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The Platelet

JOURNAL OF THE ITP SUPPORT ASSOCIATION

JUNE 2020

The ITP Support Association Team

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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

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

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

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



From ITP HQ

As I write this, like millions around the world, I am working from my home office. But the work of the Association carries on, Liz Gooch, our Fundraising Coordinator has been, magnificent in going above and beyond, thank you for your support Liz.

Our volunteers around the country have been busy drumming up support for their Local ITP Support Groups as we move from 'in person' to a digital delivery, thank you everyone.

You will read in this edition of the Platelet about our recent ITP & Covid-19 Webinar which has attracted over 5000 views since the video of the session was uploaded to our various social media channels back in April.

Our popular local group meetings are now, being moved, one by one, to a digital delivery using the Zoom video conferencing platform. This transition to digital has had the added benefit of more people being able to take part in our local meetings, which, with all the negativity of the Covid-19 pandemic is a small plus.

None of this transition to a digital delivery for our meetings would have been possible without the support of our Meeting and Webinar sponsors, you will see the names of the companies who have sponsored and supported the move to digital later in this edition of the Platelet. Thank you for your continued support.

As you would expect during this emergency, we have been receiving many, 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.

As you would expect, we have had too much Covid-19 information to publish in this journal (we would need two volumes) but we have added a section on our website dedicated to Coronavirus (Covid-19), just visit www.itpsupport.org.uk and click the link.

We are still hopeful that our Convention will still be able to take place on its (rescheduled date) in

October following our decision to postpone the event from its original date in May, fingers crossed. However, if Covid-19 restrictions remain in place we will be taking the Convention online and holding a virtual event, planning is underway for this backup if needed.

Likewise, we are still hoping to hold our ITP Patient Day in Cork, Ireland later in the year, if Covid-19 allows?

The Covid-19 pandemic around the world has also seen ITP groups in other countries 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.

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

Mervyn Morgan CEO

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Your Questions

Q *We have had many questions from Parents worried about Covid-19 and the return of their Children to School.*

A From Dr. John Grainger, thankfully it is extremely rare for children to become severely unwell following COVID exposure and most are asymptomatic. Only children who were on active immunosuppressant drugs were initially advised to shield. For all other children it is safe for the child for them to return to school when open. If there are other family members who are shielding or if the child is on medicines to suppress the immune system, then further discussion needs to take place with the consultant responsible for the child's health.

Q A mother who is worried about her son (19 years old) who has ITP. He is waiting to go back to Uni, but like many similar cases the parent is more worried than the child (albeit an older teenager). He is on Romiplostim, the dose is being reduced due to the effects on his bone marrow. The parent is worried about this point, could there be any long-term effect on his bone marrow?

A From Prof Adrian Newland, Romiplostim may cause fibrosis of the bone marrow in less than 5% of patients taking it. It is never serious and reverses once the drug is stopped. It can be picked up by changes in the peripheral blood and does not always require the drug to be stopped. ITP itself is associated with an increase in fibrosis in up to 30% of patients, this is always mild and has no clinical significance. This is due to an effect of the

increase in megakaryocytes in the bone marrow, which are the cells that produce the platelets, and the Romiplostim is only enhancing this process. It is also seen in similar numbers of patients on Eltrombopag and is an effect of thrombopoietins in general rather than either drug specifically. Without no any specifics of the case I am assuming this is the issue but it may be nothing more than an increase in the platelets over an acceptable level, which again would entail some reduction in the Romiplostim, and is a normal adjustment of the dose.

Q From Hayley, Having just read a paper about Kawasaki inflammatory disorder I would like to ask if our children with overactive/autoimmune systems are any more at risk of this?

I am currently working for the NHS and treating both Covid and Non Covid patients and have body to body contact (physio rehab) with them all day and have to complete aerosol generating techniques for sputum induction and suction. I am in a small community hospital, so we don't have the same ventilation and PPE as those in critical care and ITU etc. So overall I feel I am at more chance of getting Covid than the general population, however I am exceptionally careful at home.

I was just wondering if there were any thoughts on this as it is the opposite of those being shielded i.e. those on immune suppression.

A From Prof Adrian Newland, Kawasaki Syndrome is very rare normally, usually affecting children under 5 and if recognised can be easily treated by

intravenous Immunoglobulin +/- Aspirin. There has been a clutch of cases in children associated with Covid, the children are slightly older, and the disease is more aggressive but still responds to the usual treatment, often with steroids.

I know one of the authors from the Bergamo group and have spoken to the Italians and none of those affected had underlying ITP. Just as we think ITP does not increase susceptibility to Covid there is no reason why it should increase the risks of KS either. This is certainly not the case in conventional KS. This has not been reported from Japan which, for some reason, has the highest number of cases of KS.

While children can catch Covid, and it is currently under debate as to whether they catch it equally to adults, it is clear that they rarely suffer from it.

While Hayley is certainly in an at-risk profession, there is no reason why her children would be at greater risk of either catching the virus or having a severer outcome. This is an uncertain time we are in, but this certainly seems the position at the moment.

The vast majority of our recent questions have been Covid-19 related.

We have made available on our website the paper 'Practical guidance for the management of adults with Immune Thrombocytopenia during the COVID-19 pandemic.'

It is a consensus written by clinicians with an interest in ITP or coagulation disorders and reviewed by members of the UK ITP forum. This Abstract was published in the British Journal of Haematology on 6th May 2020.

https://www.itpsupport.org.uk/images/downloads/ITP_and_Covid_Pavord_et_al.pdf

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

1. Contact Give a Car on 020 0011 1664 or 'http://www.giveacar.co.uk/how-it-works' and say you wish to donate your scrap car in aid of ITP. It takes a couple of minutes to get your details and answer questions. Once they have your approval, a collection agent will call you in order to arrange a convenient pick-up time.

2. Your car is picked up. A tow truck usually arrives within 1 to 3 days to pick up your car, though in a few rare cases it may take up to 10 days.

3. Your car is sent to scrap or auction. Give a Car then donate all the proceeds, after administrative costs, to the ITP Support Association. Within 6 weeks you will receive a receipt for your donation, and so will we.





ITP Support 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 take place on Saturday 10th October* 2020 9:30 to 17:00hrs in the Elizabeth Room at the Royal College of Pathologists, 6 Alie Street, London, E1 8QT.

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

For tickets go to www.itpsupport.org.uk

Programme

Dr Vickie Macdonald, Barts - Treatment changes over the last 25 years; Adult ITP Registry

Dr Henrik Frederiksen, Denmark - Fatigue in ITP

Dr Nichola Cooper, Imperial - Is bleeding a problem in ITP?

Dr Sue Robinson, Guys - Pregnancy and ITP; the new Registry

Professor John Semple, Oslo, Sweden - Why does ITP occur?

Professor David Kuter, Boston, USA - Guidelines or new advances in ITP

The ITP Patient's journey (patient's stories)

Question Forum

Breakout Sessions

Prof. Adrian Newland, Dr. John Grainger, Dr. Drew Provan, Dr Gerard Crotty & Dr. Quentin Hill

This event is supported by:

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For tickets go to www.itpsupport.org.uk

The ITP Support Association, The Platelet Mission, Kimbolton Road, Bolnhurst, Bedfordshire, MK44 2EL
Web: www.itpsupport.org.uk Email: info@itpsupport.org.uk Tel: 01234 376559
Registered Charity Number 1064480

The ITP Support Association Convention 2020



Following a meeting of the UK ITP Support Association Board, we have made the decision to postpone our UK ITP Convention which was due to take place in May. The event will now take place on Saturday 10th October (same times, same venue), Royal College of Pathologists, 6 Alie Street, London, E1 8QT.

For those who have purchased tickets please note your ticket will be good for the new date, if you are unable to attend on the new date and would like a refund please email info@itpsupport.org.uk with your booking details.

There is now even more time to book your ticket, remember we are already 70% full so don't delay, to book your place visit www.itpsupport.org.uk you can also order by post, send your details along with payment to our office (address on the back page) Tickets for the event are as follows:

Members at the discounted price of £25 and non-members £35

2020 will be a huge milestone for the Association, it is not just the start of a new decade, but it will also mark our Silver Jubilee. In celebration of our 25th Anniversary our 2020 UK Convention will take place on 10th October* 2020 (9:30am to 5:00pm) at the Royal College of Pathologists in their brand-new headquarters building in Alie Street, London.

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

Past surveys of our members have made it clear that expert speakers are by far the most important requirement at our conventions, and as you will see our list of speakers for #ITPLondon2020 reads like a 'Who's Who of ITP!'

Keynote Speakers



Professor David Kuter
Professor, Medicine,
Harvard Medical
School



Dr. Nichola Cooper
Imperial College
London



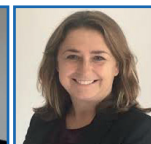
Dr. Sue Robinson
Guy's and St Thomas'
NHS Foundation
Trust



Professor John Semple
Lund University,
Sweden



Dr. Henrik Frederiksen
Odense University
Hospital, Denmark



Dr. Vickie Macdonald
Barts Health
NHS Trust

Medical Advisors attending



Prof. Adrian Newland CBE
Chair of Trustees, ITP
Support Association
Ex-Director of
Pathology at Barts
Health NHS Trust



Dr. Drew Provan
The Royal London
Hospital



Dr. Gerard Crotty
Consultant
Haematologist with
the Health Service
Executive of Ireland



Dr. John Grainger
Royal Manchester
Children's Hospital

THANK YOU TO OUR LONDON 2020 ITP CONVENTION SPONSORS



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ITP & Covid-19 Webinar



ITP Webinar

Our Webinar which took place on 16th April was a great success, since the video has been posted on our website and on our various Social Media Channels it has attracted over 5000 views.

A big thank you to all the Health Care Professionals and ITP Support Association members who gave their time to support the Webinar. Dr. Drew Provan, Prof. Adrian Newland, Dr. Sue Pavord, Dr Quentin Hill and Mrs Rhonda Anderson.



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

We are planning to hold a further Webinar in the weeks ahead, please keep checking back to our Website and Social Media channels for updates.

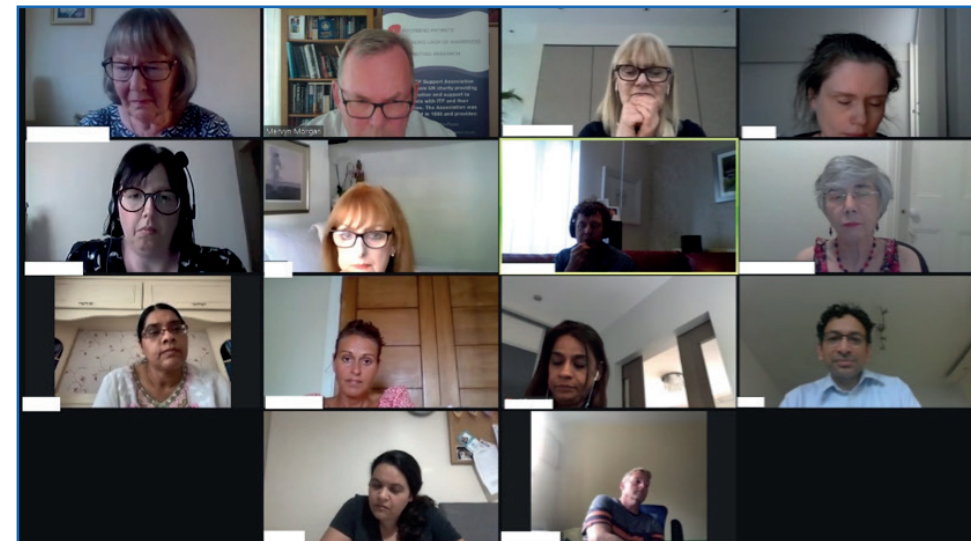
Local Group Meetings

We are now holding our Local Group Meetings using the Zoom Video Conferencing System, each one has been well received by all who have taken

part. We have already held several groups using this system, at the time of writing this article we had just finished the North West Group Meeting.

Dates and times of our Virtual Local Group Meetings are published on Facebook and our website, for the latest meeting schedule please keep checking.

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



American Perspective

The American Perspective: COVID-19 and ITP

Adam Cuker, MD, MS
Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA

COVID-19, the disease caused by the novel coronavirus SARS-CoV-2, continues to rage around the globe. As of 14 May 2020, there have been approximately 4.35 million cases and 297,000 deaths recorded worldwide. Unfortunately, our two countries have been particularly hard-hit by the pandemic.

At the time of writing there have been more deaths reported in the US (84,763) and the UK (33,186) than any other nation.*

I have been fielding many questions from my ITP patients about their risk of contracting COVID-19 and the potential impact of COVID-19 on ITP and ITP therapy. The American Society of Hematology has produced a FAQ document on COVID-19 and ITP (<https://www.hematology.org/covid-19/covid-19-and-ityp>), though it is primarily geared toward healthcare providers rather than patients. In this article, my goal is to address some of the questions my ITP patients are asking. Resources for patients are also available at the Platelet Disorder Support Association website (<https://www.pdsa.org/covid-19.html>).

Am I at increased risk of contracting the virus? What can I do to reduce my risk of contracting the virus?

Patients with ITP are not at increased risk of contracting the virus. The same commonsense measures for minimizing risk of infection that apply to the population at large also apply to patients with ITP. These include (1) Strict social distancing (at least 2 meters apart) whenever



possible; (2) Wearing a mask that covers your nose and mouth when you go out in public, especially when you are in close proximity to other people; (3) Avoidance of persons who are known to have COVID-19 or have symptoms (fever, cough, shortness of breath, etc.) suggestive of COVID-19; and (4) Good hand hygiene. More guidance on this topic from the UK government may be found at <https://www.gov.uk/coronavirus>.

If I do contract the virus, am I at increased risk of developing severe illness?

Factors that are thought to place an individual at increased risk for developing severe COVID-19 include older age, heart disease, high blood pressure, diabetes mellitus, cancer, lung disease, obesity, and smoking. Patients with ITP are not at inherently increased risk of developing severe illness due to COVID-19. However, ITP patients whose immune systems are compromised due to ITP treatment (such as steroids, splenectomy, rituximab, or other immunosuppressive medications) may be at increased risk of developing severe illness.

If I contract the virus, how will it affect my ITP?

Infections of any kind, not just COVID-19, can cause the platelet count to fall in patients with ITP. However, the platelet count does not fall in all patients. I have 5 ITP patients in my practice who have tested positive for COVID-19. One patient developed breathing difficulties and needed to be hospitalized. Her platelet count fell from a baseline of about 100 k/uL to a low of about 30 k/uL while she was in the hospital. Her platelet count returned to her usual baseline as she recovered from her infection. The other 4 patients did not require hospitalization. Their platelet counts remained stable and they did not develop any bleeding symptoms during their illness.

Should treatment of my ITP change during the pandemic?

In general, patients with ITP should be treated the same way during the pandemic as they would otherwise. Using treatments that work well for you will not only help control your ITP, but can also reduce your risk of needing to go to the emergency room or hospital during the pandemic.

That said, switching from a medication that is given in a healthcare setting (such as romiplostim**) to one that is taken at home (such as eltrombopag, avatrombopag, or fostamatinib) in order to reduce exposure risk may be feasible and desirable for some patients. Talk to your doctor if you would like to consider a switch.

If your platelet count falls during the pandemic and you require new ITP treatment or changes to your ITP treatment, your doctor may take into account the pandemic in discussing treatment options with you. For example, some ITP experts have expressed a preference for IVIG over steroids and avoidance of rituximab, when possible, during the pandemic to avoid compromising the immune system. If you require a change in your ITP treatment, talk to your

doctor about how the various treatment options could affect your susceptibility to COVID-19.

Should monitoring of my ITP change during the pandemic?

Some patients are understandably reluctant to go the doctor's office or the lab during the pandemic out of fear of exposure to the virus. If you are scheduled for a doctor's visit, talk to your doctor about whether it can be conducted as a telehealth visit rather than in-person or whether it can be safely delayed until the pandemic eases. Similarly, if you are due for bloodwork, talk to your doctor about whether it can be safely postponed until the outbreak eases in your area.

If your doctor feels that an in-person visit or bloodwork is urgent, please don't put it off. Similarly, if you notice increased bleeding or other worrisome symptoms, tell your doctor right away. Delays in urgently needed care could lead to a worsening of your situation and result in the need for emergency care or hospitalization.

	Confirmed deaths (absolute)	Population (in millions)	Deaths per million
Belgium	9,108	11.42	797.4
Spain	27,778	46.72	594.52
Italy	32,169	60.43	532.32
UK	35,341	66.49	531.53
France	27,989	66.99	417.83
Sweden	3,743	10.18	367.57
Netherlands	5,715	17.23	331.67
Ireland	1,561	4.85	321.62
US	91,801	327.17	280.59
Switzerland	1,891	8.52	222.04

* Editor's note: As of 20th May 2020, the Deaths per million due to Covid-19 was as follows.

Fundraising

A big thank you to Amanda, Will, Elle, Ben and Delphi raised £303.75 inc Gift Aid as part of the 2.6 Challenge by running the London Marathon equivalent on their treadmill in searing hot temperatures. The family collectively did this in 4 hours 20 mins.



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.

In Memory Donations to ITP

In memory of Shraya, her family and friends raised £2,471.25 including gift aid in her memory.

Our thoughts and prayers are with the family

at this incredibly sad time. We cannot begin to imagine how they get through each day, but rest assured these donations will make a difference to ITP patients, through research and patient support.

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

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.

Keeping Sane in Lockdown

Keeping Sane in Lockdown - Starlings scoffed my Strawberries and Slugs destroyed my Spinach.

By Anthony Heard

Just after being diagnosed with ITP in 2006, I decided that I wanted to start growing some of my own fruit and vegetables. I decreed that it would be part of my recovery and survival plan. It took me a year or so thereafter to start but, since 2008 my wife and I have been digging for victory. It has provided a wonderful antidote to my ITP and during these lockdown, limbo times it is even more helpful.

Our garden has been a great way to reconnect with nature, enjoy some fresh air, and get some exercise. Plus, we have had some great fresh food and hopefully done our bit for the environment. I have learned a great deal too, not least that starlings love my strawberries and slugs regularly make a meal of my spinach.

I have leaned very heavily on a number of hobbies to divert my attention from my ITP since my diagnosis. I would heartily suggest that following hobbies and interests that you may have always had and finding others that you have always wanted to try are wonderful ways to take your mind off the many stresses and strains of ITP. They have also helped fill this time in our seemingly endless Covid-19 lockdown. We have worked extremely hard to convince our modest, suburban garden to produce an amazing array of fruit, vegetables and flowers. It has taken an incredible amount of effort and has been a great learning experience at the same time. We have gained a tremendous amount of knowledge and it has truly improved the quality of our lives.

I had always wanted to use some of our garden to start growing some fruit and vegetables. With the usual time constraints of work and myriad other excuses we had simply never got around to doing anything formal. It was only in 2007 when we got

a potting shed and a greenhouse installed that we knew that we had no option but to press ahead. It was now or never! There would be no going back.

I had been inspired to grow some of our own food, because I remember as a young boy helping my Grandfather in his garden where he grew plenty of fresh produce. He and my Grandmother had set up a very productive back garden in their suburban house during World War 2 and they also had an allotment close by. I suppose they did have the British Ministry of Food to motivate them as it really was either grow your own or be hungry.

After the cessation of hostilities in 1945 my Grandparents continued in their garden as if the war never ended. They were very wise, they always enjoyed good, fresh food and were determined that it would underpin their lives and those of their children and grandchildren, including me. I couldn't help but be influenced and inspired by them.

In Autumn 2007 whilst going through some old books in our loft, I discovered one of my Grandfather's old gardening books. I had forgotten that I had any of his old books, so it was a huge surprise. Inside the book was a seed catalogue dating back to 1959 from a company called Carters Tested Seeds Ltd. The catalogue had a few handwritten notes that my Grandfather had made next items that he had ordered. It brought a tear to my eye just to see those scribbled annotations, but it was beautifully serendipitous.

The discovery of these items just seemed to confirm that it was right that I embark on my own growing project. In some ways it was like an affirmation that the time was right for me to emulate everything that my Grandparents had done before me.

So, I started to make plans, in earnest, for our garden project in the Winter of 2007/8 and I have kept a garden journal ever since. I have recorded our plans, outcomes, successes, many failures and eaten some

of the evidence. We have had numerous setbacks, lots of bruises, blisters, and a few disasters. But it has been great fun and extremely rewarding.

The trouble with growing your own produce is that the moment you have anything remotely edible it attracts various interlopers wanting their ration of it. So, you have to be ready to combat the aphids, slugs, field mice, cabbage white butterflies, squirrels, hedgehogs, cats, birds, and numerous plant diseases. You have to accept that you will lose some of your crop because you simply cannot ward off all of the visitors, all of the time.

We learned that our fruit could be protected by netting, but nature is the best referee. Our resident hedgehog family and toads and frogs from our neighbour's pond clear up our slug problem and ladybirds reduce our aphid troubles. Nature has great ways of helping you out when it helps itself!

We grow everything from seed, so the greenhouse comes into play every Spring usually in early March. It remains stuffed with developing pots of various crops at various stages of readiness right through until October. Once the seeds have sprouted and grown to a reasonable size, we move them into the potting shed for their next phase. They then get bigger and stronger before being transferred out into one of our 3 raised beds. So, from early May onwards we have produce in our 3 beds, maturing in readiness for our plates.

The whole enterprise has been great fun, albeit hard work. You really do only reap what you sow in this annual garden game and you never stop learning. There is always something new to try or a different pest that we hadn't expected, suddenly materialises. The most important lesson is to grow things that you really like and will actually eat. Temper all of this by making sure you grow produce that you know does well in your garden. Learn from previous mistakes but don't be afraid to have a go.

I am comforted by remembering something that my Grandfather once told me when I was much, much

younger. It went something like this... "If you eat locally produced food, when it is in season, prepare it simply and don't mess around with it, then you will thrive. If you eat well, then you will live well! Wise words and one's that I have always borne in mind. They are more prescient now than they were all those years ago and I think that our latest Covid - 19 limbo will push more people to look very carefully at what they are eating and where and how it is produced.

Our garden has been a wonderful distraction from my ITP over the last 13 years or so and it has had the added bonus of filling our plates, and our flower vases too. I can't pretend that it has been free from a lot of hard work. But you have to remember that if you do nothing, then you get nothing! During our current lockdown it has continued to be a fantastic diversion and a useful supplementary source of fresh food.

Even if the starlings have nibbled one or two of our strawberries and the slugs have dined on our spinach, we still have some produce left for our plates. We are constantly reminded that our garden is not just our little patch of England, we share it with plenty of other visitors who help to make it our humble abode and their home too.

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/ITPSupportAssocor.

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!

Life Under Lockdown

How is life under Lockdown for you?

Do you like being at home? Is your house sparkling clean, and have you done the major de-clutter? Are you getting nothing done because you haven't felt like it?

Do you have plenty of satisfying things to do? Are you lacking in concentration? Or are you bored?

Is your garden looking wonderful? Are your pets happy to have you there? Are you able to exercise safely, locally?

Are you feeling lonely, or have you felt low and isolated? Do you have issues with children and home school? Are you working from home with difficulty? Has your job disappeared?

How are your anxiety levels? Do you feel safe? Do you feel you have assessed your risk and living with it comfortably?

What a lot of questions, and perhaps you feel that there are more questions than answers in this crisis, and we haven't yet mentioned Covid-19. I am not going to talk about it, that is for other people to address. I am going to concentrate on how you are feeling, through my own experiences.

Everyone is telling us this is a very challenging time. Are you tired of hearing that? Every email from an organisation says this. Thanks for telling us again, and again, and AGAIN. We already know, thank you! We are living through it with various levels of difficulty.

Now some answers from my point of view, not in order.

The greatest anxiety for us was going out and getting food from the shops. Like so many people,

we could not get a home delivery. Even though I registered as a vulnerable person with my various health conditions, and we had registered with Sainsbury's. Finally my GP sent me a vulnerable persons letter, and then Sainsbury's sent us a delivery slot.

After that I received a Government food parcel. I was grateful for this, but didn't need it, and donated it to a charity. We cancelled it online, but another one arrived. This time I managed to catch the deliverer and he took it away and crossed us off his list.

However, this was five weeks after Lockdown. We asked ourselves, if we hadn't been able to get out, what we would have done for food? Family live far away. I am sure we would have managed, but some people would have found it very hard, if not impossible. We sadly think that some people must be falling through the net and fear the eventual findings along these lines.

The food delivery service has been the one single most anxiety relieving event of this Lockdown.

What are your experiences of this? Have you been able to get enough essentials since Lockdown started? Importantly, have you felt safe doing so?

To be honest, apart from the above, Life Under Lockdown is not too bad for us. I don't mind being at home. My friends are amazed at this because I was always out doing something, Yoga, art exhibitions, meetings, voluntary work and more. In fact I have a lot to do at home. The frustration is that I am not finding the time to do all the things I want to!

My interests take up much of my time, such as reading, but I have found it very hard to settle down to it, but do try to make a time for hobbies every day. I have made three quilts to give away and this has

given great satisfaction.

When we are home all day the hours can seem endless. Making a timetable of things you need to do, and would like to do, can be helpful. It is a good way to do the chores and also treat yourself with something you like, such as watching a favourite film or programme, or making a phone call to a friend. Even this can be an effort.

Everyone has a different family set up. One of our worst restrictions in Lockdown has been not seeing our two children and two grandchildren and their families. We can see them on video phone and have had some charming videos of what they are doing. Thankfully, modern technology has come into its own at this time, but it is not the same as a cuddle.

For those who don't have this communication it can be very isolating, and many people are experiencing loneliness. The Patients Association is doing a survey and their findings so far are:

'..that despite most of you being able to stay in touch with family and friends, nearly half of you are lonelier than before the lockdown.'

Mental Health is a very big issue around Lockdown. We don't know the long term consequence of this on the mental health of the nation, and indeed the world. If you are experiencing any mental health problems, be they loneliness, low mood, feelings of helplessness, wanting to harming yourself or another person, or suicide, please do seek immediate help. There are many agencies which are there to help you. Your GP, NHS111, Samaritans, Mind and many more. Sometimes just talking to a friend or relative can help relieve the pressure of mental anguish.

You may like to re-read my article in the March Platelet on Dealing with Difficult Emotions which covers many of these issues, so I shall not repeat them here.

Because we all live with ITP which is a long term condition, we may be more mindful of the anxieties of health issues and possibly find it easier to cope. My husband has been very anxious about me and my risks during this crisis. It is not just the individual, but the impact it has on family members.

We must all find our own ways to combat this, and it is not easy. Sometimes we must just accept what is.

Thanks to Mervyn, I can now do Zoom, although I am still learning. We had some very successful Zoom ITP local meetings, so this has been an excellent spin off from Lockdown. I now do Zoom Yoga classes with the teacher I had before, at the gym. This 11am class gives structure to my morning. I try to do things before and after the class, so I can feel I have achieved something in my morning. Today, being Bank Holiday, I am writing this instead.

I found it very hard to decide whether to do a Zoom Yoga class or not. I didn't do it for the first few weeks as I was doing some myself, but that became hard to sustain, so what class was I going to do? There were so many choices out there. In the end I decided to go with what I knew, even though I had to pay. Masses of choice can be difficult to navigate. I am glad of this decision. I book my classes every Sunday night for the week. It works very well and the classes are a challenge. They push me to do moves I wouldn't tackle on my own, so the guidance of a teacher is very valuable. I use this as an illustration of how difficult it may be to choose, when there is so much choice. In the end go for one thing and stick with that and don't think about how much better it may have been to make different choices.

How is the rest of your health and access to usual health care? Again, The Patients Association survey says:

' Early results have also shown some people, about a third, are having problems getting diagnostic tests they need, seeing a dentist, and getting their medicines. Just over a quarter had difficulties

getting an appointment with their GP.'

If you have a health issue that needs attention, be persistent, and if necessary and urgent enough, call 999. The NHS is there for you and the usual channels should be gone through to get assistance. This means contact your GP first, and then escalate if need be.

Please don't think I haven't had any wobbles. I have felt anxiety about the unknown and the future of my family, worried about what it would be like to become ill and die, and generally felt frustrated and unhappy and shed tears. My heart goes out to those who have experienced illness and bereavement at this very difficult time.

My son is a British Airways pilot, and who knows what the future of aviation will be? My daughter works in Mental Health in the NHS and has a difficult case load. My grandchildren cannot go to nursery and school, and that causes family problems with home/work balance and home schooling, and we cannot help.

So, what can we learn from this experience? I assure it is not all negative. Are you going to use this Lockdown experience to 'Know Thyself'? What makes you tick? Are there things you can improve?

What insights about myself have I learnt from Lockdown? Anxiety needs to be acknowledged and kept at bay with rational thought. Finding out the facts can be difficult, but worth the effort. Assess your own risk.

A structure to my day makes me feel a sense of achievement. It is easy to while away the hours on the computer and not feel satisfied from this. Other time wasting habits can prevail. Having a project or hobbies and interests to concentrate on is helpful for daily routine satisfaction and mental health.

Technology offers a great deal of choice to see films, plays, musical events, ballet, opera and sport,

the choice is yours. It is best to choose a selection of these and enjoy them, instead of trying to see them all. Resist FOMO, the Fear Of Missing Out.

Email can become a pressure. Keep it under control and tidy up your files by having a period each day to deal with it.

Our local area of Woodford Green and Epping Forest is very beautiful, and we have appreciated what we haven't noticed before, or been able to explore in the past, due to lack of time and inclination.

A daily walk of about an hour is a personal battery charger, relaxing, and lovely to see the Spring unfolding.

When your heart is full of gratitude, it cannot hold negative thoughts.

We have become closer to our neighbours. We all come out on Thursday evening at 8pm and clap for the NHS and Carers. Then we have a distanced word with them. We also have a WhatsApp group to share local information. The BBC programmes on the response of the health service are well worth watching.

People on the whole are very caring, considerate and pleasant when you meet them.

Many volunteering opportunities have been made available and people have stepped up and taken the responsibility to share and help others. Often a crisis will bring out the best in people. Allow it to bring out the best in you.

Stay safe, keep well and enjoy every day.

Rhonda Anderson
May 2020

A sixty-five year acquaintance with ITP

It began one March evening in 1955. At about 8.00 p.m. petechiae appeared on my arms and legs, followed by bruises, blood blisters on my tongue, and passing blood in urine. Mum set off on the long walk to the phone box to call for medical help while a neighbour supervised me and my younger sister. Our G.P. visited a few hours later, took one look and pronounced that I had Purpura. It was the first time I heard the term, but it seemed apt as by then purple seemed my dominant colour.

The next morning friends walking to school were surprised to see me entering an ambulance, as was Dad as he turned the corner returning from his night shift in the steelworks. So began over four weeks in the Children's Hospital being treated with cortisone.

I have vivid memories of the enforced bed rest; of watching the four occasions a syringe needle was forced into the marrow of my hip and the discomfort as the contents were withdrawn; daily blood tests and the pricking of thumbs and earlobes to absorb blood onto a circular filter paper for testing; and the senior doctors pinching the bruise free areas of my torso so that their juniors and students could watch the new bruising appear. The hospital was not child friendly by today's standards. I was allowed to sit up to eat but otherwise was expected to lie down in bed which was difficult for an eleven year old who did not feel especially ill. Parents' visiting was 6.00 to 6.30 p.m. and strictly enforced. Doors opened at six and there was a two-minute warning bell for parents to say goodbye before visiting ended.

Weeks later I was at home, overweight, and moonfaced as a result of the cortisone treatment that had been administered, friends needing to look twice before recognising me.

Some doctor had told my parents that I should not participate in sport because of the danger of a recurrence of the problem. Fortunately our family doctor had the view that I should do whatever I chose to do and enjoy my childhood.

In March the following year ITP returned and led to a hospital stay of five days before my blood returned to normal. Two days later I was running in

the school cross country race for my age group.

In the following years I ran middle distance track races, marathons, then some ultra marathons (55-57 miles), instructed at skiing, and canoeing, and dabbled at sailing, windsurfing, and waterskiing.

Our next contact was in December 1978. Resting after a mixed doubles badminton match my partner was horrified to see petechiae appear on my thighs and arms. The following morning when I visited my GP there were blood blisters on my lips and tongue, blood in mouth and throat, and bruising on back and shoulders from turning in bed in the night. Off to hospital to be told there was a haematology appointment in two weeks. Warned by my doctor that I would need to be assertive (that I should threaten to yell and scream in reception creating a scene, and mustn't leave until on the list) I demanded attendance at the clinic. Blood tests showed all was normal. A mistake in reporting and obviously wrong and soon corrected. The consultant took a sample from the sternum to check platelet production. Platelets were in single figures and even lower two days later. There seemed little likelihood that there would be a quick response to prednisolone and that one of my colleagues would have to lead the ski trip to the Dolomites the following week. A week after the first symptoms and the day before my flight, I had my third consultation with Dr. Brown after blood tests. "Do you believe in miracles?" he asked. I nodded. He told me the lab reported the platelet count was normal, but given the previous mistake he would take another sample for confirmation. All was fine. "Don't forget your medication and steroid card. It doesn't matter too much now if you break your leg. Enjoy the skiing" were his parting words. Less than 24 hours later I was on the slopes.

The Summer of 1982 it was back again. This time, like the last, I was feeling well when symptoms appeared. It took longer for prednisolone to have any effect but by October I was training for the London Marathon. As I trained with friends, I seemed to get weaker, not stronger even though platelets were normal and medication stopped after three months. Something seemed amiss but

tests a month before the race couldn't pin it down. The weakness continued. The night before the race I had what my friends referred to as "Dave's common sense attack" when I said I wouldn't be running. I then found out that they had hidden my running kit to prevent me being able to compete.

Free of ITP for a while I carried on as normal with work and family life, and competing in a few two day mountain marathons where competitors had to be self sufficient carrying tent, sleeping bag, spare clothing, stove and food, and had to navigate, visiting checkpoints on a route in the mountains.

Then it came back in 1989. Feeling good after a holiday in Brunei, Sarawak, and Thailand I was driving to college in late September for my first lecture of the academic year when symptoms appeared. My reaction—"Oh (expletive deleted)" I said, and arranged for someone to take my place. I didn't get back to work until the following July after students had left for the summer vacation. In the intervening period, steroids hadn't been effective. Dosage of prednisolone of 40mg was raised to 60mg then for one week to 80mg before a staged reduction. I rapidly gained weight, trouser seams we're close to bursting, and I was jokingly referred to as the Michelin Man. Unable to run because of the impact and potential bleeding I was swimming three times each week. The pronounced fatigue resulting from the steroids led to a progressive reduction from doing twenty lengths to achieving only four with a rest between each. Just swimming caused further bruising. It seemed likely that ITP would return yet again and steroid treatment had been less effective than previously. When platelets improved I had a splenectomy and was left with a wound that took weeks to heal and two more operations followed to deal with internal infections. Hopefully the splenectomy would work. I did take penicillin for two years but no more. After a series of eye infections I now have two weeks supply of amoxicillin to start if I feel it necessary and before seeing my doctor.

For a trip to Bangladesh and Nepal in 1996, I familiarised myself with the advice on travelling after splenectomy which I had read in a BMJ published a few months before, ensuring I had anti-malarials for visiting the coastal areas even though the friends I was visiting wouldn't be taking them. My limited immunity made me cautious. I had had

Pneumovax prior to splenectomy, and again before this trip, even though the BMJ indicated that in some instances it could trigger ITP.

All was well until 2005. Two weeks after a further dose of Pneumovax, one Saturday morning while taking our son to the climbing centre, I noticed the return of my nemesis. Off to hospital. Platelets in single figures led to immediate admission to P3, the haematology ward. That night my partner discovered the ITP Association, emailed seeking advice, and when visiting next day produced a reply from Drew Provan, and a copy of the haematology guidelines on ITP, enabling me to be better informed than most patients. I was home after a week. Prednisolone had worked.

There followed a few years of regular relapses — three in 2006, in one causing some panic among members of a meeting when they saw me bruising and starting to wipe away the blood issuing from my mouth. Spells on P3 were like an annual holiday, with good views of the city from P floor, and in the familiar company of staff who were like friends. When I wasn't bed bound I exercised every day, walking laps around the lift landings between the wards and walking down six floors and then back up to my bed for a short rest. Twice a day was maintaining a little muscle tone.

Then in 2009, with severe pain in my right calf I visited The Walk in Centre. Blood tests seemed to show DVT but the medics there were puzzled by the low platelet count, thinking the two were incompatible. Later I found that isn't so but don't fully understand how they coexist, and how low platelets can make DVTs more likely. So began a two-month spell back on P3 with bilateral DVT and bilateral pulmonary embolism. Anticoagulants couldn't be used with virtually no platelets and it was proving difficult to raise the count. It was incredibly painful leaving the bed for the short time needed to change the bedding or visit the loo. I had the bed laid flat and then angled with feet towards the ceiling— not quite like a bat but a way to ease the pain. Two bags of platelets were necessary to enable the insertion of an IVC filter to protect from errant blood clots. It was calculated that my immune system wouldn't kill them before the procedure was completed. Platelets increased and I returned home. Recovery took a long time. A neighbour had a large plastic barrel at the side of the lane which

was my target for my first walks of a few yards. Day by day he moved it further along presenting a new challenge then further still as I got stronger. I had a burning sensation in the soles of my feet, and my legs which for years had always tried to follow my instructions became rebellious, often refusing to do what I asked of them. I grudgingly accepted I am no longer young and perhaps too demanding.

Prednisolone, IVIG, tranexamic acid, cyclosporin, and rituximab, have been tried but still ITP lurked in the background and worse was to come. I had celebrated my sixtieth birthday, only nine years late, by walking up Helvellyn, my favourite Lake District mountain, when platelets dropped. Back to P3, where there was amusement amongst nursing staff when tests came back once showing platelets-zero. Surely some were hiding somewhere. One day trying to write a dedication to a friend in a book as thanks for joining me in the mountains I found that I couldn't write a word. My partner did the job for me.

I was losing concentration, and left sentences unfinished. By now, after four weeks platelets were near normal but I wasn't. Obviously there was a problem but no one could find out what was going on. Scans showed no serious abnormality, and other observations and checks provided no clarity. Then six days later I had a fit in the early hours. It took six people to get a canula into this writhing person, one holding the head, one on each leg, one for the arms whilst a nurse sucked blood from a bleeding mouth and a doctor inserted it. I knew nothing about this at the time, but over a few days regained some contact with reality. This episode of viral encephalitis really scrambled my brain. I recall hearing someone mention that I was having hallucinations and felt irritated. Why couldn't they see the words on the ceiling that collapsed into the corners when I stared at them, the green spots on visitors' clothes, the tiny cockroaches running in a circle around my partner's cheek, and the lake with the colony of beavers?

These are still vivid memories years later. Stating name and date of birth is a daily requirement in hospital as medication is dispensed or on performing procedures. It felt odd, and embarrassing, not to be able to do so, feeling I knew but couldn't tell. And naming the Prime Minister was way beyond me.

After one week I requested the use of an exercise

bike I had seen in a corridor. With a physio's approval it was placed at the foot of my bed, and several times a day I cycled for one minute, increasing to two minutes on the third day, before returning home to convalesce.

Recovery was slow and months went by before I could concentrate enough to read more than ten or twelve pages per day of a novel. Thankfully I didn't attempt "War and Peace". A year later I was driving around and life had returned to normal. Mycophenolate was keeping ITP at bay. An appendectomy and later hip replacement necessitated extra precautions but caused no problems except operation wounds taking several weeks to heal.

Over the year's prednisolone, Ivig, cyclophosphamide, tranexamic acid, rituximab, and mycophenolate helped maintain good health. Attempts to avoid indefinite impairment of my immune system by increasing platelet production were unsuccessful. When platelets were low romiplostim initially showed signs of being successful, but not for long. When mycophenolate was reduced (originally 1000 mg bd) to 250 mg twice a day, after six months, platelets suddenly dropped dramatically. Eltrombopag caused unpleasant side effects, loss of balance, general fatigue, muscular weakness and dizziness. So back to mycophenolate at 500mg twice daily, along with acyclovir (an antiviral), apixaban to prevent blood clots, and lamotrigine to protect against any further fits.

Over the years the increasing knowledge and treatment of ITP has helped me lead a happy and fulfilling life. I have learnt so much about myself and my illness, and how individual experiences are so varied. I have been fortunate that I have only been affected periodically whereas for others it is a constant in their lives. I also discovered how one committed, dedicated individual, seeking knowledge of a little known disease can harness the support of family, friends, and professionals uniting them to form and nurture an organisation that has informed so many, supported research, and developed international connections with groups sharing patient experiences. I feel privileged to be a member.

Dave Bagshaw

My ITP Story

My ITP Story - By Janet Millard

My name is Janet Millard. I live in West Sussex and at the time I became ill I was 63 years old. My story starts in July 2017. I had been for a routine blood test at the GP Surgery on a Thursday in early July. The next day I woke to find a strange rash across my chest, but as it was a very hot day, I put it down to the heat. As the day went on the rash progressed to other parts of my body, including legs and arms. Baffled but not unduly alarmed, I carried on as usual until early evening. On using the loo, I noticed I was losing blood, quickly followed by coughing up some blood. Now the rash had progressed to round my neck and I was starting to feel unwell. My family took me to the Accident and Emergency Department, where they diagnosed ITP. My platelet count was down to 8. When the doctors looked at the blood test, I had done the day before, the platelets were in normal range, so they had literally dropped over night.

I spent the next week in hospital as my platelets dropped to zero on the Saturday night. I had a severe nosebleed that lasted for twelve hours and ended up being anaemic. The steroid treatment I had been put on wasn't working, for three days my platelet count refused to rise. I had three platelet transfusions, but my immune system kicked them out as fast as they went in, the doctors said I was like a leaky sieve. By Wednesday my platelet count had struggled to 4, so it was decided to try a drug called intravenous immunoglobulins. Thankfully this worked, my platelets started to rise and by the following weekend rose to 26, the bleeding had stopped, and I was allowed home.

I had regular checkups at the haematology department, and the steroids finally kicked in and my platelets were now in normal range. After three

months the steroids were stopped, and the platelets remained in normal range for four months. I woke one morning to find bruising and a rash appearing, but thankfully this time no bleeding. The platelet count was first zero, then 17 followed by 26 before I had any treatment. The platelets had started to rise on their own accord, so the doctors decided to give no treatment but monitor me closely. The platelets kept rising slowly and five months later in June 2018, they had reached 114.

A week later after the platelets had reached 114, I woke one morning to find bruising and a rash, I also felt very unwell, but still not bleeding. As it was a weekend I waited to the following Monday as I knew there was a haematology clinic at the hospital on that day. When they checked my platelets, they were down to zero again. I was treated with a high dose of steroids and three months later these were stopped when the platelets were in a safe range, I was put on Mycophenolate mofetil, an anti-rejection drug, 500mg a day. I have now been well for the past eighteen months, the Mycophenolate mofetil is still working well and the platelets are in normal range.

The latest news is that the doctors are now considering weaning me off the Mycophenolate mofetil to see if the ITP returns, or I remain stable. They hope the immune system has been 'tricked' into not rejecting my platelets, but time will tell, and they can never say that the ITP won't return.

Janet Millard, Crawley West Sussex

Having ITP has saved my life

Having ITP has saved my life - By Pam Brookes

I know, it sounds ridiculous doesn't it, but it's true!

I was almost 57 and according to my husband, I was a few years into my menopause when I was diagnosed with ITP in May 2017. Sorry chaps, it's one of those stories but please stick with it.

I had been to the doctors earlier in the year because I just felt so tired. I was crying at nothing and was exhausted all the time. My Doctor started a series of tests which all came back normal, reassuring but frustrating. Then I had a blood test as part of a starved glucose test. A Doctor phoned me later that day and told me that my platelets were at 7, and I must go to A&E, they were expecting me and to take an overnight bag. At the hospital the Doctor tried to explain what 7 meant, told me that I didn't need to stay in and made me an appointment for the Haematology clinic.

Three day later, I was told I had ITP. What? Never heard of it. We had a long chat and I was given some reading material. It sort of made sense, the fatigue, the exhaustion but I only had one bruise, although it was odd to bruise from carrying a shopping bag with a loaf in it.

I started where everyone starts, steroids, 70 mg. I piled on so much weight but at least they were working. However, my platelets kept crashing down into single figures every time the dosage was reduced. By the November it was decided that I would start Romiplostim. Because of my weight, I had 5 injections every Friday. It was less painful to give myself 5 injections rather than having them all in one syringe. The injections worked initially but then I dropped back into single figures. Eltrombopag next. Again, it worked initially but then back down to 7 so back to the injections. I did have the odd week over 100 but mostly I was below 30.

It was now June 18 and I was bouncing along in single figures. That was when the operation to remove my spleen was first mentioned as the drugs just weren't getting my numbers up to anything near a safe level.

By now I was getting blood blisters in my mouth and my gums bleed profusely when I brushed my teeth. It was frightening to wake up in the night with a mouth full of blood. I was told to be very careful, not to do anything risky, nothing that might result in a bruise, no stepladders to change lightbulbs, soft toothbrush in the morning and only mouthwash at night and no holidays abroad.

At my weekly Haematology appointments, the nurses always asked if I had any unusual bleeding. I didn't mention it for weeks. But then, one week I decided I would mention it, deep breath, "YES" I said, "there is something, I have been having a light period for about 6 weeks but I think it's my menopause". She wasn't convinced and fetched the Sister who asked me a few questions and advised me to talk to my doctor.

I wasn't overly concerned because I was sure it was just my menopause but I talked to my doctor at my regular appointment a couple of weeks later.

My doctor made an urgent refer to Gynaecology. I had an ultrasound scan and saw the consultant a week later for the result. He told me that there was something on the scan that needed to be investigated and wanted me to sign the papers to have a biopsy taken. I asked him to talk to Haematology about it. Haematology said I couldn't have the biopsy until my platelets were at a safe level, so it would have to wait.

As I was close to having my spleen out we all agreed that I would have both procedures done at the same time.

I was now having Rituximab infusions, sometimes into my wrist because the veins in the back of my hands were mostly being difficult. My platelets were fluctuating between 0 and 30.

Pre op infusion meds and injections happened in a blur of appointments and my platelets were over 100 a couple of days before the operation.

I have to admit that the operation, or rather the not waking up afterwards had been terrifying me for a few weeks, irrational I know! I kept telling myself that they wouldn't do the operation unless they were confident that it was safe to do it, that it was their day job, that they didn't want the bad statistics, that I was being stupid. I was still terrified.

October 18th, operation day, at the hospital for 7am. The plan for the day was:

- 1- blood test to check my platelet level,
- 2- Anaesthesia,
- 3- Biopsy,
- 4- Splenectomy,

Easy?.....No, my platelets had dropped to 30 so I was no longer first on the list. Platelets were requested from the blood bank and I had to wait until they were ready. Meanwhile, I saw a team of people for each element and was reassured by their calm, professionalism. But it was a very long morning.

What had I been worrying for? The anaesthetist was wonderful, the radio was on as I drifted to sleep and a lovely nurse was at my side smiling at me as I awoke on the other side of the keyhole surgery.

After 5 days in hospital my platelets were at 266 and I had no bleeding. Two weeks later, my staples were taken out and the scars were very tidy. All good.

Not quite! I still had the appointment to get the biopsy results. As I sat there with my husband,

the Doctor calmly told me I had Stage One, Endometrial Cancer and I was to have a total Hysterectomy in the next couple of weeks. Not the menopause then... Cancer, I didn't see that coming. We walked back to the car in shock. There were tears mixed with a few swear words as I buried my face in his shoulder. But not for long. We knew about it, there was a plan to get rid of it.

I had my Hysterectomy on 23rd November, another keyhole op. We joked that my belly was beginning to look like a dot to dot book.

Two weeks later my specialist nurse phoned. She told me that the cancer had been caught very early, was contained and more importantly I was in the clear. Merry Christmas.

My cancer was in a bucket.

So you see, ITP has saved my life.

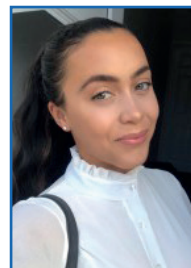
If my platelets hadn't been in single figures, I wouldn't have had the bleeding. I know that, because after my Splenectomy when my platelets were normal, the bleeding stopped. The cancer would have developed and I wouldn't have known a thing. And it wouldn't have shown on a smear test until it was stage 3 or 4.

I have been very lucky, I know that. But please let my story be a warning to you. Don't assume that your symptoms are just this or that. Having ITP doesn't mean that everything else is OK.

Please, please, please, go and get those other symptoms checked, it could just save your life.

Pam Brookes

Ella Ellis Story



We can all have a habit of believing we're invincible in some way or another. In particular in adolescence, as a young fiery spirited child, full of unscrupulous energy and an innocent sense of the world, I felt this way. Growing up, I lived a pretty cush life, awesome parents, incredible family, great friends and a wealth of opportunities. But at the age of 8, my rollercoaster journey with ITP began, of which I am sharing with you today. I hope this piece, may provide some candid knowledge of life with ITP, and particularly through the perspective of an adolescent but also offer conjure an optimistic stance on ITP, for everyone to take from.

I vividly remember, most memories as a pre-teen living with ITP. I distinctly can recall, the initial adrenalin rush, of being taken to hospital for the very first time. Directly oppositional to my parents panic stricken faces, contrasted my excitement to have time of school, lay in bed all day watching day-time TV and eat an abundance of snacks, whilst being prodded and poked by perplexed doctors. However, my enthusiasm for a relaxed bed-bound hospital life, quickly dissolved, alongside my rapidly declining platelet count. At the age of eight years old, I began various courses of treatment, and my extensive bleeding episodes became more frequent. The dwindling moral of doctors, that as a young person I would 'grow out of ITP', came more infused with every unexpected hospital visit. By the tender age of 11, I had experienced possibly every symptom ITP, could hurdle at my frail body. Severe 6-hour nosebleeds, purple/red petechiae, continuous gum bleeds and mouth lacerations, and the best part- the beginning of my (Carrie horror-film like) menstrual cycle- the joy! Not to mention, the questionable extreme- bruises, that brought frequent, uncomfortable, conversations with schoolteachers, friends-parents, that left me floundering for an articulation of a disease, I did not even really understand myself. Meanwhile, I watched my parents emotionally struggle with

the heart ache of being worried for their child. This ultimately hurt the most. I believe when you go through the motions of illness, even as small child, the power of your parents' (loved ones) feelings, is deeply affectual. I tried my utmost, to keep upbeat, happy-go-lucky Ella, that had always been, previous to ITP, but my transfer to Birmingham Children's Hospital after my local hospital became too puzzled by my condition, really hit a core.

The fear began to ramp up, as I began intensive treatment in the Oncology and Haematology Clinic at BCH. Entering new exhumed territories can be intimidating for any person, but as child, surrounded by profoundly sick children (Various oncology diseases - in particular-), I believe generated massive bouts of anxiety for myself and family included. My eventual spleen removal, ending in me busting out of my stitches, within 24 hours after operating, due to excessive blood loss, to only be told, my platelets had reached a grand total of 4, was an extremely low painful point. At this point, I really had exhausted all medical options. This was not until the miracle drug Eltrombopag, introduced to myself, after being sent for a consultation at Manchester Great Ormond Street after down right baffling the Haematology team at BCH. Back and forth, up and down, test after test, after a few terrifying hurdles. One being, an accidental overdose, which cause my platelets to skyrocket into very high 3 figures, or the violent fitting episodes from internal bleeds, when my platelets would so casually plummet.

Overall, my experience with ITP as a pre-teen, moving on until my early adolescence, rests with uncertain emotion. I can't say I'm neither grateful nor saddened by my relentless hospital endeavours. I sit somewhat neutral with positive and negative perspective of the experience. Positive; meeting an abundance of enthusiastic medical professionals (Thankyou NHS staff for everything), attending the once-in-a-life-time trip on Dream- Flight, and my sensational experience of speaking at the Houses of Commons on behalf of the ITP Support Association, are just some highlights to name a few. But the more scarring experiences, dim the light... the extreme disquiet I had for my family

(particularly parents) emotional wellbeing, the investigative questioning from concerned adults for my unexplainable symptoms, the harassment from school peers for looking sick (particularly bloating from steroid treatment never went down well, nor the disturbing mouth blood blisters.), and overall, the missed opportunities of a normal childhood, to be free, careless and just enjoy life without hospital.

Fast-forward to 19 year-old me in April 2019. A big jump I know, but after my ITP seemingly fading away at 14 years old, with successful treatment, ITP was the leeeeeeasstttt of my problems. Second year of university, full of steam (and alcohol), ultimate freedom, meeting new people, experiencing the world and most importantly (mom and dad you'll like this), collating an abundance of educational and professional experiences to set me up for the world of work- Yay!

April 2019, my best friend, Lauren and I, took to Birmingham for a concert & night-out. Upon traveling to our city destination, I noticed a few bruises up my arm. I really didn't think much of them at all, and certainly wasn't going to let a few unexplained bruises ruin our fancy night ahead. Upon getting ready for our night out, I took to the ring light mirror in our hotel bathroom to begin my extensive makeup routine. There, staring right back at me, small purple spots unnervingly transcending my upper lip. I tried not to panic, as I still was adamant about having a good night. I gulped down some wine and tried to forget what I saw.

The next day, I returned back to my university city and immediately visited A&E as the spots rapidly turned to blisters and my arms took over with purple, green tinges. I found out, fairly quickly, my platelets were back under 10. A week before my 20th Birthday. Confused, upset and panicked, I broke the news to my parents, who were equally devastated. I instantly started treatment, to initially boost my platelets count out of 'danger zone'. I started *, and reacted BADLY with acute meningitis, but not before being sectioned into quarantine for a suspected tropical virurs. But none of this, mattered to me, not my weakening health, none of it. What deeply mattered to me, was I was missing university terribly and importantly, deadlines for the all-important summer internships. I frantically forced myself, from my hospital bed, to catch up with lectures and prepare for my upcoming

internship interviews, but it was so painful and exhausting. Even more nauseating was having to actually confront my medical issues and make 'adult decisions', that previously my parents would have made, such as final say on treatment options, comprehending information etc. I realised, I not only took for granted my parents making sense of my ITP when I was younger, but completely depended on them. My parents tried to be by my side, all of the time, but logistically being in another city to them, I ultimately had periods alone in hospital which was unnerving and mentally testing. After 9 months of trial and error Romiplostim treatment, I have finally stabilised, to a normal count of around 150 – 200. Even more profoundly (to me personally), I still landed my dream internship into the Civil Service and received a scholarship to the University of Amsterdam, all whilst coping with my new diagnosis. Not without its difficulties, stress, bleeding episodes, missing the first week of my internship due to excessive bleeding and visiting A&E in Amsterdam, but I ultimately survived, and I am stronger for it.

I am still not out the 'clouds', with the ultimate all clear, but its ITP, - it might veer its ugly head again one day. But, with the bottom of my heart, I am now, sincerely grateful for my journey and have grown to appreciate the life lessons ITP has forced me to take, especially as a young-women, trying to make sense of the world. To name a few,

- 1) Appreciating family and friends. I'd be lost without my parents and their undivided attention and support. I believe ITP, in some ways, pulled us all closer.
- 2) Being grateful of wellness periods and stay hopeful throughout the bad times. ITP is often a rollercoaster disease that never stays contingent, but throws you about. Staying positive and hoping for better days and knowing they could just be just around the corner, any time soon, kept me ticking.
- 3) I AM actually invincible. ITP didn't stop me. It didn't hinder my success. I simultaneously smashed my GCSE'S from my hospital bed as a young girl, and I sure did smash my university, internship and scholarship. Learning to conquer alongside ITP.. I did that.

Ella Sophia Ellis

Global ITP Awareness week



www.globalITP.org

2020

SEPTEMBER 21-25

Global ITP Awareness Week

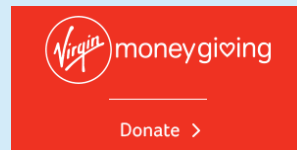
Organized by:  INTERNATIONAL ALLIANCE

A global voice for immune thrombocytopenia patients.

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

