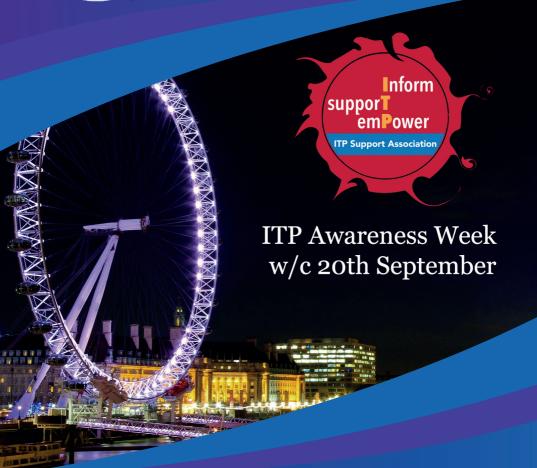


# ITP news, patient stories, advice & more...





TOURNAL OF THE ITP SUPPORT ASSOCIATION

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Charity Registration No. 1064480

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

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

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



2 **ITP** 

# From ITP HQ

Welcome to the September edition of the Platelet. It's almost here, ITP Awareness Week from 20th to the 25th.

We have included details of all that is happening during ITP Awareness Week in this edition. This years ITP Awareness Week is looking to be a very busy period with at least two virtual group meetings and the launch of our 'shared decision-making toolkit for patients', keep checking our website and social media channels for details.

Part of Global ITP Awareness Week September 20th - 25th

Global ITP Awareness Week September 20th - 25th

Since the last edition of the Platelet, we have held Virtual ITP Support Group meetings with our groups from England & Wales, All-Ireland and Scotland, all were well attended as always. We must say a big thankyou to our medical advisors who supported these meetings, prof Adrian Newland, Dr Gerard Crotty, and our new medical advisor Dr Catherine Bagot from Glasgow Royal Infirmary.



Don't forget you can still take part in our Covid-19 – Vaccine Survey, please go to our website at www.itpsupport.org.uk to take part. The initial survey results were published in the last edition of the Platelet and can also be found on our website.

Best wishes

Mervyn Morgan CEO

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# **American Perspective**

# What is vaccine-induced immune thrombotic thrombocytopenia (VITT) and is there a connection with ITP?

#### Adam Cuker, MD, MS

Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA, USA

In February of this year, a new syndrome was described in which patients developed blood clots and a low platelet count after receiving certain types of COVID-19 vaccines. This condition, called vaccine-induced immune thrombotic thrombocytopenia (VITT) or thrombosis with thrombocytopenia syndrome (TTS), is totally distinct from ITP. Nevertheless, it is easy to confuse the two because they both involve the immune system and result in a low platelet count. Many of my ITP patients have asked me about VITT and whether they are at increased risk of this condition. My goal in this article is to answer some of the frequent questions about VITT that I have received.

#### Which vaccines can cause VITT?

VITT has been reported after two different types of COVID-19 vaccines: The Oxford/Astra Zeneca vaccine and the Janssen/Johnson & Johnson vaccine. VITT has not been established as a side effect of the Moderna vaccine or the Pfizer/BioNTech vaccine.

#### What are the symptoms of VITT?

Patients do not develop VITT immediately after getting a vaccine. Instead, symptoms usually begin 5 to 30 days after vaccination. Most patients present with blood clots. Blood clots can cause different symptoms depending on where they are located. For example, some patients with VITT



have blood clots in their brain, which can cause severe headache, vomiting, or seizures. Some patients have blood clots in their abdomen, which can cause severe stomach pain, nausea, and vomiting. Other patients may have blood clots in their lungs, which can cause shortness of breath or chest pain. Most patients also have low platelet counts and may sometimes have serious bleeding.

# What causes blood clots and low platelet counts in VITT?

Researchers are still trying to understand what happens in the bodies of patients with VITT. What we do know is that VITT patients make antibodies against a protein called platelet factor 4. When these antibodies bind to platelet factor 4 on the surface of platelets, they cause the platelets to become hyper-activated and sticky, resulting in formation of blood clots. After the platelets have become hyper-activated and used to make blood clots, they are removed from the bloodstream, resulting in thrombocytopenia. It is important to note that VITT antibodies are very different from the antibodies that cause ITP. Unlike the antibodies that cause ITP do

not make the platelets hyper-activated and sticky and therefore do not cause blood clots

#### How common is VITT?

Thankfully, VITT is very rare. The incidence is still uncertain, but is probably about 1 case out of every 100,000 individuals who receive the Oxford/Astra Zeneca vaccine or the Janssen/Johnson & Johnson vaccine.

# Who is at risk for VITT? Are patients with ITP at increased risk?

VITT has been reported in both male and female adults of all ages. It may be a little more common in young women, though it is important to emphasize that, even in young women, VITT is very rare. There is no evidence that patients with ITP are at increased risk for VITT. To my knowledge, no ITP patients have been reported to develop VITT after vaccination.

#### How is VITT treated?

There are some similarities and some differences between how VITT is treated and how ITP is treated. Like ITP, some patients with VITT are treated with steroids and/or IVIG to bring up the platelet count. Unlike ITP, most patients with VITT have blood clots that are treated with blood thinners.

#### Is it still safe to get vaccinated?

YES! We strongly encourage you to get vaccinated against COVID-19 in consultation with your doctors (see the March edition of the American Perspective for more information on this topic). COVID-19 vaccines are very safe and highly effective. If you are a numbers person, think of it this way: the risk of getting VITT if you receive the Oxford/AstraZeneca or Janssen/Johnson & Johnson vaccine is about 1 in 100,000. The risk of dying if you get COVID-19 is about 1 in 150. Bottom line... getting vaccinated is the best way to protect your own health as well as that of your family and community.

# 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.
- 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.



# UK ITP Adult Registry Update



UK Adult ITP Registry – Update – September 2021 It has been another busy year for the UK adult ITP registry. The COVID-19 pandemic and lockdown restrictions meant that many of our ITP patients, clinicians and staff had to restrict their movement and stay or work from home throughout 2020 and into 2021. We therefore updated our study protocol to enable sites to consent patients remotely, via telephone and post (i.e. not requiring to see the patient in hospital/clinic) with a positive impact on recruitment. Our latest adult recruitment figure as of 9th August 2021 is 4,425 patients. In addition to this, 50 patients have been recruited to the pregnancy arm of the registry since it was created in August 2018.

Dr Vickie McDonald and Dr Sue Robinson have presented updates on both the adult and pregnancy registries helping to understand the frequency, treatments and outcomes of patients with ITP throughout all stages of life (this included the ITP Support Association Virtual Patient Convention and ITP Virtual Update Day which both took place in May 2021). Our projects have included the long term outcomes from splenectomy, the responses to different rituximab doses and the responses to mycophenolate treatment. An early review of the pregnancy data is helping us to understand how pregnancy impacts ITP and whether ITP impacts how women deliver.

In the coming months, we are revising the registry protocol further to incorporate ITP after

vaccination as an inclusion criteria, and then extend the inclusion criteria to include patients with secondary ITP. This will be an exciting development will give us the opportunity to study the causes and outcomes in these patients in more detail

We would like to extend our thanks to all our patients and site teams without whose hard work the registry would not survive. We would also like to thank in particular Dr Quentin Hill, Dr Nicky Cooper, Dr Charlotte Bradbury and Professor Mike Makris for their help and support over the las 12 months. And of course we cannot end without a huge thanks to the ITP support association for our grant and for their forward thinking focus on improving care for patients with ITP.

If you have any questions about our registries or would be interested in participating, please do not hesitate to email us on uk-itp.registryteam@nhs. net. You can stay up to date on our latest news and developments and key staff by visiting our website on <a href="https://www.amul.ac.uk/itpregistry/">https://www.amul.ac.uk/itpregistry/</a> and following us on our official Twitter page on <a href="https://twitter.com/ukitpr.">https://twitter.com/ukitpr.</a>

|    | Hospital                                | Number consented |
|----|---|------------------|
| 1  | THE ROYAL LONDON HOSPITAL               | 328              |
| 2  | HAMMERSMITH HOSPITAL                    | 192              |
| 3  | UNIVERSITY COLLEGE HOSPITAL             | 161              |
| 4  | THE ROYAL VICTORIA INFIRMARY            | 152              |
| 5  | SUNDERLAND ROYAL HOSPITAL               | 144              |
| 6  | CASTLE HILL HOSPITAL                    | 130              |
| 7  | KENT & CANTERBURY HOSPITAL              | 118              |
| 8  | CHURCHILL HOSPITAL                      | 99               |
| 9  | QUEEN ALEXANDRA HOSPITAL                | 98               |
| 10 | NORTHWICK PARK HOSPITAL                 | 93               |
| 11 | UNIVERSITY HOSPITAL OF WALES            | 93               |
| 12 | GLASGOW ROYAL INFIRMARY                 | 89               |
| 13 | THE ROYAL LIVERPOOL UNIVERSITY HOSPITAL | 86               |
| 14 | ROYAL CORNWALL HOSPITAL (TRELISKE)      | 81               |
| 15 | NORTH TYNESIDE GENERAL HOSPITAL         | 81               |
| 16 | BRADFORD ROYAL INFIRMARY                | 78               |
| 17 | PRINCESS ROYAL UNIVERSITY HOSPITAL      | 74               |
| 18 | LEICESTER ROYAL INFIRMARY               | 71               |
| 19 | ST JAMES'S UNIVERSITY HOSPITAL          | 71               |
| 20 | WORCESTERSHIRE ROYAL HOSPITAL           | 68               |
| 21 | QUEEN'S HOSPITAL                        | 67               |
| 22 | LUTON & DUNSTABLE HOSPITAL              | 65               |
| 23 | HARROGATE DISTRICT HOSPITAL             | 58               |
| 24 | NEVILL HALL HOSPITAL                    | 54               |
| 25 | ROYAL GWENT HOSPITAL                    | 54               |
| 26 | WEST MIDDLESEX UNIVERSITY HOSPITAL      | 53               |
| 27 | POOLE GENERAL HOSPITAL                  | 53               |
| 28 | PILGRIM HOSPITAL                        | 50               |
| 29 | YSBYTY GWYNEDD                          | 47               |
| 30 | BRISTOL HAEMATOLOGY & ONCOLOGY CENTRE   | 45               |
| 31 | LEWISHAM & GREENWICH                    | 43               |
|    |   |                  |

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| 32 HEREFORD COUNTY HOSPITAL  | 43              |
|--|-----------------|
| 33 MILTON KEYNES HOSPITAL 34 NOTTINGHAM UNIVERSITY HOSPITALS NHS TRU   | 43<br>IST 41    |
| 35 GUY'S HOSPITAL  | 40              |
| 36 ROYAL UNITED HOSPITAL   | 40              |
| 37 COLCHESTER GENERAL HOSPITAL   | 39              |
| 38 QUEEN'S HOSPITAL, BURTON UPON TRENT   | 38              |
| 39 CAMBRIDGE - ADDENBROOKE'S HOSPITAL  | 36              |
| 40 ROYAL DEVON & EXETER HOSPITAL (WONFORD<br>41 KETTERING GENERAL HOSPITAL   | 36              |
| 42 ST GEORGE'S HOSPITAL (TOOTING)  | 34              |
| 43 ROYAL BOURNEMOUTH GENERAL HOSPITAL  | 33              |
| 44 DERRIFORD HOSPITAL  | 33              |
| 45 YSBYTY GLAN CLWYD   | 32              |
| 46 PETERBOROUGH CITY HOSPITAL  | 32              |
| 47 SOUTHAMPTON GENERAL HOSPITAL  | 32              |
| NORFOLK & NORWICH UNIVERSITY HOSPITAL  | 32<br>32        |
| BEDFORD HOSPITAL  UNIVERSITY HOSPITAL (COVENTRY)   | 32              |
| 51 BASILDON UNIVERSITY HOSPITAL  | 30              |
| 52 THE JAMES COOK UNIVERSITY HOSPITAL  | 30              |
| ST RICHARD'S HOSPITAL  | 30              |
| GRANTHAM & DISTRICT HOSPITAL   | 29              |
| BASINGSTOKE AND NORTH HAMPSHIRE HOSPIT   |                 |
| ST HELIER HOSPITAL   | 28              |
| SCARBOROUGH GENERAL HOSPITAL SS KING'S COLLEGE HOSPITAL (DENMARK HILL)   | 28<br>28        |
| 58 KING'S COLLEGE HOSPITAL (DENMARK HILL)<br>59 LINCOLN COUNTY HOSPITAL  | 28              |
| 60 NEWHAM GENERAL HOSPITAL   | 25              |
| 1 HINCHINGBROOKE HOSPITAL  | 24              |
| 22 PRINCE CHARLES HOSPITAL SITE  | 24              |
| QUEEN ELIZABETH HOSPITAL   | 23              |
| THE QUEEN ELIZABETH HOSPITAL   | 23              |
| YORK HOSPITAL  | 22              |
| 66 WARWICK HOSPITAL  | 22              |
| WITHYBUSH GENERAL HOSPITAL NORTH MIDDLESEX HOSPITAL  | 20<br>19        |
| 59 EALING HOSPITAL   | 19              |
| TORBAY HOSPITAL  | 19              |
| 1 HEARTLANDS HOSPITAL - GOOD HOPE HOSPITA  | L 18            |
| 72 KINGSTON HOSPITAL   | 17              |
| NEW CROSS HOSPITAL - Royal Wolverhampton   | 17              |
| SALISBURY DISTRICT HOSPITAL  | 16              |
| 75 WYTHENSHAWE HOSPITAL  | 16              |
| MUSGROVE PARK HOSPITAL CONTROL OF THE METERS | 16<br>16        |
| DIANA, PRINCESS OF WALES HOSPITAL  | 14              |
| 79 KING'S MILL HOSPITAL  | 14              |
| GLOUCESTERSHIRE ROYAL HOSPITAL   | 13              |
| ROYAL DERBY HOSPITAL   | 12              |
| WEST SUFFOLK HOSPITAL  | 12              |
| ULSTER HOSPITAL  | 11              |
| BIRMINGHAM WOMEN'S HOSPITAL  STATES RUSSELLS HALL HOSPITAL   | 10<br>10        |
| 36 CHESTERFIELD ROYAL HOSPITAL   | 10              |
| MEDWAY MARITIME HOSPITAL   | 10              |
| 38 YEOVIL DISTRICT HOSPITAL  | 10              |
| 9 ROYAL HAMPSHIRE COUNTY HOSPITAL  | 8               |
| GLANGWILI GENERAL HOSPITAL   | 8               |
| 91 NORTH SUMMER NITES ATES CARE MUS SOUR   | UD ATION TOURT  |
| NORTH COMBRIA INTEGRATED CARE NHS FOUR   | NDATION TRUST 8 |
| WEXHAM PARK HOSPITAL  ROYAL SHREWSBURY HOSPITAL (Dr Dewi Eden)   |                 |
| DONCASTER ROYAL INFIRMARY  | 7               |
| AIREDALE GENERAL HOSPITAL  | 7               |
| SOUTHPORT GENERAL INFIRMARY  | 6               |
| SOUTHMEAD HOSPITAL   | 6               |
| BRONGLAIS GENERAL HOSPITAL   | 6               |
| 9 WORTHING HOSPITAL<br>00 HEARTLANDS HOSPITAL  | 6               |
| 00 HEARTLANDS HOSPITAL<br>01 JAMES PAGET UNIVERSITY HOSPITAL   | 5               |
| 02 SOUTHEND HOSPITAL   | 5               |
| 103 SOUTH TYNESIDE DISTRICT HOSPITAL   | 4               |
| 04 PRINCE PHILIP HOSPITAL  | 4               |
| 05 COUNTESS OF CHESTER HOSPITAL  | 4               |
| 106 ROYAL SURREY COUNTY HOSPITAL   | 3               |
| QUEEN ELIZABETH HOSPITAL, Gateshead  | 3               |
| 108 WHIPPS CROSS UNIVERSITY HOSPITAL   | 3               |
| 109 FALKIRK COMMUNITY HOSPITAL   | 2               |
|  |                 |
| THE GREAT WESTERN HOSPITAL ROYAL SUSSEX COUNTY HOSPITAL  | 1               |

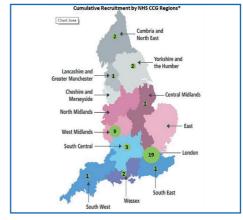
#### ITP PREGNANCY REGISTRY UPDATES

42 women have been recruited to the pregnancy

arm of the UK Adult ITP Registry (see graph below for breakdown of annual recruitment) since the arm was added in August 2018. A review of the data most common data resolution queries in April 2021 found that the top 10 most incomplete forms in the pregnancy registry are:

- •Pregnancy Registration Details (e.g. date of last period, EDD etc.)
- •Problems In Previous Pregnancies
- •Anthropometric and Lifestyle Information (e.g. booking weight, history of smoking and alcohol use)
- ·Bleeding Events During Pregnancy
- •ITP Treatments During Pregnancy (e.g. dosing, indication to treat etc.)
- •Details Of Delivery and Anaesthesia Method At Delivery
- ·Haematological Values During Pregnancy
- ·Coagulation Results At Delivery
- •Infant Details, Morbidity, Treatments and Platelet Counts
- •Information on Breast Feeding It is really important we have complete data to make meaningful conclusions.

Dr Sue Robinson (Co PI) presented analysis of data gathered over the last few years at the ITP Assembly held in May this year and demonstrated its usefulness in providing invaluable insight on the management and outcomes of patients with ITP in pregnancy This can be found on the ITPSA's YouTube channel.



# COVID-19 INDUCED ITP COMMUNICATIONS RECENT PRESENTATIONS

In May this year, Hartley Taylor hosted the ITP Updates day and the ITP Support Association held their annual convention – both via virtual formats.

From the UK Adult ITP Registry team, Dr McDonald, Dr Robinson, Dr Provan and Prof Newland had dedicated slots at both events, discussing a range of topics, including 'What is the place of splenectomy in ITP', 'What is the place of the newer treatments in ITP', 'Real World Experience in ITP' and updates from both the main Adult ITP Registry and the Pregnancy ITP Registry.

We'd like to take this opportunity to thank the ITP Support Association for continuing to support the UK Adult ITP registry, as well as all the sites who are participating in the study.

For a list of all our publications and presentations, please visit our website on:

#### https://www.qmul.ac.uk/itpregistry/latestnews-events-and-links/publications-andpresentations/

We updated the UK Adult ITP Registry earlier this year to be able to capture COVID-19 data for any patients who may have been infected with COVID-19. This was incorporated in the Comorbidities section of the database; it is a simple dataset capturing information about the severity of COVID-19 infections with fields to also capture if patients have had a COVID-19 vaccine. Now that the Oxford-run snapshot audit of management of ITP in the COVID era has finished, for those that took part, this is a good opportunity to add the cases of ITP who have had COVID into the registry! It is important

to note that under the current version of the protocol, patients who have ITP after having a COVID-19 vaccine (no prior confirmation of primary ITP) would not be eligible for the study. However, we are currently working on a substantial protocol amendment that will update the eligibility criteria to include patients who have vaccination induced ITP. We will keep you updated with any new developments in due course

#### Keep up to date with the UK Adult Registry

Head over to https://twitter.com/UKITPR and support their Twitter page. They will be using this platform to shine a light on ITP with the latest news/publications and promote any upcoming events. #ITPAware #ITPRegistry!

You can also visit their Website: https://www. qmul.ac.uk/itpregistry/



# Gemma Ankouri – Zayn's Story



'Chronic ITP' the words that came from my sons haematologist at Southampton General Hospital after his bone marrow aspiration. The words we were dreading, the words which were also a relief, as this meant there weren't any other health issues underlying. The words that my son, in his innocence, did not truly understand.

Zayn was only 2 years old when he was admitted into St Richards Hospital, Chichester, with a high temperature which would not go down even with Calpol. He was lethargic and had a purple pin prick rash on his chest, which would not go away when a glass was put on it.

It was a scary few hours, with the doctors thinking it could be meningitis. But after blood tests, it was thought that this was not meningitis, but a bacterial infection called tracheitis. Zayn was given strong antibiotics through intravenous which made him extremely poorly. After a day or so, more blood was taken and then the consultant came again to ask for more blood as they were concerned that his

platelet levels were dipping. (By this point Zayn was fed up with bloods being taken and we had to have a therapy dog in to help take Zayn's mind off of it, along with 7 members of staff to help keep him as still as possible). We were reassured that his platelets were probably low due to the infection and that they would most probably return to normal after the infection had gone.

Zayn was well enough to go home after a few days with his cannula still intact. We had to return daily for antibiotics and blood tests. Other parents will sympathise; this was not an easy task. By now, Zayn knew what was coming and got himself into such a state having bloods taken- it was heart wrenching watching him go through this. We tried everything from distractions, sweets, toys, but it really didn't help much. Eventually with time, we spent time with the fantastic play team at St Richards; Kerry and Shelly. They worked so hard to help Zayn with the process of taking his blood. They made games up and explored the equipment that was used.

The fantastic consultant, Dr Sharp, we were assigned told us about ITP and explained that this was what Zayn had, what it was. But it was acute at the moment - it could go away. A lady from the research team also gave us some information and asked if we were happy for them to access Zayn's notes, to help them with this rare condition.

As parents, this was a scary time for us. We had never heard of this condition and we were worried for our son and his future. We went home and researched on the internet for hours. What would ITP mean for our son? What would need to change in his life? It was a very unsettling and worrying time for us as parents and we would watch Zayn constantly.

Zayn was a very active toddler: he would climb, run and had no fear; we were nervous wrecks. We sat and chatted with him about his condition, trying to put it in simple context. He didn't fully understand- how could he, he was only 2!

But then we found the ITP Support Association website, the support meetings they held and Facebook groups. It really helped us. We read information and chatted with other parents who were in the same situation.

Challenges arose all the time; blood tests, a bone marrow biopsy, fatigue, pains, medication, illnesses, immunisations, should we let our son do a particular activity? We soon realised we had to let our son be the active boy he was, albeit with safe precautions and obviously, dependant on what his platelet levels are. So, Zayn learnt to ride his bike (at just 3 years old). He donned his helmet, knee and elbow pads and after just 15 minutes on grass practising, he was off! Cycling has helped Zayn keep active and fit, especially through covid- even riding 18km! We found that we needed to embrace the 'good days.' When Zayn's platelet levels were stable, he was not fatigued, agitated or telling us of pains in his legs and tummy. Zayn continues to amaze us every day. He is a resilient, enthusiastic boy with a very strong 'can do' attitude

Our next challenge as parents is school. Zayn will be starting reception this month (September). We have met with teachers and have devised a health care plan for his needs and have discussed symptoms Zayn can show. It is a daunting time, but we do not show Zayn our worries. We want this to be an exciting time for him. He is excited about his new adventure and we have talked a great deal at home about school and how he needs to be aware of his condition more than ever. Zayn has shown a better understanding of ITP, although it still frustrates him, with him often saying 'Oh I wish I didn't have a blood condition!' which is heart

breaking. But Zayn is so much more than his condition, as are all the other ITP warriors out there-you are amazing!

To all you parents out there, keep strong and keep supporting your littles ones; you are doing a fantastic job!

Zayn will be raising money for the ITP support Association and awareness for ITP this September, by doing a cycle around Goodwood Motor Circuit. If you would like to donate to his page, please visit https://uk.virginmoneygiving. com/GemmaAnkouri

## Update on Patient Mentors for the ITP Support Association

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

#### **PATIENT MENTORS**

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# Peter Lindsay -In His Own Words

I am 77 years old, a non-smoker, and might have a glass of wine from time to time. I was first diagnosed with ITP in 2015, as far as I am aware defined as having a platelet count of <150. This was picked up on a routine full blood count prior to starting treatment for a fungal infection. Platelet count on my first Haematology consultation was 104. All blood parameters including viral serology were negative. A staging CT scan of neck, chest and abdomen did not show any evidence of pathological lymphadenopathy. Three months later, with no medication, my platelet count was 142. I was then scheduled for review one year later, and then annual blood tests.

Fast forward to October 13th 2020 when my annual platelets count was 95 (usually slightly above 100). My GP advised me to have an additional routine test within a three-month period. I had had my flu vaccine on Oct 10th, so that may have a slight negative impact on my platelet count. During the intervening five years I gave little thought or importance to platelets. In my mind, ITP was of little consequence. I did not declare the condition to my travel insurance company, my thinking being, 'my platelets are slightly lower than the norm, so what?'.

On November 25th 2020 I was admitted to hospital with acute urinary retention and UTI. I was catheterised,( two attempts, ouch, ouch), and there was some amount of bleeding around the site of the catheter but there was no haematuria. A few hours later blood test results came back and my platelet count was 6. This all happened in the walk-in A&E department and the duty medic seemed less perplexed once I had quickly offered my ITP history. Whilst I am much wiser now, thanks to the ITP Support Association, I had not linked infection with a possible drop in platelet count.

I was started on a course of Co-amoxiclav to deal with the infection,(the previous four days leading

to admission I had been on Nitrofurantoin), and Prednisolone 60mg daily for the ITP. On Dec 4th my platelets were 342 decreasing to 122 on Feb 9th, by which date my Prednisolone dose had been tapered to 10mg per day. This was back around my normal platelet count.

I had my first Pfizer jab on Jan 23rd and there seemed to be no effect on my weekly platelet counts of around 120 until Feb 16th when they dropped to 22. A few days earlier, on Feb 12th, almost three weeks after my Pfizer jab, I woke in the early hours of the morning lightheaded, shivering, aching all over and had had a night sweat. The following day I was fatigued, no appetite, a headache but no fever. The following day I was almost back to normal. My suspicion was that this dramatic drop in platelet counts was a reaction to the Covid vaccination. My haematologist treated this episode as a relapsed ITP and started me on a four-day course of Dexamethasone 20ma with a view to proceeding with Rituximab if I relapsed again. My platelets were 220 after the four days on Dexamethasone. A scheduled bone marrow biopsy around this period showed nothing abnormal. My second Covid jab was brought forward in case I had to start Rituximab therapy.

I have had no further medication and my platelets have now, August 6th, settled to levels between 100 to 120 with a drop to 74 around the time of my second Pfizer jab, and 69 after a heavy cold.

In summary, I have asked for my story to be included on the website as an illustration of how infections, vaccines and viruses might affect platelet counts. I my particular case, my normal platelet level seems to be just above 100, with a likely negative impact due to future vaccines, infections and viruses, such as the common cold. I will be quick to deal with future infections and try to organise a platelet count near such events. I will be taking my ITP more seriously in the future.

# **Plasma Donation**



If you received treatment with immunoglobulin, and you live in England, NHS Blood and Transplant's communication team would love to hear from you. They're seeking people who can share their personal story to help inspire members of the public to donate plasma for manufacturing into immunoglobulin. If you'd like to know more, please email stephen.bailey@nhsbt.nhs.uk



# ITP September Awareness Campaign

ITP Awareness Week is nearly with us (w/c 20th September 2021)

#### What's on?

Monday 20th September - North East of England ITP Patient Support Group – this is the inaugural meeting of this group, it will be taking place virtually on the Zoom platform with a 7pm start. Please register at www.itpsupport.org.uk click on the patient support groups menu item and select the group you would like to take part in.

Tuesday 21st September – We aim to launch our new 'Shared Decision Making Document' called 'Making the right choices in ITP management and care'. We are very proud of this document which has been produced in partnership with the ITP Clinical Forum. Details will be published on our website and social media channels.

Wednesday 22nd September – Paediatric ITP Support Group – this group, with Dr Nichola Cooper on hand to answer questions will be taking place virtually on the Zoom platform with a 7pm start. Please register at www.itpsupport. org.uk click on the patient support groups menu item and select the group you would like to take part in.

**Thursday 23rd to Saturday 25th** will see further events in collaboration with our friends and colleagues in the USA and Australia. Details will be posted on our website and social media channels.

Please keep checking the ITP Support Association website at **www.itpsupport.org.uk** for further announcements about the campaign.

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

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

- Join us at the ITP Support Association in our September Awareness Online Event (Full details will be available via www.itpsupport.org.uk).
- 2. Engage with the daily social media postings that we will be making throughout September highlighting ITP. We will be using the hashtags #ITPaware and #alobal4ITP
- 3. Retweet and/or LIKE any TWEETS we put out & in doing so this spreads visibility of the campaign
- 4. Try posting out a few TWEETS or Facebook messages yourself here are a few that you may wish to use -
- A) ITP is a RARE DISEASE and is just one of over 6000 RARE DISEASES
- B) ITP is an AUTOIMMUNE disease, of which there are over 80 including multiple sclerosis, pernicious anaemia, type 1 diabetes, Lupus & rheumatoid arthritis
- C) About 5,000 people in the UK are living with ITP at any one time, the figure in the USA is between 60,000 & 100,000
- D) In ITP the immune system mistakes platelets as being foreign & destroys them. It can follow a virus, vaccination or some medications, but often the cause is unknown
- E) There is no cure for ITP but there are many treatments which are used to raise the platelet count.

# I SPORT PURI

Go #glo

www.Glob

A global voice for immune thro

# PLE for platelets

# bal4ITP

oalITP.org

ombocytopenia (ITP) patients

ITP ••••

## Spotlight - Where To Find Us

#### TURNING the SPOTLIGHT on where to find us

Many people on the various ITP social media forums/platforms ask questions about where to get reliable, up to date information about our rare condition and where to find the ITP Support Association.

Many people do not realise that we are available on a number of platforms so we thought that it would be a good idea in this September Awareness Month to share all of the various outlets that we can now be found on

So, the following is an up to date list of where we can be located.

The ITP Support Association – UK Registered Charity established 1995 and the first support group for ITP patients anywhere in the World....

Website - www.itpsupport.org.uk

Facebook Group - https://www.facebook.com/ITPSuppAssoc/

Twitter -

https://twitter.com/ITPSupportAssoc

HEALTHUNLOCKED forum - written by ITP sufferers for ITP sufferers.

https://healthunlocked.com/itpsupport

Instagram -

https://www.instagram.com/itpsupportassoc/

Visit the ITP Support Association YouTube Channel You Tube Channel with numerous helpful, informative & interesting videos covering a wide range of ITP related issues - https://www.youtube.com/channel/UCRkHWfVYAA1KKabjFI4L37g/videos or go to our website at www.itpsupport.org.



**uk** and click on the YouTube Social Media icon under the top menu. We have around fifty ITP related videos available and are adding more all the time. Please subscribe to the channel.

LinkedIn - We have recently joined LinkedIn so if you have not found us yet you can do so at -

https://www.linkedin.com/groups/13990747/

Finally - A USEFUL REMINDER - One thing to be aware of about all of the various forums is that any content and/or suggestions or comments on any of them can never replace the relationship between you and your doctors or other healthcare professionals nor the advice you receive from them. Always consult with and discuss your case in full with your doctor/specialist or medical professional before acting on anything.

Produced by Anthony Heard

# Several Things to Ponder by Rhonda Anderson

During our ITP Zoom calls the question of diet and ITP often arises. I have written about this in previous articles in this column. The short answer is that there is no evidence that food causes or cures ITP. Recently people have said that following a certain exclusion diet has helped them. This may be so, everyone is different, and as long as you are not excluding important elements in your diet, then follow it for your own health, comfort and peace of mind.

Gluten is one of the latest items to exclude. If you have coeliac disease, which is another autoimmune disease like ITP, then you will need to get a proper test to prove this. It is not valid if you have already excluded gluten from your diet. Coeliac disease is not an allergy or food intolerance. Check out the Coeliac UK website.

#### www.coeliac.org.uk

It is possible to have a non-coeliac intolerant to gluten. Anecdotally, people who definitely do not have coeliac disease exclude gluten, feel better, and then have gluten unknowingly reintroduced to their diet, experience undesirable symptoms again, so the gluten was causing the problems. But this is a small percentage of the population. It is possible to be intolerant to one or several different foods at the same time. If this is a problem for you, ask your GP to be referred to have tests at a specialist centre, so you are being well supervised and can scientifically track down the problem foods. This is no easy matter as it is a very complicated science, still not well understood.

#### https://www.bbc.co.uk/newsmagazine-37292174

Every ITP patient is different and every person will

react to food and drugs differently. Experiment safely, and if you find it helpful, then continue to exclude that which bothers you. This does not mean that what has helped you will help others, and that you have found the miracle cure. Beware of anything that makes claims to cure you, especially if you have to hand over any money. There is much on the internet that makes claims that are not true. However, you may also find helpful information. Anything that sounds too good to be true, probably is. Be discerning when searching the net. Stick to NHS sites and other reputable ones.

#### www.nhs.uk/conditions/food-allergy/

There is a difference between an allergy and an intolerance. A true allergy is life threatening. Some people are allergic to bee stings and swell up with anaphylaxis which is life threatening. An intolerance gives undesirable symptoms. However, confusingly, the word 'allergy' is in general usage for both reactions. Very few of us will have true allergies, but many may have intolerances to various things such as bites and stings, some foods, such as shell fish or strawberries. Why am I making this point? Mostly to clarify for people the difference, and because my daughter had anaphylaxis at 4 days old when she was born 5 weeks premature. The cause? Formula milk because it contained cows' milk protein. Most medics in the hospital did not believe that babies could be allergic to formula milk. I did succeed in breastfeeding her for 14 months

It is important not to decide that this or that is causing your ITP, or your platelets to drop. Infections have been known to lower the platelet count. To decide that it is the antibiotics that have been prescribed to combat the infection is jumping to conclusions.

Senile Purpura is the rather unattractive name of the bruises older people get due to minor trauma caused by contact with housework tasks, gardening and so on. I get regular spotty red bruised areas on my arms in particular, which is not at all pretty. I look as though I have been in a fight. I asked Professor Adrian Newland about this as my platelet count is normal. He tells me, 'As we get older the sub-cutaneous tissues thin out. These are mainly fat and support the blood vessels and give the skin its spongy feel. As the substance goes the small capillaries become more exposed and friable and liable to tear'. I am often to be seen with plasters on my arms when I get three cornered tears that bleed. I think is a good reason not to do too much vigorous housework!

The Shingles Vaccine is being offered to people over 70. GPs get paid for administering vaccines, so are keen to get a good uptake. I had to take advice on this and found out that being asplenic it is safe for me to have the vaccine, although I had previously been told by my GP not to have it. Shingles can be a very nasty illness and it is best to take up the vaccine. There is information on the ITP website and also the NHS website which it is worth reading so you are as well informed as possible. I had my Shingles vaccine this week, together with my husband, and we had no undesirable effects.

# https://itpsupport.org.uk/index.php/en/16-home/44-shingles-vaccines-and-itp

Getting out in the fresh air and taking some exercise no matter how much we resist, is always a feeling of achievement when we actually do 'forest bathing' which can help us to feel so much better. Basically this is enjoying a place where

there are trees, slowing down, becoming very aware of your surroundings, deeply relaxing and even meditating. Even indoors, sorting something out, even for 15 minutes can make us feel better.

Covid Anxiety is gripping many people. My friend cancelled her trip to France to meet up with her American family due to feeling too over anxious and losing sleep, to be able to cope with the stress of organising the trip with tests and so on, and also the anxiety of being in contact with strangers in places like airports and aeroplanes, not to mention all the technological hassles. Many of us will feel the same.

I am going on a coach trip to Edinburgh in a fortnight and have concerns about access to places and being in more crowded spaces, but hope to overcome the concerns and enjoy the trip. I am looking forward to it and planning what books to take, although there is little time to read apart from the coach journey.

Whatever journey you take this summer, I hope you enjoy the pace and the place you are in, even if it is not far away, maybe a neighbour's garden. Leave the impatience and frustration behind, live in the moment and enjoy what you do, whatever it is.

Rhonda Anderson August 2021

•••• ITP

## **Fundraisers**

#### Aleks Conversano

Aleks Conversano raised £381.55 (inc GA) by cutting her hair off and donating it to the Little Princess Trust (a children's cancer charity). ITP has affected someone very close to Aleks which is why she decided to raise vital funds.



#### Corporal Ben Baily

Ben pictured top left in his very grey ITP tee-shirt!

Corporal Ben Baily and four colleagues decided to take part in a gruelling (and muddy!) Summer Wolf Run 10k Obstacle Race. Ben was diagnosed with ITP in December 2018 and quotes "Luckily I am now in remission and am able to take part in things like obstacle races, which before, would have been unthinkable." A total of £286.50 was raised as well as donation to the Royal Air Force Association. The ITP Support Association is very grateful for these funds.



#### Joseph Grosvenor

We were extremely grateful to Joseph Grosvenor (below) for training and competing in the Greensand Country 50km race. Despite spraining his ankle playing Rugby the week before, Joseph sadly couldn't complete the race but managed to raise an amazing £1,325.30 (inc Gift Aid).



#### The Burford Trust

The Burford Trust donated £500.00 towards our funds. We are indebted to the support the Trust has given the association over the last few years.

#### Atlas Trading Limited

Atlas Trading Limited - the collection tin held in their shop has raised yet more funds - £180.50 since early June!

#### Virgin Money Giving

Virgin Giving, sadly we have just been informed that the Virgin Money Giving donations platform is being closed in November so we will need to source another donations platform, however from (June to August a wonderful £1300.02 was raised, a huge thankyou to everyone.

#### Facebook

Facebook Fundraisers, a huge thankyou to all our fundraisers on Facebook who raised a total of -£734.94

#### Amazon

Amazon Smile donations continue to pick up thanks to people using Amazon more frequently during lockdown, the latest amount was £68.16, thank you all.

# **New Christmas**

Our new Christmas Cards for 2021 are £3.50 for a pack of 10 We also have lots of ITP branded items available



# Cards for 2021

cards with envelopes. To order go to www.itpsupport.org.uk. ble on our online shop at www.itpsupport.org.uk



# 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 qift 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 qift.

#### 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.

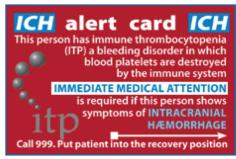
#### Order a free ICH alert card

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.





# ency In ITP these

Emergency treatments include: oxygen, platelet transfusions, highdose IV steroids, IV immunoglobulin In ITP these symptoms can have a slow onset like a dripping tap and are SERIOUS

OThe ITP Support Association.

More information for clinicians can be found at:

www.itpsupport.org.uk/ICH



ITP · • • • • •

## **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 is 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 asplenics
- 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 BE 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  | _ м    | r [       |      | Mrs                        |      | Miss      |      | Ms    |    |    | Dr     |     | Other |
|--|--|--------|-----------|------|----------------------------|------|-----------|------|-------|----|----|--------|-----|-------|
|  | NAME   |        |           |      |                            |      |           |      |       |    |    |        |     |       |
|  | ADDRESS  | RESS   |           |      |                            |      |           |      |       |    |    |        |     |       |
|  | ADDRESS  |        |           |      |                            |      |           |      |       |    |    |        |     |       |
|  | POSTCODE   |        | TELEPHONE |      |                            |      |           |      |       |    |    |        |     |       |
|  | EMAIL  |        |           |      |                            |      |           |      |       |    |    |        |     |       |
|  | Let us keep in touch   | Opt in | P         | leas | e tick th                  | e bo | х         | ] Em | ail [ |    | os | t 🗌    | Ph  | one   |
|  | 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  |        |           |      |                            |      |           |      |       |    |    |        |     |       |
| S  | 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   |        |           |      | 31st Januai<br><b>UK</b> * |      | 0<br>Over | seas |       | FC | DR | OFFICE | E U | SE    |
|  | GENERAL DON  | IATION |           |      |                            |      |           |      |       |    |    |        |     |       |
|  | RESEARCH DO  | NATIO  | N         |      |                            |      |           |      |       |    |    |        |     |       |
|  | TOTAL ENCLOS   | ED     |           |      |                            |      |           |      |       |    |    |        |     |       |

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