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ITP Support Association

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

SPECIAL EDITION

Global ITP Awareness Week

26 - 30 September 2022

Coordinated by INTERNATIONAL ALLIANCE
A global voice for immune thrombocytopenia patients.

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The Platelet

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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

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From ITP HQ

Welcome to this 'Special Edition' of the Platelet Journal dedicated to ITP Awareness Week. In this edition we have reprinted a selection of patient stories that have appear in these pages in recent years.

We also have all the usual favourites such as the 'American Perspective', this month Dr Adam Cuker from Pennsylvania Hospital writes about ITP and Fatigue, many of you would have watched Dr Cukers interesting talk during our 'Symposium on Fatigue' at our Convention earlier in the year.

In addition, we have an update on the work of the Adult ITP Registry from Dr Vickie McDonald and a fascinating article from Haroon Miah, 'Data Manager and Study Coordinator' for the ITP Adult Registry, titled 'A week in the life of the ITP Data Manager', Haroon explains the work that goes on in the background to ensure the data can be used to support treatment options and help to define treatment guidelines.

ITPSA Trustee Mr Derek Elston has been on his travels over the Summer, firstly representing the Association at the European Haematology Association Congress in Vienna which was followed by the Protein Plasma Therapeutics Association (PPTA) Conference in Berlin shortly after. Derek has provided us with a detailed report which I hope you will find interesting, there is so much going on behind the scenes, all for the benefit of patients.
Regular contributor to these pages, our Senior Patient Mentor Mrs Rhonda Anderson writes about 'Being a Patient Mentor' this has also had input from out other two mentors Derek Elston and Karen Smith.

Moving on to ITP Awareness Week, please keep checking on our website and social media channels, we will be sharing lots of updates from our friends at other ITP patient organisations around the world, plus on Day One (26th September) of Awareness Week we will be holding a Nurses Update Meeting (Virtual), this will be chaired by Nurse Consultant Louise Taylor and ITPSA CEO Mervyn Morgan, details of how to book are on our website and in these pages.

On Wednesday 28th September we will be holding a virtual Paediatric Meeting with Dr Nichola Cooper and members of her team on hand to answer any questions, if you have a child with ITP please register and join us on the 28th.

This edition of the Platelet also includes details of our latest Patient Perception Survey, if you have not already done so, please take the time to complete, all of your inputs goes towards helping us map out our plans for the future benefit of ITP Patients, remember the last survey resulted in the publication of our Shared Decision Making Booklet called 'Making the right choices in ITP Management and Care', this document has seen 1200 hard copies posted out and over 6,000 digital downloads since its publication 12 months ago.

Special thanks must go to all the fantastic fundraisers who have gone that extra mile to support the Association, again details are included within these pages.

Finally, by the time you read this you should have a few days left to get any applications sent in for our ITP Scholarship Programme, details are in this issue of the Platelet.
I could write lots more but just a reminder during September please keep checking our website and social media channels for further updates.

Mervyn Morgan CEO

Contents

American Perspective

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

Many of my ITP patients report that they are tired all the time. That they barely have the energy to make it through the day. That they feel exhausted, even when they first wake up in the morning after a full night's sleep. That they choose to opt out of social and recreational activities because they just don't have the energy. Some of them even tell me that fatigue is the worst part of their ITP, worse than the low platelet counts or bleeding symptoms.

If my patients' concerns resonate with you, you may have ITP-associated fatigue. My goal in this edition of The American Perspective is to address common questions about ITP-associated fatigue including what it is, how common it is, what causes it, and how it can be treated.

What is fatigue?

The colloquial definition of fatigue, according to the Oxford English Dictionary, is a feeling of being extremely tired, usually because of hard work or exercise. We all know the feeling of fatigue in this sense -- it's the tiredness we feel after a long day's work.

When we talk about ITP-associated fatigue, we are not referring to the colloquial definition. Rather, we are talking about medical fatigue. The medical definition of fatigue is different from the colloquial definition in two respects. First, medical fatigue is so severe that it interferes with an individual's ability to function and enjoy a normal quality of life. Second, medical fatigue occurs in the absence of hard work or exercise. We all know this feeling too -- it is the total lack of energy we feel when we're sick, for example when we're home with the flu.

How common is fatigue in individuals with ITP?

Research studies indicate that about 40-50% of ITP patients suffer from fatigue. Fatigue is much more common in individuals with ITP than in the general population. High rates of fatigue in ITP have been reported in adults and children, and in studies all over the world, from the UK and Europe to the US and Canada to India and Japan. In the ITP World Impact Survey, a large study involving more than 1500 patients from 13 countries, 50% of respondents reported fatigue and 65% of these individuals classified their fatigue as severe. Remarkably, fatigue was the most common symptom reported, more common than bruising, petechiae, anxiety around unstable platelet counts, or any of the other 11 symptoms queried in the survey.

What causes ITP-associated fatigue?

There are multiple potential causes of fatigue in patients with ITP and causes may differ among patients. Some patients may have more than one reason for their fatigue.

Inflammation leading to something called "sickness behavior" is probably a major contributor to ITP-associated fatigue in many patients. When we get the flu, our bodies become inflamed. Inflammatory chemicals called cytokines cause us to feel fatigued. In the context of the flu, the fatigue serves a purpose. It encourages us to stay in bed, rest, and reserve our energy for fighting off the infection. This tendency to stay in bed when we have the flu is called "sickness behavior". Some patients with ITP also have "sickness behavior" due to increased inflammation and elevated cytokines. But unlike the flu, which usually goes away after a few days of rest, ITP is longer-lasting and patients must learn to cope with their fatigue as they navigate their daily lives.

All sorts of other factors may also contribute to ITP-associated fatigue. Some patients with ITP have other illnesses that cause fatigue (for example, underactive thyroid or depression). Medications used to treat ITP such as steroids may cause fatigue or interfere with sleep. The stress of having a disease like ITP, itself, can be fatiguing. Bleeding due to low platelets (for example, heavy menstrual periods) can cause iron-deficiency, which is associated with fatigue. Some patients with ITP reduce physical activity for fear of bleeding, which can lead to deconditioning and decreased energy.

What can be done to treat fatigue?

There are many treatment strategies available for improving fatigue. In general, treatment of fatigue should target the cause(s) of fatigue in an individual patient. If you feel that you are experiencing fatigue, be sure to mention it to your physician. Your physician will need to perform testing to identify what is causing your fatigue. For example, if you are found to have an underactive thyroid, you will need treatment with thyroid hormone replacement. If you have iron-deficiency, you will need iron supplementation. If steroids are disrupting your sleep, you and your doctor should seek an alternative to steroids. You should get regular exercise and practice good sleep hygiene. In some cases, a sleep aid such as melatonin may be warranted. If anxiety or depression are interfering with your sleep, you may benefit from counseling and/or medical therapy.

Some ITP patients report that fatigue tracks with their platelet count. They are most fatigued when their platelet count is low and they experience an energy boost when their platelet count goes up. Make your physician aware of whether you feel better when your platelet count is higher. You and your physician can use this information to develop treatment goals that help you feel your best.

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

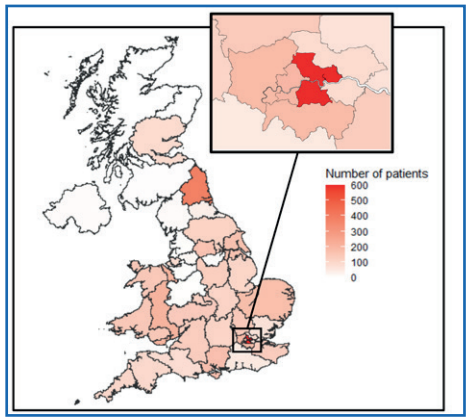
1. Contact Give a Car on 020 0011 1664 or 'http://www.giveacar.co.uk/how-it-works' and say you wish to donate your scrap car in aid of ITP. It takes a couple of minutes to get your details and answer questions. Once they have your approval, a collection agent will call you in order to arrange a convenient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

It is always really nice to be able to update the work of the registry and the team in ITP. We have consented 4850 patients to the main Adult ITP registry, with over 100 sites open to recruitment or following up patients in the registry; 73 patients have been consented to the pregnancy registry. We are open to adding more sites/hospitals to the registry to help boost recruitment even further. Below is a diagram to show the heat map of the recruitment of patients in the UK broken down by regions.



Since the last edition of the Platelet Magazine, we've been busy linking with various academic and research groups to analyse the data from the registry and working on some very interesting projects. Some of this work has been presented in ITP related conferences and academic meetings, such as the ITP Support Association Annual conference; the ITP update day, ASH, BSH and ISTH. We have also published a paper on the 'Incidence of adult primary ITP in England' in the European Journal of Haematology.

As we continue to work on these projects, we will also be expanding the registry to capture data on patients with secondary ITP. This will build on the work that we did last year to collect data on COVID-19 infections and vaccines. Dr Quentin Hill from Leeds Teaching Hospital will be the lead Co-Investigator for this arm of the study.

Thanks to the steering committee teams and support association for funding. 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 https://www.qmul.ac.uk/itpregistry/ and following us on our official Twitter page on https://twitter.com/ukitpr.

Dr Vickie McDonald
Consultant in Haemostasis and Thrombosis, Clinical lead for ITP services
Honorary Senior Lecturer, QMUL

A week in the life of...the UK Adult ITP Registry Data Manager

There are several elements to my role as the Data Manager and Study Coordinator at the ITP registry. The first thing I do each day, however, when I get into the office is check my diary and see what meetings I have scheduled for the day. This helps me to plan around any potential meetings and also prioritise my workload to ensure I am prepared for the meeting/meetings. If an update report or task is required from me for the meeting then I can make sure I have everything ready.

Emails are a big part of any job these days; no matter what the role and so a large amount of time will be spent on email management. The bulk of our emails will be from research staff at various hospitals where the registry is open and they require help with data entry or a study management query. Other times, sites will send us consent forms for new patients and so we have to process these and make sure we update the recruitment information in our local databases. We have over 100 sites open in the registry and so there are many emails to deal with in a given week.

In research, data is an integral part of publishing meaningful papers/articles and so a big part of this role is to review the data that sites enter on our online database and flag up any missing or incorrect data. Sites can then in turn review the flagged-up queries and complete the missing or erroneous data. This task ensures that we have fewer data gaps when it comes to analysis.

Another aspect that I have been spending more time on recently is data cleaning and data analysis. This is where we are looking at a specific group of patients, e.g. patients who receive IVIg or Rituximab, and try and gather all the data related to these patients, such as platelet counts after a treatment, bleeding events observed during the time of treatment etc. This essentially involves, taking spreadsheets of numbers and figures, like pieces of a jigsaw puzzle and putting everything together to give you the bigger picture! There's a whole host of coding, filtering, slicing and problem solving involved – you have to be a bit of a detective and have an inquisitive mind; elementary my dear...! Sorry, couldn't resist!

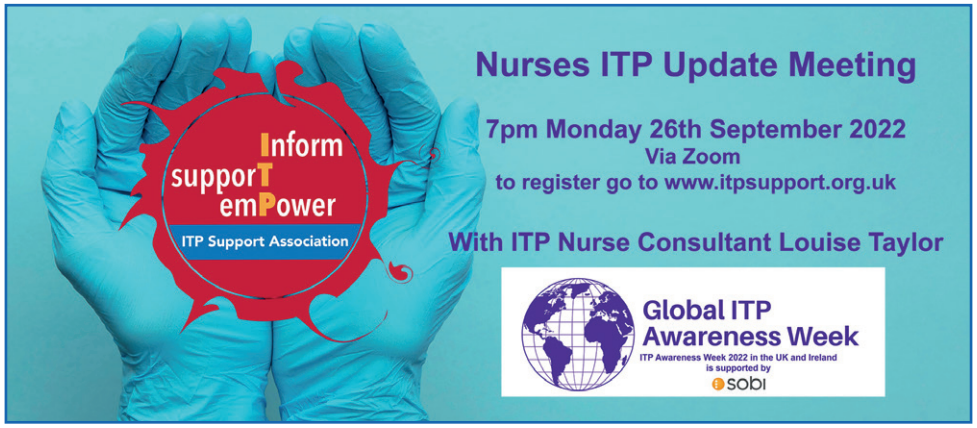
Some of the other adhoc/recurring tasks in this role are things like producing updated reports and charts for progress reports, study management group and steering committee meetings, taking the minutes in meetings, creating newsletters, updating the registry website, filing or maintaining the Trial Master Files and dealing with phone calls. On top of all this, I have to make sure I am on top of any statutory and mandatory training (Good Clinical Practice, clinical governance and health & safety).

As part of the UK Adult ITP registry, we are also collecting blood samples from patients. This will enable us to perform genetic analysis and look for factors involved in the development of ITP as well as disease severity and progression. The research sites will send the blood samples to our laboratory team and I have to sort the bloods samples so that we can send them off for DNA extraction. The DNA contains the genetic information that will help us unravel the mysteries associated with diseases such as ITP.

What I love about my job is that, whilst I may not have much direct contact with our patients, I have an impact on what happens in the treatment pathway of the patients. Ultimately, the work a data manager does, enables doctors, nurses and allied health professionals to continue maintaining the care of a patient without worrying about the admin side of things, so that eventually we can produce guidelines that will better direct these clinicians and regulatory authorities on what choices to make when treating patients with ITP.

Mr. Haroon Miah
Data Manager and Study Coordinator.

NURSES ITP Update Meeting



As part of ITP Awareness Week we will be holding a special virtual meeting designed for Haematology Nurses who have an interest in Immune Thrombocytopenia (ITP).

ITP Nurses Meeting, hosted by Louise Taylor ITP Clinical Nurse Consultant and Mervyn Morgan CEO UK and Ireland ITP Support Association.

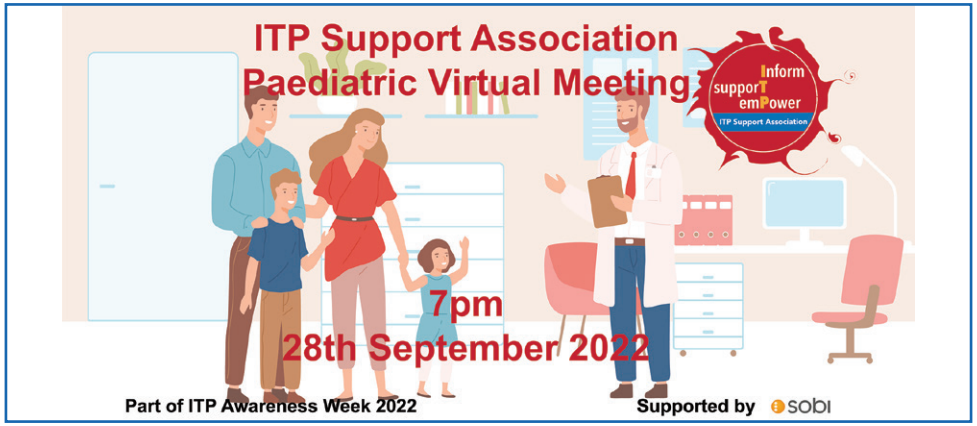
The meeting will take place over Zoom on Monday 26th September starting at 7pm.

The agenda will include the following:

- Introduction to ITP
- Treating acute verses long term patients
- Supporting Nurses giving ITP Meds in Day Units and Clinics
- Shared Decision Making

To register go to: https://bit.ly/3KamGtd

ITP Paediatric Virtual Meeting



The ITP Support Association is pleased to announce as part of ITP Awareness Week, it will be hosting the Paediatric ITP Support Group Zoom meeting at 7pm on Wednesday 28th September 2022.

We will be joined by Dr. Nichola Cooper and members of her team who will be on hand to answer any patient questions. Please register your details and you will be sent a Zoom link near the date to enable you to take part in the meeting.

To register go to: https://bit.ly/3PqQ8w3

ITP Patient Perception Survey 2022

Over the years the ITP Support Association has carried out many surveys covering the subject of Immune thrombocytopenia (ITP). Many of you would have been aware that the association has now established a growing network of Local ITP Groups around the UK. Much of the feedback from local groups has covered subjects ranging from treatment at GP Surgeries or Local Hospitals to fatigue and mental health issues resulting from ITP.

We are now inviting feedback from ITP Patients about the level of care received and perception of how ITP affects daily life. Your answers will be kept confidential – only the result summaries will be published.

This survey has been sponsored by Sobi. Sobi had no editorial control of the preparation of this material, and the content, views and opinions expressed herein remain those of the authors.

To complete the survey please click on the following link: https://www.surveymonkey.co.uk/r/ITPSAPPS2022

The UK & Ireland ITP Support Association Academic Scholarship Programme

The ITPSA has been providing ITP patients and family members with reliable information and support through its many channels (website and social media), publications, regular patient meetings and annual conferences. During these difficult times we realise that many ITP patients and their families are finding it a struggle financially whilst living with a chronic disorder, which is why we at the ITPSA have launched its scholarship fund. We also believe that education is the key to success.

Who is Eligible for the Scholarship?

Awards are restricted to Sixth Form students, current College or University students, or adults who have gone back into full time education (as of September 2022) who have ITP (Immune Thrombocytopenia).

How to Apply?

Please provide an 800-to-1000-word essay which details how your ITP has resulted in your growth as a person; what you learned about your own strengths and weaknesses. Tell us about your ITP Journey. Please note the winning entries will be published in the Platelet Journal and on the ITP Support Association website and Social Media Channels. Applications must be submitted with the application form and emailed to info@itpsupport.org.uk.

If you feel that having a chronic illness such as ITP has helped you choose a career path, describe how, and explain why you feel this way and what you have done to meet these educational goals. Explain what your plans are for the future in meeting your educational responsibilities, in light of your struggles with a platelet disorder.

https://bit.ly/3Taqize

Angela Smith – An ITP Journey

(First published in March 2021)

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

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

Not so! Fast forward to 2004, six years later. Suddenly I noticed the tell-tale rash on my legs. I have no idea of the cause of my relapse. Could it have been that it was around the time my husband was diagnosed with cancer? I would be interested to know if a diagnosis has ever been related to stress. So, I was again having Prednisolone and again each time when it was decreased my platelets dropped. Eventually the platelets stayed up and I appeared to be in remission once more. I can't quite remember the exact timing, but this lasted for two or three years. Then the platelets were down again and this time nothing seemed to help for very long. At one time I experienced being an inpatient in a Spanish hospital which was interesting, the care was excellent.

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

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

ITP Story by Chris Hart

Hi my name is Chris Hart I am 66 years old currently living in retirement in Cornwall. My story starts back in 1995 when I noticed my body was covered in bruises and blood spots, a day later I had started to bleed from my gums and nose. My wife took me to our local hospital where they gave me blood tests and told me my platelet count was 1. The Dr's then took a bone marrow sample from my sternum to check for leukaemia this showed a healthy production of platelets

After numerous people coming in to look and take photos for the records (there apparently there had never been anyone with a platelet level of 1 in the hospital) by this time my mouth was covered in blood blisters. The decision was taken to give me high dose steroids and admit me to the ward. After four days of steroids my count was still 1. They then decided as the steroids had no effect they needed to give me plasma this was administered via a cannula over 5 days one bag per day. This seemed to have the desired effect and my levels increased to double figures I think high 30's

On the 10th day I was discharged from hospital having been told by the Dr they think it was ITP the I then being idiopathic and if it happens again like this get yourself to hospital. The downside of the steroids was it induced diabetes which I have had ever since.

In the following years on many occasions I would bruise easily or suddenly see blood spots on my arms or legs but didn't do anything about it as it wasn't as bad as that first time and usually disappeared after a few days .

Roll on to June 2022 I awoke to find my body again covered in bruises and blood spots, I had a blood test at my local surgery and within 12 hours had a call to get down here asap. My platelet count was 3 The haematology dept had contacted my GP and told him to give me steroids immediately I explained last time 27 years ago they had no effect but he said this is what he had been told to do and I was to report there in the morning unless I felt I needed to go to A&E if I had any bleeds.

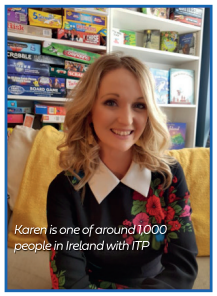
That night I started to bleed in my mouth so got my wife to drive me to hospital after a wait of an hour I was seen by a triage nurse who I saw googling ITP. I was then fast tracked onto a day ward where my bloods were cross checked for a plasma infusion. Just as the plasma was being set up a Dr and nurse from the haematology dept came rushing in explaining we don't do this anymore we look to treat the cause not the symptoms. I spent a few hours whilst more bloods where taken they came back with platelet level at 1. I was given a course of Eltrombopag and sent home to come back two days later. These drugs were giving me horrible side effects, nausea, dizziness, itchy skin and fatigue. On returning for my next appointment my level was still 1 they wanted to up the dose but I said I wasn't happy to do that so the suggestion was to try an injection Nplate (romiplostim) this was given on Fri 24th June, it's now Sun 26th June and I'm sitting writing this hoping my levels go up on this drug.

The one positive out of all this is that there is much more knowledge and options available than being left for 27 years with no support even though it shows on my medical records from 1995.

Chris Hart

'Chronic illness is a lonely thing' by Karen Tomkins (First published in December 2021)

For the past year I religiously text my husband, Shea, every Friday afternoon. There's nothing unusual in that, but the weekly message contains just a number, no words. Triple digits and we're happy; single digits and it's time to get family in to mind the children and pack a bag for hospital.


Karen is one of around 1,000 people in Ireland with ITP

The number I text is my platelet count. I am one of approximately 1,000 people in Ireland with ITP (immune thrombocytopenia), a rare blood disorder in which the immune system mistakenly attacks its own platelets. It can occur in pregnancy, follow a virus, vaccination, or certain medications, but for most people the cause is unknown.

I learned about the importance of platelets in my first pregnancy, in 2007. As the Syntocinon drip unleashed contractions from hell on this novice labourer, I remember the midwives telling me that I only barely made the threshold for an epidural with a platelet count of 80 on the day. It meant absolutely nothing to me; I got my epidural and my baby boy, Jack, now heading for 14 years of age.

My gestational ITP was confirmed earlier on in my second pregnancy, in 2010, when my platelets fell into the 30s. A normal platelet count ranges from 150,000 to 450,000 platelets per microlitre of blood. This is usually referred to by the first three numbers 150 - 400. With ITP, a "watch and wait" approach is often adopted by haematologists when a patient's count is between 100-50 and often down to 20-30. Mild bleeding and bruising sometimes occurs when the count is less than 50.

The risk for serious bleeding doesn't occur until the count becomes very low – less than 10. Internal bleeding and a bleed on the brain are the biggest risks at this point, which can be fatal. The UK's ITP Support Association lists blood in the eyes, bleeding from the ears, blood in the urine, bleeding from the gut and a bleed into the brain (in a small number of cases) as severe symptoms of a very low count.

Thankfully, the ITP in that second pregnancy was managed with immunosuppressant Prednisolone steroids throughout. I had another epidural and another baby boy, Harry.

As predicted, the ITP went away and as predicted, it came back again on my third pregnancy, five years later. I began to take a high dose of steroids at nine weeks as my platelets were already hovering at 30.

Christmas morning

Announcing the happy news at 12 weeks was quickly met with despair.

Christmas Day 2015 at our Co Wexford home: Santa had been and gone and the boys, aged eight and five, were deep in an ambush of new Nerf guns. I smiled through their excitement but couldn't ignore the bleeding I had noticed when I went to the toilet. But what does a pregnant mother do on Christmas morning when it looks like the inevitable is happening? In between carving the turkey and greeting family, the bright red blood was hard to ignore. But it only happened when I went to the toilet and my mouth and lips were filling with black blisters. I sneaked upstairs to phone the midwives on the University Hospital Waterford labour ward. No cramping, no clotting, no blood apart from in the toilet. "Keep an eye, it could be spotting. Come straight in if it gets worse."

It's hard to find anywhere to go on St Stephen's morning when you're killing an hour waiting for the phlebotomy department to process bloods. But I didn't have to worry. We weren't far from the hospital when their number flashed up on my phone. "Are you close by? You need to get back straight away. Your platelet count is at 1 – this is really serious, Karen."


Karen recovering from spleen removal surgery at The Dunmore Wing, UHW.

Under the care of haematologist consultant Prof Ezzat Elhassadi, I was given a platelet transfusion and started what would become countless rounds of intravenous immunoglobulin (IVIG), a type of antibody treatment, extracted from the combined plasma of more than 1,000 screened blood donors. It's given intravenously over a few hours. On a non-medical note, I can tell you it comes in a cute little glass bottle. Not so cute when you need 3½ glass bottles every time, which took up to eight hours.

Dangerously low levels

My unborn baby was thriving, but my ITP was still dipping to dangerously low levels. Surgery to remove my spleen and a medical termination were mentioned as treatment options. The pregnancy was causing a risk to my life if my platelets plummeted and couldn't be feasibly increased. It is said that the eye of the storm is often the calmest place to be, and that's where I, my husband and my baby stayed. My own multidisciplinary team of family, friends, neighbours, and the parish priest were all working around the clock helping us out at home.

In March 2017 I woke up with a blinding headache, a body of bruises, a mouth full of blood blisters and a platelet count of 1

I became a regular at the oncology and haematology day ward for weekly, sometimes fortnightly rounds of IVIG along with tapering off steroids. The treatment and the prayers worked and at 36½ weeks, consultant obstetrician Dr John Bermingham persuaded my beautifully healthy little girl, Daisy, to make her appearance.

Unfortunately, my ITP journey didn't end there.

In March 2017 I woke up with a blinding headache, a body of bruises, a mouth full of blood blisters and a platelet count of 1. In the four years that followed, it was apparent that I had progressed from gestational to chronic ITP. A bone marrow biopsy didn't show anything sinister – just bad blood which I had to accept and learn to live with.

I've seen a lot of Prof Elhassadi and his team since then. We've worked through many different treatments from steroids, new high-tech drug Eltrombopag to four rounds of a biologic called Rituximab and Mycophenolate (also used to stop the body rejecting organ transplants) – some of which I lost my response to, while others caused unpleasant side-effects.

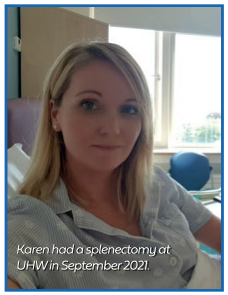
I returned to work as a news broadcaster, incorporating my haematology outpatient appointments as a way of life. When my platelets dropped, I'd go back on steroids and then taper off them slowly. The longest stint of taking them was for 10 months in which time the biggest side effect was steroid "moon face" and tighter clothes.

I'm grateful for the fact that despite having my platelets at "life-threatening" levels, I never experienced the awful stuff I find on Google at 3am when I can't sleep

Covid lockdown was worrying but my platelet level stayed above 100 without any treatment throughout. I'd like to think it was in part due to the chakra rebalancing I had done by a faith healer. I've drunk oceans of beetroot juice and papaya leaf extract, I've tried a plant-based autoimmune protocol diet, I've touched a relic of Padre Pio, I've boiled up Chinese herbs that stank the house out, I made my husband rearrange our bedroom to move us out of a geopathic stress vortex and I meditate and run every day when I'm well. And still, regardless of what I do or don't do, ITP has always found me again.

Begin treatment again

Last August, I got a phone call from the hospital just after I read the main lunchtime news on WLRfm. Not quite headline news, but my platelets were at 17 and it was time to begin treatment again. This time, I opted for N-plate – a weekly subcutaneous injection of Romiplostim administered in a day ward at UPMC Whitfield hospital in Waterford.


Karen had a splenectomy at UHW in September 2021.

For more than a year, I devoted every Friday to getting this injection, which is a two-hour round trip and a day chalked off my calendar. While Romiplostim has had varying degrees of success, I found it very inconsistent and although I can't attribute the onset of frequent ocular migraines and severe joint-pain as direct side-effects, my quality of life slowly diminished. My recent 40th birthday fell on a Friday – injection day – sweetened only by the kind gesture of chocolates from the day ward staff.

Twenty-four hours after receiving the Moderna Covid vaccine in April 2021, my platelet count was back at 1. It stubbornly rose and I let go of my stubborn refusal to consider a long talked-about second line of treatment – splenectomy. In people with ITP, the immune system treats platelets as foreign and destroys them. The spleen is responsible for removing these damaged platelets and so, in about 70 per cent of cases, removing the spleen can help to keep more platelets circulating in the body.

I'm grateful for the fact that despite having my platelets at "life-threatening" levels, I never experienced the awful stuff I find on Google at 3am when I can't sleep. However, chronic illness is a lonely thing and I'm guilty of masking my pain, fatigue and worry with fake tan, gym leggings and a smile. It forced me to give up working full-time as a news journalist, although it helped me to find my real passion as a children's creative audio writer, for which both my radio series won IMRO awards, in 2020 and 2021.

Antibiotics for life

On September 9th, I took my 70 per cent chances and Prof Fiachra Cooke laparoscopically helped me bid farewell to the little organ that I might be better off without.

"It's not you, it's me," I whisper to the empty space in my upper left abdomen which used to house one of the chiefs of my immune system. In

Karen after winning an IMRO award for her work in 2020

its place I've had all necessary vaccines and will have to take low-dose antibiotics for life.

One-week post-surgery saw my platelet count rise to 783. This dropped to 45 after a month, but it climbed again without any intervention and today my platelet count sits at 100. It's still early days and I have other treatment options if this doesn't work in the long term. But for now, I have high hopes, a high platelet count and no bad blood.

This article was first published in the Irish Times and has been reproduced with the kind permission of Karen Tomkins.

ITP – An Invisible Disability? By Susan Weall

I have learned so much in the last 18 months since my surprised diagnosis of ITP in February 2021. Thanks to the ITP Support Association for two virtual conferences and some Zoom Forums over the last 18 months to provide more information.

Probably like me, if you have ITP, your platelets continually fluctuate, sometimes when you expect it as you do not feel well, and at others, unexpectedly when you feel the best you have done for weeks.... You do learn to slow down and to try to avoid planning too far ahead, particularly on post treatment days. I have found this so hard as although I am now retired, I had jobs where my project planning and implementation skills have resulted in changes in people's lives. Sitting back and seeing how a day/week will go and that I can do little to change the outcome has been challenging. The unpredictability frustrates me, but I am learning to be thankful for the good weeks/days.

My ITP was triggered by the Astra Zeneca vaccine in Feb 2021 when little was known about this reaction. Loss of energy, black mouth blisters, small spots on my torso, was not as I first suspected shingles after a family bereavement, and long months of caring. I am so thankful that my GP asked for photos after a phone consultation and speedily organised blood tests, that resulted in emergency hospital admission within hours, with a platelet count at 5.

My husband could only drop me at the hospital entrance, and then I had to try to explain to him by phone what was happening when I understood so little myself. Nose bleeds that would not stop and ENT interventions, that I would rather erase from my memory. Wide awake nights after high steroid doses, various treatments to help me gain some stability, slowly increasing platelet numbers, as I started to grapple with the life implications of ITP.

My platelets initially recovered, then dropped as steroids were stopped. I started Eltrombopag but after a few doses I was admitted to hospital with heavy nosebleeds, and more ENT treatment, more successful this time. I was started on Romiplostim Easter 2021 whilst in hospital, Progress was enough for me to have Pfizer as my 2nd vaccination in May. Side effects of Romiplostim from my tiny dose gradually became more intense but my platelets dropped after a few months and the dose was increased. Weekly hospital blood tests and appointments for Romiplostim injections became a way of life. My husband walked round a local park each time, with a habitual coffee stop that changed to an ice cream stop as the months continued. He was released from this when I was well enough to drive myself for the 10 miles round trip. Again, I am thankful for my local hospital team looking after me. I did manage to have a 3rd vaccination in November.

It began to feel like an ongoing 'rinse and repeat' cycle with my weekly platelet score the first thing friends and family asked. They said things like 'how many weeks do you need to have the injections?', 'why can't you do what you did last week, you had more energy?', 'Is it cancer?', 'When will you be cured?', 'Just take it easy and you will be better', 'You are on week 75 of injections? etc etc and the hardest one 'But you look so well this week, how come your numbers are so low?.

After 6 months on Romiplostim, with continuing side effects etc, my consultant haematologist at Poole referred me to Dr Nichola Cooper and her team at Hammersmith Hospital, Imperial College Healthcare NHS Trust. This was so helpful to myself and my husband to meet an ITP specialist face to face as all my local appointments were by phone. That first appointment in January 2022, gave me confidence both in travelling post pandemic to London from Poole in Dorset, and that I was on the best treatment for me at this stage of my ITP. After my 2nd appointment in London, I agreed with the Poole hospital team to move to self-administration of Romiplostim.

Whenever I start to hope that my platelets are reaching a level approaching and just over a 100, and with this the possibility of increasing the time between injections or the level of dosage as I am sensitive to the Romiplostim. I then get a rogue week of low platelets and the uncertainty returns. So, the balance of life shifts again but I am thankful for my team of medical support and the NHS. Now to face the 4th covid vaccination in the coming months but also my first holiday outside the UK.

Sometimes I would like to talk to someone who developed ITP after the AZ covid vaccination, as it came so suddenly and unexpectedly. But on reflection, whatever the circumstances of our initial diagnosis, it is the same for all of us in this select group with a rare blood 'invisible disability' disorder.

Life with ITP- By Rhona Bowie (First published in December 2020)

More often than not, in order to reflect on something, the event or experience in question usually has to be over and your thoughts, and feelings on the matter finalised. However, I must confess that my feelings on this matter are certainly not finalised, nor am I sure they ever will be.

Immune Thrombocytopenic Purpura. By now, everybody reading this knows what ITP is. However, at sixteen years of age, when I got diagnosed, I didn't have a clue. Our bodies attack the platelets that clot our blood, meaning we bleed constantly and freely from everywhere in the body. When it's put like that it seems almost insignificant, merely a trivial cog that has become rusted in the well-oiled mechanisms of our bodies. Although, it's not quite that simple is it?

Hospitals have this unique feeling about them, as if time isn't real and nothing seems quite right. Let's be clear, no one likes spending their time in the hospital, it's eerie and too big and is riddled with sick people. And in the summer of 2019, I became one of them.

After undergoing weeks of stress whilst sitting my lifeguard exam, I finally went to the doctors about the weird rash that was covering me head to toe. Within days I lay in a hospital bed, confused and beyond exhausted, with a needle jammed in my arm ready for a blood transfusion that didn't go ahead. Instead I had to take twenty steroids a day for four days in the hopes of resetting my immune system and to stop my platelet levels dropping below ten.

The hospital practically became my holiday destination that summer and even now, not once, has that eerie feeling that something's not quite right left me every time I enter the hospital that I have become so well acquainted with. By the time that you're reading this, it will have been around a year and six months since my diagnosis. And I must admit that at the grand age of seventeen that still sounds like a tiresomely long period of time and to be truthful these past months have felt that way too. It's a hard concept to wrap your head around. That the world cannot stop and wait for you. That everyone around you will continue to move on, without you. It was a painful revelation as I lay in a stuffy hospital room with the sunlight glaring through the windows. Why did no one seem to understand that life had thrown me this curveball when I hadn't even learnt to catch yet? My ITP diagnosis forced me to come to the realisation, one I'm certain we all have at some point in our lives: that life does not stop to wait for you and the world continues to turn.

Anger. It's a word used so frequently to describe a feeling of mild irritation that sometimes we forget how it really, truly feels. But now I can remember. How overwhelming it is. To feel anger behind everything that you do. Anger pooled in the deepest pit of my stomach, through my arms and legs, deep in my bones. First, anger at myself, at my body for letting me down at such an early stage in my life before it had truly even begun. Second, anger at the world that it kept on spinning when my own world felt like it was crashing and tail spinning into darkness. Finally, anger at everyone else. That they got to carry on, complaining about mundane everyday inconveniences. If I'm being honest, which is a challenge in itself, my view on the world changed. And not in the classic coming of age movie scene like way. I was bitter, more negative than I have ever been in my life. My patience and empathy were dwindling, things that I had always relied upon to keep me sane. Which only made me feel worse. I knew it wasn't a sound outlook to have: that I had some sort of right to feel the way I did, as though my problems were greater than everyone else's. It's challenging, to admit to yourself, let alone someone else, the

selfish thoughts you have but I know that that is only part of the process. Of grieving the person, I was and accepting this new version of myself.

It doesn't take a genius to come to the conclusion that there is an endless list of issues in the world. Poverty, homelessness, murder, pollution, famine and disease. And that barely scratches the surface. So why was it okay to feel as though the world owed me something? As if having this illness deserved some sort of explanation as to why? Why me? Why this age? Why this particular disease? All the cliche questions. As though every single other person in the world was not also fighting a battle of their own, many far more extreme than mine. So, is it okay to feel so hard done by and kicked to the curb by life, when other people's problems can be considered as far worse? I struggled with this concept for so long, and this is where my earlier confession reveals itself, as I still have not discovered the answer to this question. Some days my head feels calm, the tide is low, the waves slow and methodical and the sun shines. And on these days I feel like I don't have the right to complain at the cards I've been dealt, at the sheer idea that I've been robbed from a fuller life. Then, there are the days where the tide rises, the waves are high, crashing against the rocks and the sky turns bleak to match my outlook on the world. It feels so incredibly unfair to be stuck with this illness and to have no explanation as to why. However, I've realised as I'm sure most people do, that unfortunately, sometimes life is just unfair, and we have to learn to run with what we've got. Which is what I do. I'm hopefully to continue my studies at university in addition to carrying on my competitive swimming.

Hope. An exceedingly dangerous emotion. It can be the only thing in the world that keeps a person going, propelling them through life and without it, we are lost. It doesn't seem right that it can be stripped away in the blink of an eye. For me it was the word "chronic" being uttered from the doctor's lips. Although I must admit my hope of going into spontaneous remission was dwindling at each low blood result, it was still there, clinging to every fibre of my being. So to hear my worst fear confirmed, that in fact my ITP was here to stay, for the rest of my life, with no cure and nothing to help it was definitely a kick to the stomach. I think that maybe it's difficult to reflect upon and find the answer to my burning questions because the reality has not yet hit me. That I will have this autoimmune blood disorder for the remaining years of my life on this earth. And here comes the kicker, I still don't think I have it in me to regret my illness. Initially, as I'm sure is obvious from my diary like confessions, there was a less than positive change in myself but one that was necessary nonetheless. There is a definite process, one that after you are crushed as a person and are sitting alone questioning the meaning of life itself, one must go through. Although the thing is, this process is forever ongoing, reflections forever changing and yet the world forever turning. So, I'm certain that in another few days, few weeks, few months and most certainly few years my reflections will have shifted. But for now they are as follows; life can be unfair and the sooner we realise that the better, anger is an ugly emotion but one that is occasionally necessary to move on, good days and bad days are valid and must not be underestimated and finally, hope is an emotion that we could not, and should not, live without.

My ITP Journey by Paul Stacey

(First published in March 2021)

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

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

I eventually left hospital on my 55th birthday and the next stage was to discover what had caused the haemorrhage. I was sent to the haematology department of my local hospital and after more tests (including a bone marrow biopsy) I was finally informed that I had ITP. The platelet level had become very low and had not been able to repair the bleed as would normally have been the case. It was a relief to finally discover what had caused the problem although I had no idea what it was and how it would affect me. I took the steroid Prednisolone for a while, which had the desired effect of raising the platelet count. However, the count fell as soon as I was taken off them and I was not keen on the side effects. The haematologist then prescribed Eltrombopag and I have been taking it ever since. My platelet count is checked following my monthly blood test and my average count is currently 92. Fatigue is the most significant side effect of the condition and this was quite distressing in the early days.

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

My ITP Experience by Ian Salter

(First published in March 2016)

At the time I first was diagnosed with ITP I was a sixty-four-year-old male, newly retired and enjoying living part time in Cyprus and part time in the UK.

I was in Cyprus when I noticed bruises on my arms and legs. I thought it was due to over enthusiastic DIY, but the bruising persisted and on my return to the UK I rang up my GP. She suggested a blood test. I offered to ring the health centre on the following day to arrange an appointment with the nurse. Instead, the Doctor wanted to know how quickly I could get to the surgery as she wanted the test done straight away. This started alarm bells ringing. Our health centre doesn't do immediate appointments.

As the nurse was taking the blood the inside of my arm from elbow to palm turned black. "How long have you had that" she asked, "only since you put that needle in" I replied. She rushed off to get the Doctor.

I was sent home to await the results of the blood test and two hours later received a phone call from the Doctor. "Your platelet count is quite low, and we want another test to confirm it. We would like you to go to the hospital straight away for another test". By this time, I was becoming very suspicious, should I take an overnight bag I asked, "Yes just in case" was the reply. Doctors are the masters of understatement.

On arrival at hospital, they showed me to a bed, I wondered why I needed a bed for a simple blood test, but all became clear. They took the blood and shortly after that a doctor arrived, He explained that in a normal person the platelet count is between a hundred and fifty and four hundred and fifty, mine was three. I was to stay in bed and not go anywhere as a fall could cause a haemorrhage. Luckily, I did not need the loo.

A nurse arrived and connected me to a drip that gave me intravenous platelets and I began to resign myself to a long stay.

I spent the following week in a medical assessment unit undergoing numerous tests which happily ruled out things like leukaemia and prostate cancer. Finally, the doctors told me that I had ITP. "IT-what" I responded, I had never heard of it. Nearest thing I had suffered from was PMT and that was second hand!

They gave me sixty milligrams of prednisolone per day with no mention of the side effects, but a promise that when my count reached twenty, I could go home.

I started to learn some of the side effects of steroids. When some friends visited me, they kindly left an enormous bar of chocolate, one of those Cadbury Dairy milk things that are about a foot long. The following day when they called, it had all gone.

Lesson 1: Steroids affect your appetite.

We were due to move house in two weeks and between hospital visits, my wife heroically organised removal men, packing and contacted numerous utilities whilst I was unrealistically relaxed in hospital, feeling quite high.

Lesson 2: Steroids affect your mood.

After a week my count had reach fifteen and the doctors decided I could go home on the strict understanding that I did not lift or do anything that could risk injury.

Not easy when you are moving house.

The family rallied round and came over to do the final packing and get us moved. For a laugh my grandchildren made me a suit of bubble wrap to protect me during the house moving. I began to suffer from cramp in my legs and my hands would go into spasm causing me to drop whatever I was holding. Lesson 3: Steroids cause muscle cramps.

I was treated as an outpatient in the care of the haematologist at our local hospital and over the following three months my count rose to one hundred and fifty, whilst the steroid dose was reduced. After a year the steroid dose was down to one five milligram tablet every other day but within a month my count had fallen to fifteen.

Over the next five years I was given numerous treatments. Cyclosporin had a marginal effect on my count and my kidneys began to suffer so that treatment was stopped.

Rituximab (low dose) combined with steroids maintained my count at about fifty for several months until the steroid dose was reduced to five milligrams per day at which time the count fell.

Mycophenolate had little effect on my count which remained in the twenties. Intravenous immunoglobulin caused a bad reaction with flu symptoms and high blood pressure.

In Aug 2010 I was given a larger dose of Rituximab combined with steroids. This raised my count to one hundred and fifty. The steroids were gradually reduced and in June 2011 were stopped altogether, by August my count had fallen to twenty-nine.

Splenectomy was suggested, I was told there was a seventy percent chance of success. I agreed and the operation took place in October 2011.

Initially my count rose to over four hundred but once I stopped taking steroids it fell and by January 2012 it was at thirty and the haematologist concluded that the operation had not worked, so back on the steroids.

I was referred to the specialist at Manchester where I was subjected to numerous tests.

Dapsone was prescribed for two months, whilst reducing the steroid dose, however once the steroids stopped my count fell rapidly.

In October 2012 my count was sixteen and I was taking steroids when I started injections of Romiplostim. Within nine days my count had risen to six hundred and thirty-two and the steroids were stopped. Over the next twelve days my count fell to four and the steroids were restarted.

This up and down pattern continued for the next three months with my count reaching over six hundred following each injection but then falling to single figures.

This finally stopped in March 2013 when the rate at which my count fell eased and it levelled off at about two hundred and fifty where it has remained ever since, without the need for steroids or Romiplostim.

Hopefully, (it is not easy to type with your fingers crossed) this remission will continue.

So, if doctors tell you that there is no cure for ITP they may just be wrong.

My ITP Story by Linda Willis

(First published in June 2016)

When I was first diagnosed with ITP it was August 2010, and I was 62 years old. Whilst on holiday in Italy I noticed a lot of bruises which I put down to clumsiness, and bleeding gums which I thought was a dental problem.

When back home I went to my GP for a routine blood test form for the blood pressure medication I was on. Having had the blood taken, we set off on the bus to do some shopping and had a pub lunch. When we got home there were numerous answerphone messages asking me to contact the surgery at once. A very concerned GP said my blood results needed to be repeated, and that I should go immediately to the Haematology department at the local hospital who were expecting me. It turned out that my platelet count had been 1, and was the same when repeated.

I was told not to move too much and admitted to hospital. I was started on Prednisolone, and after a bone marrow biopsy which confirmed diagnosis, I was discharged 5 days later with a count of 7.

I was monitored as an outpatient every few days and then weeks. My response was good at first, although I was awake most of the night, was permanently ravenous and started to gain weight.

In January 2011 I relapsed, so treatment changed to Azathioprine with a poor response. This was followed by Dexamethasone but I couldn't tolerate the side effects. I then had intravenous Rituximab.

By November 2013 my platelets were still low, with bleeding, and I had gained over four stone in weight. It was suggested that I take one of two options – splenectomy, which I declined, or Romiplostim. We had a couple of lessons from the Nurse Specialist on the injections and began doing them at home, my husband becoming very skilled at preparing and administering.

It took a lot of ups and downs and dosage adjustment but I now have 500mcg every 6 days. We had to buy an extra fridge to accommodate the supply of Romiplostim! It is not without side effects – headache, muscle and joint pain – but these are usually only for 24 hours and can be relieved with strong painkillers.

My count is now 10-20 at it's lowest point and 30-45 at best, although this may not be entirely accurate as manual examination of my blood film showed some large platelets, and these are unable to be counted by the analysis machine. However, I am symptom free and able to enjoy life.

European Update by Derek Elston

Lockdown due to covid has eased and there has been a resumption of face-to-face conferences both here in the UK and abroad. Europe is no different and two conferences organised for the European Haematology Association (EHA) and the Protein Plasma Therapeutics Association (PPTA) were scheduled. We are stakeholders in each and have for many years, played an active role therein and attended their conferences. Like many organisations, these two important organisations did not wish to delay their conferences any longer than necessary and both chose June as being the right month to meet. Thankfully, they did not clash with the dates but only by a day in-between one finishing and the other starting. EHA organised their face-to-face congress to start on the 8th June in Vienna, finishing on the 12th with the hybrid or virtual presentation from the 15th – 17th June. PPTA commenced the evening of the 13th June in Berlin! With some careful planning and thanks to Austrian Airlines, who were excellent, we managed to make leaving one and arriving at the next, on time – just but sadly missed the virtual.

European Haematology Association.

This important event in the European haematology calendar was as ever, an interesting event even if being smaller than normal. We estimated that the normal 12 – 15 thousand delegates were reduced to around 7,000 but the number of presentations for all the various conditions was still impressive over the course of the congress. These totalled 160 plus poster presentations. The following week the virtual presentation amounted to a further 66 on the 15 – 17th.

We were pleased to meet Drs Nicki Cooper, Maria Scully and Sue Pavord at congress. Drs Cooper and Scully made presentations on ITP and TTP respectively. Both were research related to the two conditions and were sponsored by the scientific working group of EHA. In addition to these, there were several presentations relating to platelet disorders not necessarily related to ITP.

The patient organisation held four joint symposiums during congress and considered Diagnostic Regulations: Fair pricing of orphan drugs: Personalised medicine trials and Bureaucracy in clinical trials: Regulating Innovative Therapies. All sessions were very well supported and whilst they were directed at the market in Europe, much was relevant within the UK.

The board of EHA is extremely progressive. The chair, Prof. Elizabeth McIntyre haematologist from Paris, and immediate past president Prof. John Gribbon from London, together with a succession of other former presidents and board members, have over several years, promoted the role of the patient in being involved with clinicians. From the early days of only one person being involved representing on condition, to now 14 representatives for 14 conditions, we have formed a structured committee which has been approved by the EHA board and is now a formally recognised committee within this organisation. The inaugural meeting was held in Vienna and your truly was elected chair of this committee with Vice Chairs Dr.Androulla Elefthera from Nicosia and Zak Pemberton-Whitley from Worcester.

Protein Plasma Therapeutics Association June 13 – 16th Berlin.

This is an international organisation with their head office in the States with other offices in Tokyo and Brussels. I have been the representative for ITP in Europe for several years. It is primarily

an association for the manufacturers of equipment used for the collection of blood products and advocating for the advancement of safety regulations for organisations both manufacturers and also companies that use the equipment to extract and separate the blood products. The congress is named the International Plasma Protein Congress. This year they had an attendance of just under 300 from industry, medical practitioners, nurses, and professional organisations particularly IPOPI (The International Patient Organisation from Primary Immunodeficiencies)

Interesting that this year was focused on the severe shortage of plasma worldwide. The USA is the major supplier for the rest of the world and thanks to the changes is allowing Mexicans to enter USA to donate for a fee, the USA's production has slumped, and this has affected the rest of the world. PPTA are active in negotiating with the American Gov. to change this back.

I had the opportunity to meet Gerry Gogarty who is the plasma Programme Director for the NHS who have for some 18 months been collecting plasma for fractionation and production of plasma products including `Ivig' He made a remarkably interesting presentation on the UK situation and how it is growing. His talk was followed by David McIntosh from United Kingdom Plasma Action who was interesting. He was a director of the NHS in Glasgow for many years.

You will all have seen the adverts in the Platelet asking for more donors. It is especially important to access more plasma to meet the domestic demand from many immunodeficient conditions, various blood disorders and mental therapy. It raises the question of whether the UK should permit an independent regulated industry with paid donors to supplement the NHS production

The EU are now in agreement for compensation to be paid to donors to regulated organisations and follow the United States. Each country within the EU will be able to decide their own lever of payment. Germany is one country that already has a payment scheme. There are others.

At the IPPC there is always a PLUS meeting which is a platform for protein users. This is a consortium of seven patient organisation of which we are one. This organisation represents people living with treatable rare plasma related disorders such as haemophilia alpha-1 and immunodeficiencies among others like ITP. The steering committee comprises Johan Prevot of IPOPI; Brian O'Mahony, CEO Irish Haemophilia and Frank Willerson, Alpha-1 Belgium.

The meeting discussed the shortage of plasma and agreed that representation needs to be made continually to respective governments to provide for an increase in production of the various plasma products.

Being A Patient Mentor by Rhonda Anderson

The idea of having members of the ITP Support Association supporting other ITP patients, was instigated many years ago. Our founder Shirley Watson MBE, saw the need for patient to patient dialogue.

Although we are not allowed to give medical advice, Mentors have lived experience of ITP, and the impact it has on the patient and their families and carers.

The annual Conventions brought ITP patients, families and medical experts together to learn more about ITP, in a safe and friendly, open environment. The overwhelming consensus was the value of talking, asking questions and receiving support, especially from the medics, who had the answers that were currently available. Many patients were very reticent to speak to the doctors, but with some encouragement they did, and found much comfort in the information conveyed and how much doctors wanted to be involved and help.

Following this success, Shirley asked patient members in various parts of the country, to become contacts for chatting and support. Each one had unique experience, some being the parents of children who had ITP, and it was very helpful for other parents to speak to them.

It was my job to call all these people on the Contact List once a year, to see how they were going, and chat about their experiences and see if they wanted to continue. We owe a debt of thanks to all those initial members who helped in this very important way. The system was changed and we now have fewer people and somehow our title has become Patient Mentor, which is an improvement on Contact List!
Doctors are not always available and that is where Patient Mentors come in. We are available not only on the phone, but also on email, at any reasonable hour. We usually hear from patients in a flurry after the sending out of the quarterly journal, The Platelet.

All sorts of queries come up and with our experience we can listen, talk, reassure and answer many questions. Phone calls can last more than an hour and patients are always pleased to have a listening ear, and feel very grateful to unburden their worries, and ask what they see as simple questions, they do not want to bother their doctor with. Sometimes we realise that patients need further expert medical input, and we can refer them onto our medical advisors for the all-important medical advice or referral to a Centre of Excellence hospital.

Our advisors are unstinting in giving their generous time and information to support patients. We are very thankful for their input to the ITP Support Association. We know they love talking to patients and helping them. Some say this is the best and most rewarding part of their work.

One of the ways support and self-help has happened over lockdown, has been the Zoom calls. These are an invaluable arm of the Associations support network with doctors attending. Patients support and inform each other too. Dates are published on the website.

Patients themselves are in the unique position of having the condition, whereas the clinician treating them is without that experience of living with it, and all that entails for physical, emotional and mental health.

One Mentor has medical knowledge and she has been very helpful to people who ask her about that, and her own experience of the treatments she has had. That gives her a unique insight and special satisfaction in helping patients, using her own lived experience.

How can we help you?

Another Mentor encourages you to get in touch. We are always available to lend an ear, pass comment and hopefully put minds at rest without providing medical advice.

We know what it is like getting the diagnosis of ITP. This can be very difficult for patients and families and friends.

We are able to help patients on their journey and enable them to feel less isolated.

We know the side effects of treatments and are able to discuss with patients steps that might ameliorate them or how to discuss with their clinicians, so that they can have a better quality of life.

We are able to convey that there are different treatments out there and that it is possible to get a referral to a Centre of Excellence.

We are able to convey a positive attitude towards the disease and ways to cope. Passing on the knowledge that we are all different in our presentations and reactions to treatments.

Between ourselves Mentors get support from the other Mentors and the Association and the Doctors. Zoom meetings have meant we can put a face to them and to patients too. Face to face contact, even if on Zoom, is very valuable.

In addition other support groups can mean a lot to us, so we appreciate that ITP patients may also take comfort knowing they have a friendly ear, away from their hospital or family settings to discuss their disease.

In conclusion, Patient Mentors are very pleased to help patients. It is a source of satisfaction and privilege to be able to speak to you and reassure you.

Here is the list of ITP Support Association Patient Mentors.

Rhonda Anderson, Karen Smith & Derek Elston

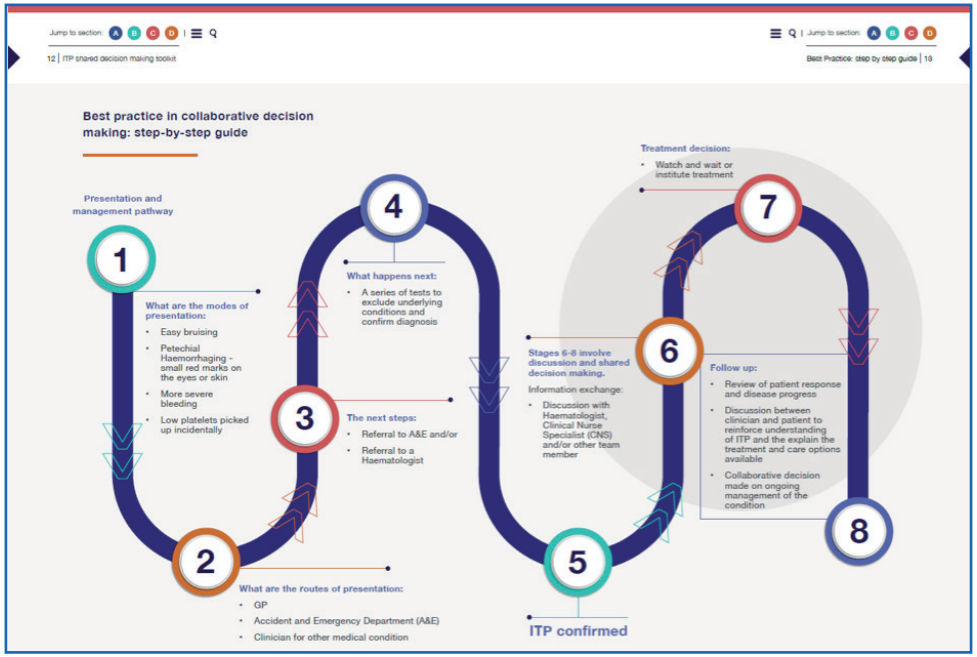
PATIENT MENTORS

Rhonda Anderson
Tel: 0208 504 2688
E-mail: rhonda.anderson@virgin.net

Derek Elston
Tel: 0151 625 8213
E-mail: derek.elston@itpsupport.org.uk

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

Shared Decision Making Document available in Six Languages



'Making the right choices in ITP management and care' – A shared decision-making toolkit for patients.

To download the English Language version click this link: Making the right choices in ITP management and care.

The toolkit is now available to download in French, German, Italian, Spanish and Portuguese please visit our website at www.itpsupport.org.uk.

Ground-breaking new toolkit launched to support patients with rare blood condition to take ownership of their care.

Shared decision-making toolkit developed for people with Immune Thrombocytopenia (ITP) - a rare autoimmune blood disorder that causes a shortage of platelets and bruising.

Toolkit developed via a multi-stakeholder ITP Expert Working Group led by the ITP Support Association and the UK ITP Clinical Forum.

The toolkit will facilitate improved treatment and care by empowering and educating patients – and reminding healthcare professionals – about the importance of ongoing collaborative decision making in the management of ITP.

As part of Global ITP Awareness Week (20-25 September), the ITP Support Association and the UK ITP Forum are pleased to launch Making the right choices in ITP management and care – A shared decision-making toolkit for patients.

The toolkit is a response to the results of a patient survey made by the ITP Support Association in 2020. The survey highlighted inconsistencies in the diagnosis and management of ITP – which

can negatively impact patients.

It defines what best practice collaborative decision making in ITP management and care looks like and provides a practical guide to help patients, carers and healthcare professionals achieve this.

This material allows the patient to develop knowledge, skills, and the confidence needed to make managed and informed decisions about personalised health and care. It will ensure that more ITP patients are on care plans that appropriately suit their lifestyle and individual circumstances, improving their quality of life – which can be severely impacted if an individual is placed on a suboptimal care plan.

This toolkit is ground breaking in that it is one of the first haematological conditions to develop specific guidance in response to National Institute for Health and Care Excellence (NICE) recommendations for shared decision-making practices to be implemented across all conditions.

The toolkit is endorsed by the Royal College of Pathologists, Royal College of Physicians, The British Society for Haematology, and the Genetic Alliance UK.

The ITP Expert Working Group and partners are calling for this best practice guidance to be adopted across all healthcare settings in the UK.

Professor Adrian Newland, Chair of the ITP Support Association, said:

"Following our recent patient survey, the ITP Support Association identified significant disparities between patient experiences of care and whether individual preferences were considered in care management plans. We decided that we should bring together a group of haematologists with a particular expertise in ITP to develop this toolkit that, we hope, will empower patients to hold collaborative and honest discussions with their clinician which in turn will result in better outcomes and quality of life."

Dr Quentin Hill, Chair of the UK ITP Forum, said:

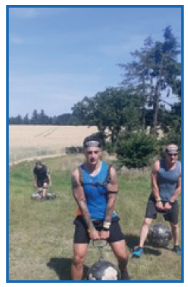
"The ITP toolkit is an excellent introduction and companion document to support and empower patients. It guides them step by step though the journey of diagnosis and medical care. A collaborative approach is more rewarding for patients and clinicians, and I have no hesitation in recommending that the ITP Toolkit is given to all patients at presentation."

Dr Sue Pavord, Consultant Haematologist, Oxford University Hospitals and ITP Expert Working Group member said:

"It has been a real pleasure working with patients and the ITP Support Association in preparing this Toolkit. Mutual understanding and joint decision-making is crucial when planning management which is suitable and acceptable to the individual patient. I encourage all NHS trusts and haematological teams to review the Toolkit and refer to the guidance when deciding on treatment and care with an ITP patient."

Fundraisers & 'In Memory' Donations

Fundraisers



Ben Baily and two work colleagues took part in the Spartan Beast 21km race in July. Says Ben "In the end we covered a total of 24km in just under 3 hours in 30 degree heat!" A total of £500.00 was raised, a fantastic result!

Sam Bateman completed the Potters 'Arf Marathon and raised £157.50. Says Sam "I was diagnosed with ITP at the start of this year, and currently under haematology outpatient care to try and increase my platelet levels. I feel it's important to raise some awareness about the condition, and my friends have been super-supportive."

Michael Taylor decided to do an 833 km walk in Camino del Norte, Spain in memory of his mother, Julie Ogle. He raised a total of £1,922.00 which is a tremendous amount!

Monika Jurcic undertook a truly magnanimous mission taking part in a Namibia Desert challenge with temperatures over 40 degrees whilst running and cycling across the desert! £1,809.87 was raised. We will be publishing an update on her trip on our website.

Simon Needham competed in the Doncaster Half Marathon in June. This event had been cancelled twice due to covid. The association is very grateful for the £657.68 total raised.

Give a car scheme - Thanks to Mr Greenwood for the proceeds of his car being scrapped. The charity received £160.00

As always, a huge thankyou to all of this editions fantastic fundraisers, wonderful effort.

In Memoriam

In memory of Margaret Joan Wallbank £230.00 was raised in donations at her funeral

£100.00 was donated in the memory of Anthony Dunnicliffe

£2,262.50 has been raised in the memory of a young man named Joshua Murray, whose life was tragically cut short earlier this year. Our thoughts are with his family and friends.

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

Leaving a Legacy

Thank you for considering leaving a gift to the ITP Support Association in your will and helping to fund the work of the ITP Support Association and research into Immune thrombocytopenia.

There are 3 main types of gift you can make:

- residuary – a share in, or all of, what's left of the value of your estate after family and friends have been taken care of
- pecuniary – a specific sum of money
- specific – an item such as jewellery or a piece of art

The advantage of leaving a share (also known as a residuary gift) is that it stays the same over time and you won't need to change your will to keep up with inflation.

This planning form guides you through the steps you need to consider when you write your will and it helps you gather your thoughts and plans in one place.

Visit **www.itpsupport.org.uk** and download our Making a Will Planner Form

If you already have a will and you want to include a gift to the ITP Support Association (sometimes called a legacy), there may not be any need to rewrite it.

You can ask a qualified professional such as a solicitor to add an amendment (called a codicil). As a general rule, if the change you wish to make is quite small or simple, you can use a codicil, and if the change is more significant or complex you should make a new will.

Visit **www.itpsupport.org.uk** and download the Codicil Form for the ITP Support Association.

Suggested wording for making your gift to the ITP Support Association

This suggested legal wording will assist your solicitor in drawing up or amending your will to include your gift to help our vital work.

Wording for a residuary gift

I give the residue of my estate to The ITP Support Association, The Platelet Mission, Kimbolton Road, Bolnhurst, Beds, MK44 2EL Registered Charity Number 1064480 * for its general charitable purposes (which includes research). I further direct that the receipt of the Chief Executive (CEO) or other proper officer of the said charity for the time being shall be a full and sufficient discharge for the said gift.

Wording for a gift of money or an item

I give the sum of £_____ (or the item specified) to The ITP Support Association, The Platelet Mission, Kimbolton Road, Bolnhurst, Beds, MK44 2EL Registered Charity Number 1064480 for its general charitable purposes (which includes research). I further direct that the receipt of the Chief Executive (CEO) or other proper officer of the said charity for the time being shall be a full and sufficient discharge for the said gift.

Note

We can not recommend a particular solicitor to make your will but we suggest you contact the Law Society who can provide details of solicitors in your area, including those who specialise in wills. We always recommend that your will is drafted by a qualified professional such as a solicitor as their businesses are regulated by law.

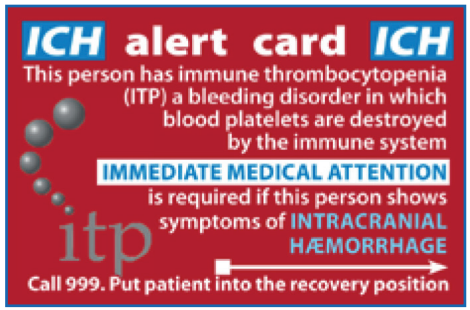
Order a free ICH alert card

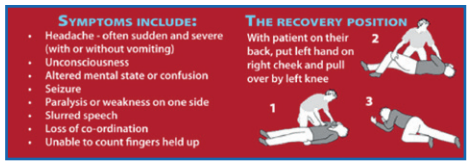
Having an ICH alert card is rather like taking out travel insurance. You hope you'll not have to ever use it but it is there to give you peace of mind in case the worst happens.

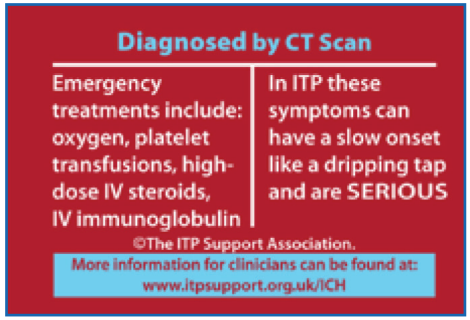
It is very rare for anyone with ITP to have a brain haemorrhage (ICH), but if it should happen to you, fast action by you or those around you, plus prompt scans and specific treatment by emergency doctors can help prevent a serious situation becoming a disaster. The ITP Support Association's ICH alert card was developed in 2012 with assistance from Professor Adrian Newland, who said 'ICH is very rare in patients with counts over 10, and even in those under 10 is only usually seen if there are other complicating factors.'

The card's purpose is to make patients aware of the early warning signs of ICH and to alert paramedics or A&E staff that these signs in ITP patients must be taken seriously. We have sent batches of ICH alert cards for distribution at ITP Clinical Centres and other interested hospitals. Our medical advisors strongly suggest that ITP patients should carry one just as people on steroids carry steroid information cards, and people with epilepsy carry alert cards to help in the event of a seizure.

If you or your child have ITP and don't already have one of these folded red plastic alert cards, you can order yours now by sending your request with an SAE to: The ITP Support Association, The Platelet Mission, Kimbolton Rd, Bolnhurst, Beds, MK44 2EL. The cards are free but donations are appreciated.







Ways To Donate

ITP Support Association switches to JustGiving.com

ITP Support Association switches to **JustGiving.com** as its default fundraising/donation partner following the announcement by Virgin Money Giving that they would be closing their site from the 30th November and will no longer be accepting donations.

Mervyn Morgan, CEO of the ITP Support Association said we joined Virgin Money Giving in early 2020 thinking like many Charities that the Virgin brand would provide a stable and long-term solution for the Charities fundraising and donation requirements. Sadly, with the news of its closing this was not the case, however we are pleased to become part of the JustGiving family and look forward to a long and fruitful future on their platform.

Please visit our page at **https://www.justgiving.com/itpsupportassociation** and make a donation.

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 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

Publications List cont...

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?
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	☐ Mr ☐ Mrs ☐ Miss ☐ Ms ☐ Dr ☐ Other		
NAME			
ADDRESS			
ADDRESS			
POSTCODE		TELEPHONE	
EMAIL			
Let us keep in touch	Opt in ☐ *Please tick the box*	☐ Email ☐ Post ☐ 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	*After 31st January 2020 *£15 UK *£20 Overseas
GENERAL DONATION	
RESEARCH DONATION	
TOTAL ENCLOSED	

FOR OFFICE USE

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,
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