normally to the Covid-19 vaccine and show the same response as any other person. The response may be reduced in patients who have recently received Rituximab (within 6 months) or are taking immunosuppressive drugs but this will still provide protection and the benefits outweigh any reduction in response. Splenectomy does not affect the response to the vaccines.

Q 3. The Pfizer vaccine has a supposed success rate of 95% (e.g., a 5% failure rate), could ITP patients be in that 5%?

A There is no suggestion that ITP can decrease the rate of response to the vaccine and the failure rate would be no different than that seen in the general population with any of the vaccines available. In general, responses may be less with any vaccines in older males, but this reflects the decline in

immune response seen in this group. This cannot be predicted, and the potential benefits of vaccination are greater than any theoretical risks of poor response.

Q 4. I was diagnosed with ITP and although it was never proven, they believed that it was triggered by my typhoid injection. Since the age of 17 (I am now 28 years old), I have been ITP free, and my platelet count has been 'normal'. I still have an annual blood test to check on my platelet count, but I am cautious about getting the COVID vaccine in case it triggers my ITP again.

A A reduced platelet count has been reported in very small numbers of patients after vaccination for many different viruses, including the common ones, such as measles-mumps-rubella (MMR), Haemophilus influenza, hepatitis B virus, human papilloma virus, varicella-zoster, diphtheria-tetanus-pertussis (DTap), polio, and pneumococcus. The reduction is usually relatively mild and is transient. In the patient with underlying ITP, however, it may be more frequent but is still usually only a short-term problem. It has been shown that the risk is less than 10 per million doses of vaccine, covering all the common vaccines. The COVID-19 vaccine trials have not reported this in the studies so far but the numbers given the vaccine were much less. As of mid-February 15 million doses had been given in the UK and 25 cases of thrombocytopenia had been reported to the MHRA. We are aware of some cases in patients with ITP receiving the vaccination so although it remains a rare possibility, the risks are outweighed by the benefits of receiving the vaccine. In Covid-19 infection thrombocytopenia is relatively frequent occurring in up to 20-30% of patients with mild disease but may be over 60% in those who are severely affected. In these the mortality rate is much higher. It is recognised that in patients with ITP the platelet count may fall markedly in any patient who becomes infected.

Q 5. I am concerned about whether a vaccine would work post splenectomy as I thought the vaccine worked by getting the body's immune system to recognize anti bodies and then kill the virus, but with no spleen I was wondering how my body could do this?

A The spleen is only one part of the body's immune system that produce th antibodies in response to vaccination and infections that helps to protect us all from the serious effects of the many viruses and bacteria to which we are all exposed. It is estimated to be about a third of the immune system in terms of mass but following removal the remaining lymphoid system will compensate for its removal.

In ITP the spleen is also important as it captures and destroys platelets that have been coated with autoantibodies and this is the main reason for its removal. With access to newer treatments, and the high failure rate, splenectomy is becoming much less frequent. Patients who have had a splenectomy have an increased susceptibility to a small number of infections and should be up to date with their pneumococcal, haemophilus influenza and meningitis vaccinations. Flu vaccination is also recommended. Experts do not believe splenectomised patients are at increased risk of COVID-19 infection but are susceptible to bacterial infections and must be vigilant with their prophylactic antibiotics during this time.

Q **6. At a previous ITP Convention, I remember one of the speakers talking about ITP and T cells. I did not fully understand at the time, but now with the vaccine from Pfizer saying it will target 'T cells', I was wondering whether this vaccine would be better for patients with ITP or whether we should avoid it?**

A In response to infection the body produces antibodies but it also responds by developing a cellular response with one of the subsets of lymphocytes, known as T cells. Antibodies latch onto infective organisms in the blood stream but T cells may also help destroy infected cells. They are also important in establishing immune memory and this is important for establishing longer-term term immunity from infection. It has been demonstrated that a T-cell response is stimulated by all the vaccines being trialled. Normally the response persists long after antibodies can no longer be detected and this is likely to be the case following the Covid-19 vaccines. The response does not impact on the ITP itself and all the vaccines can be used in ITP.

Q **7. Are there any ITP Treatments that could react with any of the new Covid-19 vaccines and negate the vaccines effects?**

A As has been mentioned higher doses of steroids (over 20mg), immunosuppressive drugs and Rituximab may reduce the response to the vaccines, however, this does not mean that this will significantly reduce the resistance to Covid-19 infection. It is generally considered that any response is better than not having the vaccination.

Q **8. Once I have had the vaccination does that mean that I am safe from catching Covid-19 and should I continue the general precautions?**

A Current evidence from Scotland and from Israel in patients who have been vaccinated compared with those who have not shows a major reduction in infection in the vaccinated group that may be as high as 90%. There is even an effect within 3 weeks of the first vaccination. In those who become infected it appears to lead to an infection of much reduced severity. It is, therefore, important that all patients with ITP are aware of the information regarding their risk stratification and whether they are considered clinically extremely vulnerable. They should be familiar with COVID-19 protective measures and self-isolation as appropriate, maintaining mental well-being, and who to contact if they are feeling unwell with fever and cough or are having difficulty breathing.

It is generally accepted that Vitamin D is important in the first line of defence against infection and the body's response to infection. Vitamin D levels are generally lower in the obese, diabetics and people of BAME origin and also tend to be lower in men than in women. Although it remains controversial additional Vitamin D may help increase the body's resistance to the impact of infection and taking supplements, over and above the normal diet, may be worthwhile. When taken at recommended doses there are also no recognised risks and their use should be discussed with your clinicians.

UK & Ireland Virtual Convention 2021

Annual UK and Ireland Convention 8th & 9th May 2021

Due to the ongoing Covid-19 Pandemic and restrictions on Social Distancing our in-person Convention in London has been put back to 2022.

However, thanks to the wonders of modern technology we can still have a fantastic event in the virtual environment (just like in 2020). Therefore, we are pleased to announce that our Annual UK and Ireland Convention will be held on 8th and 9th May 2021. As with the 2020 Convention this year's event will also be virtual, and you can pre-register

(Free) by going to www.itpconventionuk.org/registration. Please note if you registered for our 2020 Convention you will be automatically registered for the 2021 event, but to be safe it may be worthwhile if you check your login credentials for the Convention website, last year's Convention recordings are still available to view.

The agenda for our 2021 Convention is as follows:

Agenda and speakers subject to change, please be aware the Sunday session may start earlier than advertised in this draft agenda.



UK ITP Support Association – Virtual Convention May 8th and 9th 2021 (Agenda & Speakers subject to change)

| Saturday 8 th May | Session |
|------------------------------|--|
| 10:00am – 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. |
| 11:00am – 11:15am | Introduction <ul style="list-style-type: none"> • <i>Mervyn Morgan</i> |
| 11:15am – 11:40am | How I treat ITP in 2021 <ul style="list-style-type: none"> • <i>Dr David Kuter</i> |
| 11:40am – 12:05pm | Is bleeding a problem in ITP <ul style="list-style-type: none"> • <i>Dr Nichola Cooper</i> |
| 12:05pm – 12:30pm | Fatigue in ITP <ul style="list-style-type: none"> • <i>Dr Henrik Frederiksen, Denmark (TBC)</i> |
| 12:30pm – 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. |
| 1:30pm – 1:50pm | Covid, Vaccines and ITP <ul style="list-style-type: none"> • <i>Dr David Kuter</i> |
| 1:50pm – 2:10pm | UK Audit of ITP in the Covid-19 era <ul style="list-style-type: none"> • <i>Dr Sue Pavord</i> |
| 2:10pm – 2:30pm | Q&A on Covid-19. Chair: Prof Adrian Newland <ul style="list-style-type: none"> • <i>Dr David Kuter, Dr Nikki Cooper, Dr Sue Pavord</i> |
| 2:30pm – 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. |
| 3:00pm – 4:00pm | CONCURRENT – Breakout Session – Women’s’ issues <ul style="list-style-type: none"> • <i>TBA</i> |
| 3:00pm – 4:00pm | CONCURRENT – Breakout Session – Adults issues <ul style="list-style-type: none"> • <i>Dr Vickie Macdonald</i> |
| 3:00pm – 4:00pm | CONCURRENT – Breakout Session – Children’s’ issues <ul style="list-style-type: none"> • <i>? Dr John Grainger</i> |
| 4:00pm – 4:25pm | Why does ITP occur? <ul style="list-style-type: none"> • <i>Professor John Semple, Oslo, Sweden</i> |
| 4:25pm – 4:55pm | Letter from America What is the current position with the thrombopoietins <ul style="list-style-type: none"> • <i>Dr Cindy Neunert or Dr Adam Cuker – (TBC)</i> |
| 4:55pm – 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. |
| Sunday 9 th May | Session |
| 1:00pm – 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. |
| 1:30pm – 1:50pm | What is the place of splenectomy –the Adult Registry <ul style="list-style-type: none"> • <i>Dr Vickie Macdonald</i> |
| 1:50pm – 2:10pm | Current treatment in Paediatric ITP <ul style="list-style-type: none"> • <i>Dr John Grainger</i> |
| 2:10pm – 2:30pm | What is the place of the newer treatments in ITP <ul style="list-style-type: none"> • <i>Dr Drew Provan</i> |
| 2:30pm – 3:00pm | Patient Story <ul style="list-style-type: none"> • <i>Mervyn Morgan</i> |
| 3:00pm – 3:15pm | Real World Experience in ITP – a patient survey <ul style="list-style-type: none"> • <i>Dr Vickie Macdonald</i> |
| 3:15pm – 3:45pm | 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. |
| 3:45pm – 4:45pm | Live Q&A Webinar <ul style="list-style-type: none"> • <i>Prof Adrian Newland (Chair)</i> • <i>Dr Drew Provan</i> • <i>Dr Sue Pavord</i> • <i>Dr Nichola Cooper</i> • <i>Dr Quentin Hill</i> • <i>Dr John Grainger</i> • <i>Mrs Rhonda Anderson</i> • <i>Dr Cindy Neunert or Dr Adam Cuker - TBC</i> |
| 4:45pm – 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. |

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.

AMGEN argenx GRIFOLS PRINCIPIA BIOPHARMA ucb Omph CREATIVE AGENCY

The banner features a central red location pin icon containing the text 'Inform support Empower ITP Support Association'. Surrounding this are several smaller location pin icons in various colors (green, orange, blue, red) each containing a different icon representing digital communication: a smartphone, headphones, a laptop, a computer monitor, a person silhouette, a tablet, a smartphone, and a laptop.

ITP Support Association Group Meetings

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

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

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

England and Wales ITP Group Meeting - Next Meeting: 8th April 2021 7:00pm

Scotland ITP Group Meeting - Next Meeting: 22nd April 2021 7:00pm

All-Ireland ITP Group Meeting - Next meeting: TBA

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

Research Funds Appeal

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

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

Fundraisers & 'In Memory' Donations

FUNDRAISERS

The association received a total of £760 from 3 individuals donating to research.

Daniel & Rachel Sutton donated £462.50 In lieu of wedding presents.

Atlas Trading Limited continue to excel with a further £330.36 from their collection box.

£68.75 raised from Lucy Hall for selling homemade masks.

Julie Bulpin raised £50.00 in lieu of xmas cards.

We would also like to thank all those on Facebook who raised a total of £1,490.80.

Finally, thanks to everyone who donated via our Virgin Giving page, £1,988.18.

Given all that people are facing with the Covid Pandemic we are amazed at the level of Fundraising that is still taking place, a huge thank you to everyone involved.

IN MEMORY DONATIONS

£250.00 from Door4.com - one of their work colleagues, Lee Tomblin sadly passed away in November 2020. Leon Calverley, Managing Director of Door4.com said "It felt only right to divert a portion of the funds we would use on Xmas gifts to your association, in recognition of the work you do for people with Lee's condition".

Empress Mill also donated £62.50 in memory of Lee Tomblin.

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

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



Angela Smith - An ITP Journey

My first encounter with ITP was in 1997. I was in Northern India with my husband at the time, our travels there were adventurous and filled with the unexpected, so a few bruises didn't really make a big impact. It was only on the flight home when I found I had mouth blisters and realised the extent of my bruising that I knew something was seriously wrong. Spending just enough time at home to have a bath, I presented myself to my local A and E. I was dismayed when they didn't hesitate to admit me, apparently my platelets were undetectable and my iron levels extremely low. It took a few days for a diagnosis and I was referred to as "this week's interesting case". It was suggested that the condition had been triggered by quinine based anti-malarials.

There followed a year of intermittent transfusions and treatments with Prednisolone. Each time my platelets were raised to a satisfactory level the improvement lasted about three weeks, then my platelets would plummet to below five again. Then suddenly, they went up and stayed up and I was able to discontinue all treatment. At that point I imagined I was cured, that was the end of ITP for me!

Not so! Fast forward to 2004, six years later. Suddenly I noticed the tell-tale rash on my legs. I have no idea of the cause of my relapse. Could it have been that it was around the time my husband was diagnosed with cancer? I would be interested to know if a diagnosis has ever been related to stress. So, I was again having Prednisolone and again each time when it was decreased my platelets dropped. Eventually the platelets stayed up and I appeared to be in remission once more. I can't quite remember the exact timing, but this lasted for two or three years. Then the platelets were down again and

this time nothing seemed to help for very long. At one time I experienced being an inpatient in a Spanish hospital which was interesting, the care was excellent.

The ITP came and went for several years and at one point I had a course of Rituximab, which had no effect. Splenectomy had been mentioned to me several times, but I had always rejected it, thinking it too drastic. However, in 2011 I finally made the decision. I had a transfusion before the operation, which was done by "keyhole surgery". I was in hospital for three days and was fully recovered in about two weeks. No ill effects, but I do keep a supply of penicillin in case I feel I am starting with a severe infection.

Now after ten years, aged 77, my platelets are still checked annually, and my last count was a wonderful 210. For me, splenectomy was the answer and I know how very fortunate I have been. It is not unknown, I think, for a relapse to occur after splenectomy but, so far, so good and I'm incredibly thankful for all the excellent care I've had from the NHS, not forgetting the very helpful ITP Support Assoc.



Humans of Scotland

Humans of Scotland: Living with serious long term conditions by Linda MacMillan

Humans of Scotland is a Health and Social Care Alliance Scotland campaign that highlights the voices of those with long term conditions, disabilities and those who are unpaid carers.

The aim is to raise awareness and spark debate around the topics and issues raised.

Police Scotland staff member Linda MacMillan, an Information Assistant at Pinnacle, West Command shares her experiences of living with long term conditions.

“Back in 2006 the Chief Inspector I was working with took me aside one day and expressed concern about the number of bruises I had on my arms. I was so embarrassed therefore decided to get it checked out.

I went to my GP the next morning, who sent me to the Haematology Ward at the RAH, as my platelets were very low so I was in a bit of a panic. The haematologist stated I had glandular fever and diagnosed me with ITP (Immune Thrombocytopenia Purpura). I then had blood taken every few months and I felt extremely lethargic. I also developed joint and muscle pain at this point.

This carried on for a few years and then on Easter weekend of 2010 I felt really unwell. I had so much pain all over my body, I could hardly move. I called 101 and was advised to attend the out of hours GP. The GP I saw sent me straight to A&E in a wheelchair. I stayed in hospital for ten days, having numerous tests done.

A few weeks later I received a call to come in and

see my consultant as specialised blood tests confirmed I had Lupus (SLE). I was confused, scared, sad, still sore and unbelievably tired, but it was great finally to put a name to what was wrong.

Soon after this, I was still off long term sick from work and I woke up one morning with blood clots in my mouth and a red/purple rash over the lower parts of my legs. My GP sent me straight to A&E. They took some blood and discovered my platelet count was one. A normal platelet count ranges from 150-400. I had to have a blood and platelet transfusions. This didn't help my platelet count so they decided to give me an IVIG transfusion. I ended up really unwell after this and was sent for a head CT scan as the doctors were worried I had a bleed on my brain. Thankfully I didn't, it was just side effects from the IVIG but I really thought my time was up at this point. Eventually, my platelet count began to climb and has remained steady except for a particularly bad episode in 2013.

My conditions remain relatively stable on various medications. It's hard knowing I will be taking medication for the rest of my life but no one wants to be in that position. I'm very lucky to have an understanding employer as I've had quite a few long term absences. I receive assistance from Access to Work getting help going to/from work and special equipment at my desk to enable me to do my job.

ITP is classed as a rare disease, with only 3-4000 diagnoses in the UK and Lupus is still mainly unknown. I do all I can to raise awareness of both conditions and I encourage people to give blood as I was very lucky to be a recipient myself.

My ITP Journey by Paul Stacey

My ITP Journey Like most people, I was accustomed to occasional headaches, especially stress-related episodes. A couple of Ibuprofen usually dealt with them effectively. However, the intensity and location of the headache I experienced one Friday evening in June 2016 was on a completely different level. At the time I thought a couple of tablets would again do the trick. There was no improvement in the morning, and we phoned NHS111 for advice. I was told that it was probably a migraine and was prescribed some medication. As a seemingly fit and healthy Secondary School Head of PE, I rarely took time off and expected to be fine for work on Monday morning.

Unfortunately, the pain had not abated and would not do so for the next 3 weeks. Two visits to my GP surgery followed and a migraine remained the probable explanation. On the first of these visits, I was prescribed Aspirin, which in retrospect could have been very dangerous. I dutifully followed the advice, but it became apparent that the pain was not subsiding, and I was taken to my local hospital. Examinations ensued and it was decided that I probably had meningitis. My employer was informed, and I was given a course of antibiotics. After scans and a lumbar puncture, it became clear that I had in fact suffered a subarachnoid haemorrhage - a brain bleed and a form of stroke. I was rushed by ambulance up to Kings College hospital and spent the next few weeks under their marvellous care. I cannot speak highly enough of the staff there. Unfortunately, my stay was lengthened as I had contracted *Clostridium difficile* along the way, probably as a result of the antibiotic treatment.

I eventually left hospital on my 55th birthday and the next stage was to discover what had caused the haemorrhage. I was sent to the haematology department of my local hospital and after more tests (including a bone marrow biopsy) I was

finally informed that I had ITP. The platelet level had become very low and had not been able to repair the bleed as would normally have been the case. It was a relief to finally discover what had caused the problem although I had no idea what it was and how it would affect me. I took the steroid Prednisolone for a while, which had the desired effect of raising the platelet count. However, the count fell as soon as I was taken off them and I was not keen on the side effects. The haematologist then prescribed Eltrombopag and I have been taking it ever since. My platelet count is checked following my monthly blood test and my average count is currently 92. Fatigue is the most significant side effect of the condition and this was quite distressing in the early days.

Given the nature of my practical job and the possible ramifications if it were to happen again, I had to leave my job and take early retirement. With my son just starting university, I had intended to work for at least 5 more years. The most challenging aspect of my retirement has been becoming accustomed to the reduction in social interaction. Going from the full-on nature of my teaching job to unexpected retirement was difficult and at times remains so. I find that having a structure to the day helps and I am fortunate to be able to exercise at the gym and play golf (pre-Covid lockdown). As ITP patients, we have a rare blood condition which many professionals are still not familiar with. As my case demonstrates, it can be an arduous journey just to find out that you have the condition. I do not blame any of the professionals who failed to correctly diagnose my original haemorrhage as that was not the most likely scenario. I have spoken with my GP surgery and discussed my case for their own information/development. I feel very fortunate that I am now generally well and am able to lead a mostly normal life despite the traumatic events over four years ago.

My ITP Story by Dale Gregory



Hi, I was diagnosed about 16 years ago when I was 40 but probably had it quite a long time before that, I just never bothered going to see the doctor about the bruising. I do not do doctors.

I found out because my wife made me go for an MOT at the doc's because she thought my diet was bad (it was pork pie, dripping, bacon etc), after a blood test they found my count was in single figures and thought I had Leukemia!! so gave me a bed in the local hospital and after a few more tests and days in the Cancer ward they diagnosed me with ITP and started me on Steroids. That was a bit of a relief to be honest.

I stayed on them for a while but suffered side effects so took myself off them one weekend and found my platelets were steady around 30 which apparently was fine. I started having 6 monthly blood tests to make sure it stayed around that number. I did not change anything in my life they said I was fine with 30 so lived with that count, knowing when it dropped, generally when I felt unwell, and again knowing when it returned to my normal because I did not bruise as much. I was told 30ish was my norm and tiredness were the ITP way of life.

In 2013 I had to have a tooth out in hospital, so they put me on steroids for 3 weeks and my count shot up to 100 or so and the tooth was taken out and my platelets returned to 30ish soon after. All was good and I continued to live a normal life, riding my motorbike with the club, and doing everything I had always done, just being careful not to hit my head, and also put up with the tiredness. A year or so after I went to annual blood tests.

In late 2018 my wife died and from then to early 2019 I was really run down and around February had a really bad chest infection, and noticed I was bruising worse than normal so thought I'd check my count at the hospital, I never bothered with my local quack, I was an outpatient and, on their books, so could go and get checked out when I wanted.

My count was 3. They did all the usual panicking, booked me a bed, and started me on steroids (Prednisolone) which had a brief affect, enough to get me out of hospital at least, but it then dropped again to single figures.

From then until now, February 2021, I have tried Ivig which took my count to 30 for a day and gave me a massive 3-day headache, then it dropped again. I tried Eltrombopag (Revolade) which I hated and suffered loads of side effects and it did nothing for me, then was put on Romiplostim (Nplate) which again blipped my count up and down numerous times. Currently my count is holding at 10 and the side effects are constant and horrible, I briefly stopped the injections for some relief, then started again and as usual, side effects but no positive effects.

I did stop drinking this year to see if that was causing an issue, it was not, but I have not started up again yet just thinking about it, I do miss my whiskey. My next drug I am trying with the Romiplostim is Mycophenolate. My consultant thinks a cocktail may work better; I am not convinced. I have discounted a splenectomy numerous times and will continue to do so. No means no.

Maybe 10 is my new norm I do not know, but if I stop the drugs it goes down to 3 or 4, so maybe 3 is my new norm, anyway I continue to live life to the full, bruising like a ripe banana and trying not to fall off my motorbike, or at least hit my head. I count myself lucky I am not a spontaneous bleeder, just a bruiser, (I do bleed a lot when I hurt myself in the garage, gaffer tape is great for stopping it), and get big lumps when I knock myself, and obviously being tired all the time which is really annoying.

I do not worry about it, what is the point, I changed hospitals after getting a second opinion from Dr Quentin Hill at Leeds hospital (top bloke, knows his stuff) which annoyed my consultant. They were not really engaging with me anyway, and I did not like them. My new Consultant seems to know more and really wants to help, I have a lot more confidence in her, sadly my body just does not want to respond to anything. Maybe a whiskey might help. Anyway, that's my story, pretty mundane really.

I keep waking up in the morning so thank God for another day and get on with life.

Bereavement, Loss & Healing - By Rhonda Anderson



We have recently had a sudden death in my Australian family. My cousin's daughter, 60 years of age, died in her sleep for no apparent reason. This unexpected loss has shocked the family and set me thinking about bereavement and loss and the effects it has on us.

When we get the diagnosis of a rare, long-term condition, such as ITP, we go through the same grieving process.

The shock of having a long-term condition diagnosis will not be new to members who have ITP, and their families. Most likely you were well and didn't even know you had ITP, let alone know what ITP was. Probably your first question was, 'What is that?' Your second question may have been, 'Will I die?' And your third question, 'How did I get it?' And then, 'Is it contagious?' and 'Is there a cure?'. You can feel quite isolated, trapped and helpless, akin to being in unknown territory with no way out.

You will most likely know the answers to these questions by now, and can get information from the ITP website (itpsupport.org.uk). I plan to concentrate on the impact a long-term condition can have on you and your family and friends.

We usually associate the word 'bereavement' with death, but there are many other forms of loss in our lives that can also cause us to experience bereavement. The loss of a relationship, loss of a job, loss of possessions, financial loss, loss of status, retirement, change of circumstances, loss of freedom, loss of choice, any kind of regret in your life associated with loss, loss of health, and so on. Many of these can be associated with the Covid-19 pandemic the whole world has been experiencing for over a year.

Just as bereavement has stages that most people go through, so you may oscillate around certain well-known feelings, emotions and behaviours.

Cruse Bereavement Care (cruse.org.uk) is the biggest bereavement charity in the UK and they list these common feeling when someone dies. Shock, numbness and feeling nothing at all, Pain, Anger, Guilt, Low Mood and Depression, Longing, Physical Feelings.

Pain can be caused by loss. If you already have physical pain this can get worse. It is surprising how grief can affect the physical body. Feeling 'broken-hearted' can be a physical pain, as can anxiety and dread. Nervousness and loss of confidence can manifest in gut pain and disturbances, often called IBS, Irritable Bowel Syndrome. 'Butterflies in my stomach' is a common saying when we are anxious and nervous.

With loss of health, you may feel that you cannot do the things you used to enjoy. This might include contact sports, skiing, boxing, bungee jumping and other rather risky pastimes. You may feel that travel is no longer possible. (We hope that it will be possible for all of us in the not-too-distant future...!) Even simple journeys may make you anxious, being away from your doctor and hospital, your home comfort zone and your well-known area.

This can lead to guilt as other members of the family feel they cannot enjoy the things you used to do together, and that can curb their activities and feelings of enjoyment with life, so they feel disappointed and frustrated.

When you go out with friends, and discuss your ITP, they may find it very hard to realise that you have a condition because it doesn't show up, you are not going to have an operation and you may not be on medication or treatment. You and your family may also find ITP very difficult to comprehend and come to terms with.

All these difficulties can make you and your family and friends feel angry and change your behaviour

from being reasonable and able to cope, to lashing out at the slightest provocation.

The general anxiety of knowing that you are going to have to deal with this condition for the rest of your life, that is, until you die, can bring on a lot of unwelcome feelings of low mood, depression and despair. You may feel your life has been taken over by your disease and this was definitely not in your plan. Life has been turned upside down in one hospital visit and you want to scream and shout about it and hit something. Make sure it is not another person! It is normal to have these feelings.

Although we are talking about ITP, this will be the same for any long-term condition diagnosis. As we get older, we may have more than one to deal with, such as cardio vascular disease, diabetes, lung conditions, arthritis and so on. The feelings will be similar, coping with these changes in our health and in our lives. You may long to turn the clock back to when you were well, but the realisation that this is not possible can be devastating. Acceptance can take a long time.

Other things that long-term conditions can manifest are fatigue, difficulties in family relationships and confusion as to the best advice and treatment. ITP is a rare disease, so some doctors may not have heard of it. To be fair, I have found medics better informed these days. The ITP Support Association is there to help and support us and we have an excellent team of Medics who give generously of their time and expertise.

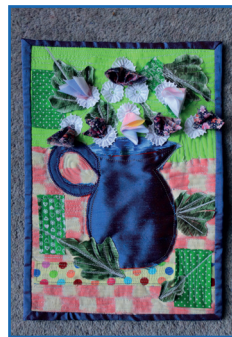
So, what plan of action can you adopt to aid the healing process? If you want to change your life, you have to work at it, there is no doubt about that. No magic wands to take the strain, you have to do the work to make change happen, but it will be worth it. Take small steps to achieve the things you would like to do, and always think of what you CAN DO and not what you cannot do.

All of these ideas apply to Lockdown too and any other situation where we are not able to follow our own desires and wishes. We have had our lives severely restricted and this does not sit easily with us. However, we do know it is for our own good, and concentrating on the positive and not the negative can be helpful to accept the things we do not feel comfortable with or have control over.

In this column I have previously talked about the common-sense approach to a healthy life style. You know what they are, but putting them into practise is harder than snapping your fingers, so here is some help.

Start with an easy one. Get good quality sleep. Make your sleeping room comfortable, with no light after lights out, suitable temperature, no devices or other distractions. Wind down about an hour before bed. Relax with a book, music or mindfulness exercise. No caffeine or sugary drinks before bed, and smoking and alcohol can be disruptive to restful sleep. Go to bed and get up at the same time every day, and keep to a general daily routine including meals, activities such as work, shopping, hobbies and relaxing. Good sleep helps with mood, concentration and general enjoyment of life. I called this an easy one, but truthfully, I don't find it easy at all! I have some bad habits such as going to bed too late and doing email late.

You might find Matthew Walker's book, 'Why Do We Sleep' useful, or his TED talk at https://www.ted.com/talks/matt_walker_sleep_is_your_superpower



Mindful breathing can help anxiety and frustration, and take the relaxed feeling into your following activities. There are many tips on these things online and many self-help books available. Choose one that suits you and do some of the suggested activities to see if you like them. Persevere for at least two weeks

when starting a new regime and then decide if it is for you, or you may need to try something else that suits you better.

People younger than me, (that's a lot of people!), recommend (headspace.com). This App is free for a short time and then you can pay for it if you like it. There are many Mindfulness ideas to use on the net. The book I like is, 'Wherever You Go, There You Are', by Jon Kabat-Zinn, founder of

the modern Mindfulness movement. More and more Clinicians are turning to Meditation and Mindfulness as ways to still the mind and achieve improved health physically and mentally, for themselves and their patients. Our minds play a huge part in our health and wellbeing and the sub-conscious is much more important than was previously thought.

Exercise is a good way to feel the fresh air and sunshine and to get your 'Forest Bathing', 'Nature Bathing' or 'Daylight Bathing' time each day. This is time outside in nature. If you have a garden and cannot go outside your home boundary, you can still walk around your patch and enjoy the signs of spring with plants unfolding, and creatures that visit you. There are many online routines for just 10 minutes of exercise, but find what is good for you and stick to this several times a week. Build up the time so you have 150 minutes of exercise in a week. Try exercise with a friend. Making social contact by phone or in person is an essential part of our mental health and wellbeing tool box.

Eat a sensible diet with fresh fruit and vegetables and wholegrains, cut down on meat and animal products. Experiment with making new dishes that you can incorporate into your weekly shop for ingredients. Ask friends if they have easy recipes with the ingredients you like, and exchange ideas. This is good social contact and you have something delicious to eat at the end, even eating together on Zoom.

Some people find it helpful to keep a journal or diary of their activities and feelings, and what they are thankful for every day, to raise their mood and be grateful for what they have got instead of concentrating on what they haven't got. Catch negative thoughts, Challenge them and Remove to the positive thought pattern. Replace them with a positive thought or action. Be aware of how your thinking is shaping your mood and move to the positive thought pattern. Do an activity to move you on. Every Mind Matters has excellent tips on how to make yourself and your family feel better. (tinyurl.com/anrxt7v)

Do something you have always wanted to try or revisit an old hobby. Making things

concentrates the mind and can give feelings of great satisfaction, self-esteem, sense of purpose and achievement. Some people find cooking creative. I make quilts and give them away. It is always worthwhile to give a gift you have spent time and effort on designing and making, and to see it being used and loved.

Flowers are uplifting and I continue buying bunches each week in my home delivery supermarket order to give to friends within walking distance from home. A short socially distanced door step visit to keep in touch, with a bunch of fresh roses, tulips or spray carnations cannot fail to raise a smile. They do not cost much, but give abundant pleasure and brighten the lives of friends who may be feeling isolated and lonely. It also gives me much satisfaction to see their gratitude and to know they have those flowers for a time to remind them someone cares about them. I have also baked a few cakes to similarly give away. I do keep a bit for us too, and everyone loves homemade cake! Helping others is a boost to ourselves, our endorphins and our immune system.

Please yourself with TV or devices, reading, a hot bath or anything you find relaxing. Something you really want to do, no matter how simple and effortless, can make you feel very satisfied. Being kind to yourself and others is all part of the healing process.

It is important to keep well mentally as well as physically and I hope some of the ideas above will help. It is normal to have ups and downs in mood, especially when bereaved for whatever reason, but if you feel overwhelmed, seek help through your GP or Mental Health Services or the Samaritans. ([samaritans.org](https://www.samaritans.org))

Please let me know how you get on trying some of these ideas. We can look forward to better times ahead and the weather is getting warmer.

Good luck, keep smiling and stay safe and well.

Rhonda Anderson
March 2021

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 HAEMORRHAGE**
 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



The MIND really MATTERS!

By Anthony Heard

Now that the last of the festive satsuma's have finally been finished and the most wonderful time of the year is now just an empty Advent calendar, it's time to move on.

Yes, another New Year and never have we needed more, to check that the old one really has left the building. Goodbye 2020 and very good riddance.

The last 12 months have been pretty unpleasant for all of us. Let's be clear, 2020 was absolutely horrible. With Covid-19 and the inherent health risks it presents, the seemingly endless lockdowns, so many restrictions & so much uncertainty, it's been tough.

None of us like uncertainty but then add in the issues that we folk living with ITP already have to think about and even more so those of us who are on immune suppressing drugs to control our enigmatic condition. Ladies and gentlemen, I present to you the perfect storm !

I have written before about the impact of being diagnosed with and living with ITP on our mental health but the latest Covid-19 pandemic and everything that goes with it, clearly ratchets things up a few notches. The impact that it has had on our mental health is one of the most testing and often hidden aspects of the pandemic.

It is important to understand that we all have different levels of tolerance for uncertainty and stress. We all have different perspectives and we need to recognise that what one person may find easy to adapt to and live with, another person may see as a major crisis. I always try to

remember the old saying that you should never judge someone before you walk a mile in their shoes.

The initial impact that my ITP had on me when I was diagnosed in 2006 was definitely more mental than physical. I had never been unwell before in my life so the arrival of ITP completely shocked me, knocked my confidence and undermined my self belief.

Trickier still was getting across to other people, the mental fatigue that the illness inflicts upon us. It's the uncertainty. We are on the lookout all the time for any signs of mystery bruising, nose bleeds, gum bleeds or worse. It's part of our routine.

But, over time, I gradually learned to cope with it and my ITP diagnosis prompted me to reassess the direction that my life needed to take as I moved forward. It gave me an opportunity to take a good look at the things that I really wanted to do and how I wanted to do them. I got the chance to completely reprioritise and reorder my life.

Now I am not suggesting that everyone do exactly what I did but I can definitely recommend reassessing where you are & what you want to do. It is probably something we all say that we will do but never get around to. Life just happens while we are making other plans, sounds familiar !

As we forge ahead with new optimism for 2021, the following are

Things that I have found helpful -

1. Talk to your family and friends about your ITP - it helps to let those closest to you know what you are going through, what they might expect from you & how they can help.

2. Join the regular ITP Support Association ZOOM Local support group meetings & the Annual Convention. They are a wonderful way to connect with others & have eminent specialists in ITP available to put questions to.

3. Make use of the FREE ITP Support Association HealthUnlocked platform at <https://healthunlocked.com/itpsupport>. It is a forum written by us, for us to share experiences, knowledge & support each other.

4. Read the ITP Support Association website regularly as it has plenty of up to date, reliable information, frequently updated.

5. Do NOT feel alone. The ITP Support Association has a panel of Patient Mentors available FREE of charge to MEMBERS. We also have FREE of charge to everyone (Members or not) a lively Facebook Group, TWITTER & Instagram Feeds.

6. TWITTER - Please feel free to Direct Message me on my personal TWITTER feed if you want a chat or someone to sound off to. None of us know all the answers but we can all help each other. My TWITTER feed is @PatchIPurple.

7. Keeping busy. Especially with Covid-19 lockdowns & restrictions we have all felt more isolated than usual.

The Following things are those which have kept me busy during lockdown (many of them part of my routine pre Covid-19 too) -

A) Gardening, I have been growing some of my own fruit and vegetables for the last 10 years & I am never short of work to do. Roll on Spring !

B) Reading, I read on average one book per week but still cannot bring myself to love E-Books. Must be my age !

C) Listening to music - I have over 3000 vinyl records so I have plenty of material to get through. Music has always been a huge passion but during this pandemic it has become vital.

D) Listening to PodCasts - my favourites are sport, music, gardening or book related.

E) Visiting favourite museums/galleries online - personal favourites are The Wallace Collection, The Sir John Soane Museum, The National Gallery, The Ashmolean, The British Museum, Tate Britain , The Museum of London & The London Transport Museum but options are numerous.

F) Using the Future Learn programme of FREE online courses at <https://www.futurelearn.com> to

explore a wide range of subjects.

G) Utilising You Tube to explore information from the ITP Support Association and the Platelet Disorder Support Association, & of course any other subjects that may interest you,.

H) Listen to the Radio - I tune into the Robert Elms Show on BBC Radio London most mornings & BBC Radio Berkshire for local news.

I) Watch some TV - my favourite for 2020 was The Queen's Gambit on Netflix but there is plenty available on all channels, especially the BBCi player.

J) Keeping in touch with family, friends, colleagues via Zoom, Skype, FaceTime or just pick up the phone.

K) Watching an online /virtual music performance, my chosen venue is Ronnie Scott's and they have regular FREE live streams at <https://www.ronniecotts.co.uk>

L) Getting some exercise, A 30 minute brisk walk daily is enough. Just ensure you observe the Covid-19 social distancing & other guidelines BUT don't overdo things (always consult your medical professional about how much exercise you should or can do).

M) Writing, I try to post something every week to

my blog but you may wish to start writing or take up another creative hobby like painting, drawing, cooking, photography, etc...

AND - Finally - Don't forget to eat a healthy, balanced diet, drink plenty of water and get restful sleep.

Here's to a happy, healthy 2021!

Anthony Heard

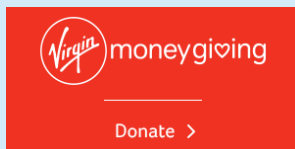
March 2021



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

