



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



# The Platelet

JOURNAL OF THE ITP SUPPORT ASSOCIATION

JUNE 2022

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Charity Registration No. 1064480

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

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

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



# From ITP HQ

Firstly, my apologies for the delay with the publication of this edition of the Platelet, it was almost ready to go to print when I was admitted in to Hospital, but I have been allowed out for a few days so here we go.

Welcome to the June 2022 edition of the ITPSA Platelet Journal, the theme of this edition is our recent Patient Convention. The whole event is still available to watch at your leisure by going to [www.itpconventionuk.org](http://www.itpconventionuk.org), if you have not already done so, you will need to register once you are on the site.

We would like to say a huge thankyou to each and every one of our medical advisors and convention speakers who gave up their time to share their knowledge and advice with the patients attending the 2022 ITPSA UK and Ireland Convention, thank you.

In addition, you will also find details of our forthcoming Virtual patient Support Group Meetings which are taking place in June and July and looking further ahead, ITP Awareness Week in September.

We also have our regular 'Letter from America' with an interesting article by Spero R. Cataland, M.D. who discusses 'Revisiting Splenectomy for Treating ITP'.

You will also see details of how to take part in the latest I-WISH Survey, many of you would



have completed the original I-WISH survey back in 2018, this is your chance to take part in the Worlds largest survey of ITP patients.

Talking of surveys, please keep a look out for our own ITP Patient Perception Survey which will be launched later in the summer, our last Patient Perception Survey was the catalyst for our recent ITP Toolkit 'Making the right choices in ITP management and care'.

Looking further ahead, we are also sharing the initial plans for this year's ITP Awareness Week which takes place at the end of September, lots taking place, read more in this edition.

**Mervyn Morgan CEO**

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## ITP Shared Decision Making Document

### 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](http://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 through 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."

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

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

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

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



# ITP Support Association Convention 2022

## The UK and Ireland ITP Support Association Annual Patient Convention 2022

The focus of this edition of the Platelet is to look back on our recent Annual Patient Convention.

As this was another virtual event (due to Covid) the setup was an international effort with a production studio in the USA and other speakers around the UK and Europe.



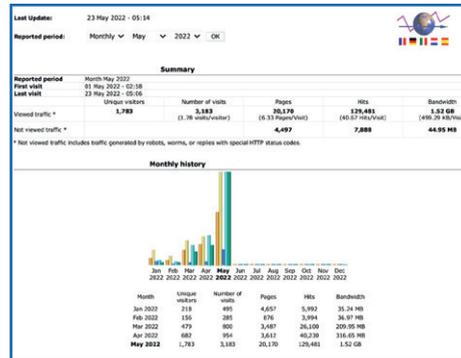
To open this year's UK and Ireland ITP Support Association Patient Convention our CEO Mervyn Morgan welcomed everyone to this year's event, which is our third and hopefully last Virtual Convention as we emerge from Covid-19.



Looking ahead to next year we hope to welcome you all to the Royal College of Pathologists in London in 2023 on Saturday 13th May for our first in person Patient Convention since 2019.

Mervyn continued by saying, 'setting up this virtual convention has been a huge undertaking that would not have been possible without the support and guidance of our Medical Advisors, many of whom are making presentations over this weekend, the Associations Board, in particular our chair of trustees, Prof Adrian Newland CBE and vice chair Mr Derek Elston, Board Member Anthony Heard, our Patient Group organisers, volunteers, members and supporters all around these British Isles.

The 2022 event is following in the footsteps of last year's Convention with a huge number of visitors registered from over 30 countries.



The International coverage of these conventions is in the main down to an organisation that called the International ITP Alliance, we are proud to say that the UK ITPSA is a founding member alongside the PDSA in the USA.

This organisation brings together the ITP Patient organisations from around the globe. For all of our international friends there is a full list of all the member countries on the ITP International Alliance website, please visit [www.GlobalITP.org](http://www.GlobalITP.org).

Everyone who used the Conventions Virtual Platform should also say thankyou to IT wizard behind the

platform we used, Mr Jeff Cooper from syndikast.com.

Before I start talking about each of the talks that took place of the Convention weekend, we should also thanks our event Sponsors:



Our Gold Sponsor UCB Pharma, and our other event sponsors Novartis, Amgen and Argenx.



In addition, we must also give a big shout out to Grifols who have sponsored the Convention platform that we used for this years event.



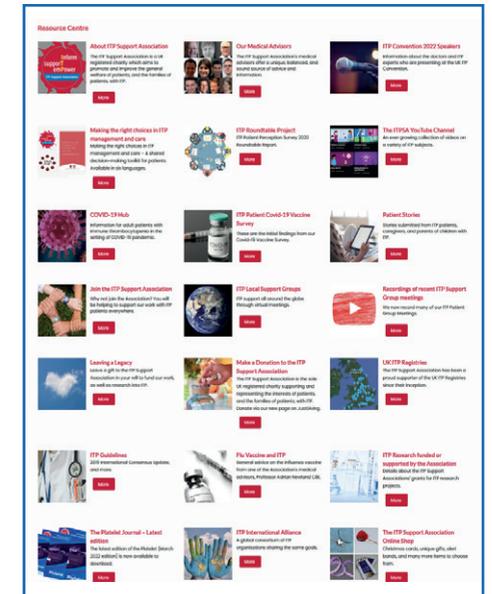
Without the support of companies such as these it would be exceedingly difficult for the Association to undertake the work; we do for those with ITP.

We will go over each of the various talks that took place during our Convention, remember if there is a talk you would like to catch up on, or re-watch then go to our Convention Platform website at [www.itpconventionuk.org](http://www.itpconventionuk.org), if you have already registered, then just login and watch, if not then register and you will have two days' worth of fantastic talks to catch up on.

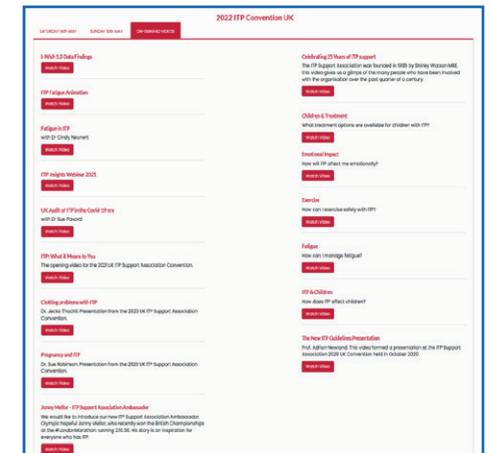
Also the Resources page on the Convention website was bigger than ever this year with lots of ITP information, please take a look, lots to see.

In addition to the resource centre, we also have a

large selection of 'On-Demand' Video's with extra talks by top ITP experts such as Dr Cindy Neunert, Dr Sue Pavord and many more.



We will highlight just a few of the many interesting and informative talks that took place over the two days of the convention, first we have Dr Drew Provan, the subject of his talk was an 'Overview of Controversial Topics'



Dr Drew Provan is no stranger to our ITP Support Association Conventions he is currently Emeritus

# ITP Support Association Convention 2022 continued...



Reader in Autoimmune Haematology at Barts and The London School of Medicine and Dentistry.

Dr Provan covers controversial areas within the following topics:

**What's controversial in ITP?**

- Diagnosis
- Quality of life for patients
- COVID
- New guidelines
- Old and new treatments
- How have we managed ITP during the pandemic
- What next after the pandemic?



Next we had another long-time supporter of the ITP Support Association Dr. David Kuter, Dr Kuter is Director of Clinical Haematology at Massachusetts General Hospital and Professor of Medicine at Harvard Medical School.

The subject of Dr Kuter's talk was 'New Treatments – can we cure ITP', this is a very complicated area with a huge amount of research currently underway, however there is currently no cure for ITP, although Dr Kuter says in his summary that most patients can be effectively treated with minimal distress.

**Can we cure ITP?**

- Probably not yet
- Active research
- Many novel treatments under study
- Most patients can be effectively treated with minimal distress
- Participate in clinical trials
- What is needed?

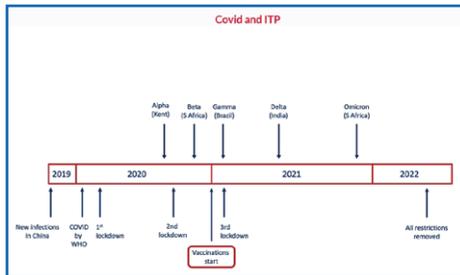
The next topic is one that has been at the front of most peoples minds in recent years, Covid and ITP.



We welcomed for the first time Prof Mike Makris, Prof Makris is the President of the European Association for Haemophilia and Allied Disorders.

He continues to work at the Sheffield Teaching Hospitals NHS Foundation Trust as a Consultant Haematologist specialising in Haemostasis and Thrombosis.

Prof Makris will be talking about Covid and ITP and the incidence of thrombocytopenia during the pandemic plus the delivery of care for ITP during Covid.



After lunch on the first day of the Convention we had presentations from ITPSA Board Member and Chair of the UK ITP Forum Dr Quentin Hill who talked about 'Post vaccination ITP and the UK Audit', this was followed by



Dr Sue Robinson who Chairs the British Society for Haematology Transfusion Task Force and is a writing group member of the National Institute for Health and Care Excellence transfusion guidelines, specialist committee member NICE quality standards

for transfusion and Serious Hazards of Transfusion (SHOT) working group expert. Dr Robinson discussed,

'Whats new in Pregnancy and ITP'

**What's new in Pregnancy and Immune Thrombocytopenia**

Sue Robinson



We also had a talk from Prof Waleed Ghanima, Prof Ghanima is Head of Research and a Consultant Haematologist at the Østfold Hospital, Norway. Professor in the Institute of Clinical Medicine at the University of Oslo, Norway.

Prof Ghanima talk is titled 'Is there still a place for Rituximab in the era of Covid and Thrombopoietins?' We also had a superb talk by friend of the Association and a Platelet Disorder Support Association Convention in the USA, Prof Terry Gernhiemer, Prof Gernhiemer is Professor of Haematology at the University of Washington in Washington State, USA. Prof Gernhiemer will be talking about Mycophenolate Mofetil.

**Mycophenolate For Acute, Refractory And Relapsed ITP**

Terry Gernsheimer, MD  
Professor of Medicine, Hematology  
University of Washington, Seattle  
May 2022

Many of our members are always interested in the latest news on ITP research, Dr Phillip Nicholson gave a talk about Research in ITP in the UK, Dr Nicholson works in the Birmingham Platelet Group and in the department of Haematology at the Queen Elizabeth Hospital, Birmingham. He also chairs the UK-wide, registrar-led research network some of you may have heard off called HaemSTAR. Dr Nicholson was awarded the BSH-NIHR Researcher of the year award in 2019 for his work with this group.

**HaemSTAR**  
Speciality Training Audit and Research

**A single 1 g/kg dose of IVIg is a safe and effective treatment for ITP**

Pip Nicolson  
Clinical Lecturer in Haematology  
Chair of HaemSTAR

University Hospitals Birmingham NHS Foundation Trust

To open Day Two of our Convention we started with updates on both the Adult ITP Registry with Dr Vickie McDonald followed by the Paediatric ITP Registry with Dr John Grainger.

Readers will be aware that the ITP Support Association supports both of these ITP Registries thanks to the generous donations of its members and supporters. Dr McDonald is a consultant haematologist with a specialist interest in platelet disorders at the Royal London Hospital. Dr MacDonal also oversees the Adult ITP Registry. Dr McDonald will be giving an update on the Adult ITP Registry which is supported by the ITP Support Association.

**Update from the Adult ITP registry**

**The United Kingdom Adult Immune Thrombocytopenia Registry**

Dr Vickie McDonald  
ITP support Association update,  
15th May 2021

Queen Mary University of London

Dr John Grainger, he is no stranger to our Conventions, he is also one of the ITPSA Medical Advisors and also the Chair of British Society of Haematology Paediatric Haematology committee.

**Update from the Paediatric ITP Registry**

**Paediatric ITP registry update**  
ITP Support May 2022

Dr John Grainger  
John.grainger@bmt.nhs.uk  
www.uk-ITP.org

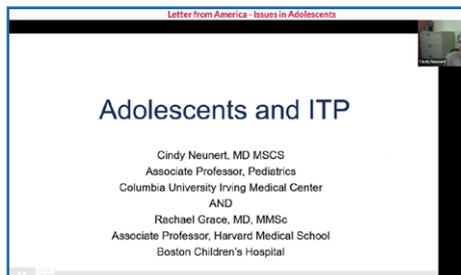
# ITP Support Association Convention 2022 continued...

**12:05 – 12:30 – Dr Cindy Neunert and Dr Rachel Grace – Letter from America – Issues in Adolescents**

Many of you, who watched the convention would have read the regular 'Letter from America' articles in this journal. Many of the recent articles were written by our next speakers Dr Cindy Neunert, Dr Rachel Grace.

Dr Neunert is a paediatric haematologist in White Plains, New York and is affiliated with multiple hospitals in the area, Dr Grace is a paediatric haematologist and clinical researcher at the Dana-Farber/Boston Children's Cancer and Blood Disorders Center. She is also the medical director of both the Haematology Ambulatory Program and the Haematology Clinical Research Program.

Their talk is titled - Letter from America – Issues in Adolescents. This is one talk to watch if you child has ITP.



For the second half of Convention Day Two we held our Symposium on Fatigue in ITP, sponsored by UCB Pharma.



Fatigue is one main topics discussed at our patient meetings, this ranges from the level of extreme fatigue to brain fog. In our 'on demand' video section there is a video on the findings from the 'World Impact Survey (I-WISH 1.0) which highlights fatigue as a key symptom of ITP, 50% of patients highlighted this as against only 31% of physicians. As a side the latest World Impact Survey I-WISH 2.0 is now open, details are in this edition of the Platelet.

One of the many highlights from the Fatigue Symposium was the talk from Greta Burroughs, Greta wrote a book about her ITP journey which started when she was first diagnosed almost 20 years ago. Greta's talk gives us a glimpse of her struggle with fatigue.

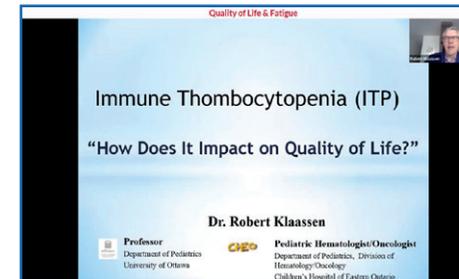


The symposium continued with a talk from Dr David Cuker, another of our 'Letter from America' contributors. Dr. Adam Cuker is a haematologist in Philadelphia and is affiliated with multiple hospitals in the area, including Pennsylvania Hospital and Hospitals of the University of Pennsylvania.

Dr Cuker talked about the Mechanisms and treatment of Fatigue in ITP.



This was followed by another of our international friends, Prof Robert Klassen, Professor in the Department of Pediatrics at the University of Ottawa in Canada. Prof Klassen talk focused on the Quality of Life with ITP.



We concluded our symposium on Fatigue with a live Question and Answer session with some of the worlds top ITP experts, Prof Adrian Newland, Dr David Kuter, Dr Nichola Cooper, Dr Rachel Grace plus from the ITPSA Derek Elston and Mervyn Morgan.



Everyone at the UK and Ireland ITP Support Association would like to thank all of our speakers for giving their time to take part and support patients but we would also like to thank all who logged in over the weekend of the event and since. Remember you can watch every minute of our 2022 Convention by going to [www.itpconventionuk.org](http://www.itpconventionuk.org).

Thanks again to all of our sponsors our Gold Sponsor and Symposium Sponsor UCB Pharma, and our other event sponsors Novartis, Amgen and Argenc.

In addition, we must also give a big shout out to Grifols who have sponsored the Convention platform that we are using over this weekend.

Without the support of companies such as these it would be exceedingly difficult for the Association to undertake the work; we do for those with ITP.

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## Letter From America

### The American Perspective: Revisiting Splenectomy for Treating ITP Spero R. Cataland, M.D.

Removing the spleen has historically been a very effective treatment option for many hematologic conditions including immune thrombocytopenic (ITP). In the past 15 years there have been numerous new medications that have received regulatory approval for the treatment of ITP that work by increasing the production of platelets, (romiplostim, eltrombopag, avatrombopag) or inhibiting the destruction of platelets (fostamatinib), with even more new treatments on the way. Coupled with the other existing medical therapies available to treat ITP, it might be expected that performing a splenectomy to treat ITP might not be necessary any longer. The enthusiasm for splenectomy for the treatment of ITP seems to wax and wane over time for both providers and patients. Splenectomy for the treatment of ITP though still provides the greatest chance to alter the course of ITP and induce long-term remissions or cures of ITP. It also carries the greatest risk for patients compared to any other treatment for ITP, therefore careful consideration and discussion of the risks and benefits of undergoing a splenectomy for ITP (as well as the certainty of the diagnosis of ITP) with their physician is essential.

The spleen is the major site of removal of antibody coated platelets in patients with ITP in addition to housing lymphocytes that may be responsible for producing anti-platelet antibodies that lead to the removal of platelets. Given this it makes sense as to why removing the spleen has the best chance of modifying the disease. In one reported study that



combined the results of 47 case series studies of splenectomy for ITP, 66% of patients were able to achieve a normal platelet count after splenectomy that persisted for over 10 years. Complications (discussed below) occurred in approximately 13% of patients that underwent an open, surgical splenectomy and roughly 10% of patients that underwent a laparoscopic surgical technique (uses 2-3 small surgical ports rather than the typical larger, surgical incision).

The most significant risks from the removal of the spleen stem from the spleen's role in fighting infection and the clearance of antibody-coated bacteria from the blood stream. Because of its role in fighting infection, especially from bacteria categorized as encapsulated organisms (bacterial cells covered by an outer layer that helps the bacteria to cause disease), infection is the most significant lifelong risk for patients that undergo a splenectomy. For this

reason, patients are vaccinated against these encapsulated bacteria prior to surgery and receive regular booster vaccines after surgery. After splenectomy antibiotic therapy is promptly initiated for splenectomized patients that develop a febrile illness. Pediatric patients, more so than adult patients, may also be prescribed prophylactic antibiotics to prevent infections. Mortality rates for the surgery itself are also a consideration and are 1% with the open surgical procedure and 0.2% for the laparoscopic surgical approach.

Patients with ITP are also known to have a greater risk for venous thromboembolic disease compared to patients without ITP, and this risk is thought to possibly be increased in ITP patients after splenectomy. Cardiovascular complications including pulmonary hypertension are thought to be increased after splenectomy, but there is no clear evidence for this to date.

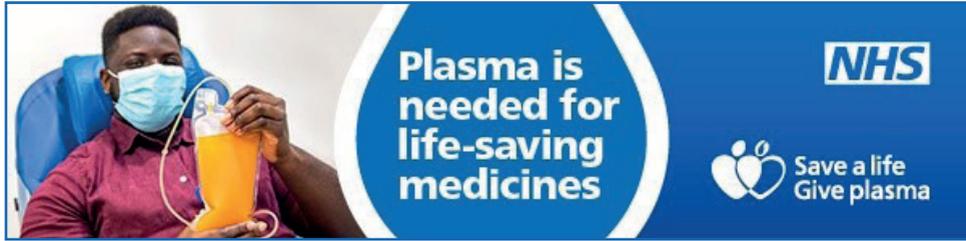
If we accept the idea that splenectomy remains a good treatment option for ITP, the next obvious question is who should undergo splenectomy for ITP? Given the potential for ITP in adults to spontaneously go into remission 20% of the time (most commonly in the first year), it is generally recommended that adults wait at least one year after diagnosis before undergoing splenectomy. It is also thought that younger patients are more likely to respond to splenectomy, but there is no clear age cutoff that predicts a decreased response to splenectomy. Studies have used various tests to attempt to predict who would be most likely to respond to splenectomy, but to date there is no reliable means to predict who will respond to splenectomy, and who will not.

The development of several new treatment options for ITP in recent years has positively impacted the lives of patients with chronic ITP, allowing them to live a normal life without

persistent concerns for bleeding complications from their ITP. These treatments come in many forms (oral, subcutaneous, intravenous) also allowing patients more freedom and control over the type of treatment they choose. However, for patients who have grown intolerant of the need for ongoing treatments due to side effects, or the impact on their lives from having to make regular trips to the clinic for monitoring or treatment, splenectomy should be considered a reasonable option to treat their ITP. As with any other ITP treatment, the relative risks and benefits of a splenectomy should be discussed with their physician so that an educated and informed decision can be made by patients.



# 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](mailto:stephen.bailey@nhsbt.nhs.uk)



# PTI Argentina Update

## Global ITP News

### "PTI Argentina, La Historia de Kiara?"

My name is Rubén De Francesco, and I am the father of a now 21-year-old girl, Kiara, who was diagnosed with ITP 7 years ago and still lives and suffers its consequences nowadays. My idea to contact families going through the same situation where Kiara, covered in bruises, was receiving treatment for a disease that practically none of the health professionals that were in the hospital had ever heard of.



What we have achieved.

Along these 7 years we've grown and accomplished a lot, here in Argentina. We have a loyal following of over 2000 families on social media, getting and sharing information and experiences. At the present time, with ZERO support from sponsors, and volunteering our time, we are managing to put together first-class chats 3 or 4 times a year (even during the pandemic) with some of the best of our health professionals who, kindly, offered to share their knowledge of ITP with people from all over Argentina and Latin America. We've been invited to various TV and radio programs and appeared in newspaper articles to talk and raise awareness about ITP. A leukemia association (ALMA) helps us

with their knowledge on access to treatment and medication to help our patients get the care they deserve.



From the ITP Support Associations in both The US and the UK, we got the inspiration, commitment and the information needed to keep our ITP community informed and going.



We look forward to your booklets in Spanish to share with our patients just as we are doing with the American version of it (also in Spanish) where my family and I appear in the cover.

To all the ITP community in The UK and Ireland a big hug from Argentina.

Gracias!  
Rubén

# Global ITP Awareness Week



**Global ITP Awareness Week**  
26 - 30 September 2022

Coordinated by



**INTERNATIONAL ALLIANCE** A global voice for immune thrombocytopenia patients.

**GlobalITP.org**

Plans are underway for ITP Awareness Week 2022, these include a Paediatric Virtual patient Support Meeting plus a special edition of the Platelet Journal containing Patients ITP stories, if you would like your ITP story included please email it to [mervyn.morgan@itpsupport.org.uk](mailto:mervyn.morgan@itpsupport.org.uk).

There will also be other surprises, keep checking back to our website at [www.itpsupport.org.uk](http://www.itpsupport.org.uk).

ITP Awareness Week in the UK is sponsored by:



# Spotlight - Where To Find Us

## TURNING the SPOTLIGHT on where to find us

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

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

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

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

Website - [www.itpsupport.org.uk](http://www.itpsupport.org.uk)

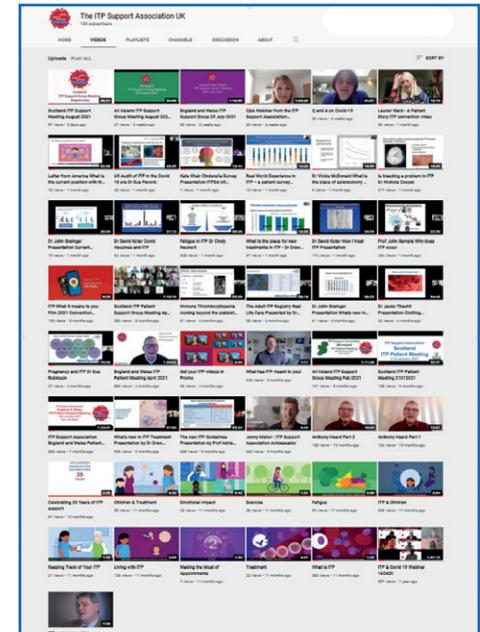
Facebook Group - <https://www.facebook.com/ITPSuppAssoc/>

Twitter - <https://twitter.com/ITPSupportAssoc>

HEALTHUNLOCKED forum - written by ITP sufferers for ITP sufferers. <https://healthunlocked.com/itpsupport>

Instagram - <https://www.instagram.com/itpsupportassoc/>

**Visit the ITP Support Association YouTube Channel** You Tube Channel with numerous helpful, informative & interesting videos covering a wide range of ITP related issues - <https://www.youtube.com/channel/UCRkHWfVYAAIKKAbjF14L37g/> videos or go to our website at [www.itpsupport.org](http://www.itpsupport.org).



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

LinkedIn - We have recently joined LinkedIn so if you have not found us yet you can do so at - <https://www.linkedin.com/groups/13990747/>

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

Produced by Anthony Heard

## Questions

**Q** I would be interested in the views of the panel with regards to fatigue in ITP.

We know from surveys that the number one issue with patients is fatigue but surprisingly or not, this was not the case with some physicians, as shown in the I-WISH survey a year or two back. There have even been cases of some Doctors refusing to accept that fatigue is a symptom of ITP even though it is now recognised as a common symptom of the condition. In addition, the recent shared decision-making document published by the ITPSA and the ITP Forum also highlights that fatigue can be under recognised by Healthcare professionals.

What would you say to a patient who finds themselves in the position where their clinician does not take fatigue into account with their treatment?

**A** It's really important to look for other causes of Fatigue and to make sure you're not missing anything else. One of the other things that also needs to be considered is iron deficiency, which is a commonly missed problem, particularly with ITP patients.

So, the first thing is to make sure there's nothing else going on. Second, it's really important to have a good relationship with your GP / Consultant, that's something we all need to work on.

In addition, if you're seen by someone who hasn't got a lot of experience with ITP, that can be a problem, so make sure you have a copy of the new shared decision-making document to share with them.

How frustrating it is for all of us because we don't have treatment for fatigue yet, but we are at the point of actually recognising fatigue and trying to document fatigue, this will benefit all in the future.

Interesting point raised within Dr Adam Cukers presentation was the variations in the level of fatigue reported by patients with ITP around the world, appears higher in Western countries, can this all be put down to cultural differences or are

other factors at work?

**Q** That was an interesting point in Dr Cukers presentation if you can please watch the video. The point being the variations around the world of people's perception of fatigue, in some cultures, the level of fatigue was shown as a lower percentage than that identified by patients in Western countries.

**A** Some countries interpretation of the questions is very different to that of those in the West due to the patient's background and cultural differences.

These are just a fraction of the many questions received during both Question-and-Answer sessions at the Convention, please watch the videos.



## Fundraisers & 'In Memory' Donations

### Fundraisers

Atlas Trading - total of £187 raised since March from the ITP collection tin

Facebook fundraising (donations in lieu of birthday presents) a total of £1,208.97

Thank you to everyone who selects us as their charity of choice when making purchases using Amazon Smile- £107.05

Neil Watts kindly donated his scrap car value of £282.24 in the Give a Car scheme. He said that he appreciated the support the charity provided his mother in the past.

Simon Needham completed the Doncaster City Half Marathon in 2 hrs 16 mins 39 secs!. Simon managed to raise £488.75p including 'Gift Aid' thru his 'JustGiving' fundraising page, adding to this amount is the £141 raised in 2020 under the 'Wonderful' platform, so the Grand total raised for ITP support Association is ... £629.75p. The event was tough, but he really enjoyed it. Thank you Simon.



### In Memoriam

Mrs Pat McNeil sent in £100.00 cheque from the Hawick Darts League in memory of her late husband Billy McNeil.

The association received donations in memory of the late Mrs Alison Featherstone Hale totalling £848.75.

We also received some anonymous in memory donations - £711.69, our thanks but also condolences to all concerned.



# The I-Wish Survey



## The I-WISH Survey

Do you have immune thrombocytopenia/ idiopathic thrombocytopenia (ITP)?  
Would you like to share your experience of this disease?

### What is the survey about?

The survey aims to understand how ITP impacts your life and how you cope with it on a daily basis.

### Who can take part?

We are looking for patients who have a confirmed diagnosis of ITP and are over the age of 18, to complete a short online questionnaire.

### Why is the survey being conducted?

The survey will be used to understand patients' perceptions towards their ITP, and how ITP can be managed more effectively. The survey results may also be published in scientific literature. All information will be anonymised.

### How can I take part?

The survey is now open and will close in the middle of July 2022. If you would like to take part in this industry-sponsored survey please contact [info@itpsupport.org.uk](mailto:info@itpsupport.org.uk).



## Leaving a Legacy



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

### There are 3 main types of gift you can make:

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

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

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

Visit [www.itpsupport.org.uk](http://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](http://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](https://www.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/itsupportassociation> 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 in less than nine months. Facebook has 'no fees' which means 100% of the contributions are donated to the ITP Support Association.

## RAISE MONEY FOR ITP WHEN YOU SHOP ON LINE at no extra cost to you!



You shop directly with the retailer, same goods, same prices, but by signing up (for free) on Easy Fundraising and Amazon Smile a 0.5 percentage of whatever you spend comes directly to ITP at no extra cost to you.

Go to [www.easyfundraising.org.uk/causes/itsupportassociation](https://www.easyfundraising.org.uk/causes/itsupportassociation) and use the links on the easyfundraising site to take you to your chosen retailer. You'll get access to hundreds of exclusive discounts and voucher codes. Join the 53 supporters who have raised almost £600 for us so far!

Go to <https://smile.amazon.co.uk/> and enter ITP in the search box to sign up to supporting our charity whenever you shop on Amazon.

## Publications List

### BOOKLETS

#### Know about ITP

core information booklet

#### Fatigue in ITP

about this hidden symptom of ITP with suggestions on how to cope

#### What did you call it?

question & answers about adult ITP

#### What did you call it?

question & answers about childhood ITP

#### ITP 'n stuff

question & answers about ITP for teenagers ITP and pregnancy what to expect with a low platelet count in pregnancy

#### Drugs that cause or aggravate thrombocytopenia

drugs to avoid with ITP

#### Splenectomy

About open and keyhole surgery, indium labelled spleen scan, and aftercare

#### Holiday insurance & travel guide

advice on travelling, flying, vaccinations & insurance

#### Protocol for dentists treating patients with ITP

to give to your dentist

#### Guidelines for schools, clubs and playgroups

to give to a child's school

#### Choosing your sport

which sports are safe with ITP?

#### James/Jessica tells his/her story

a book about ITP for newly diagnosed children

#### 'I have chronic ITP'

a follow-on booklet for children whose ITP doesn't remit.

### FACTSHEETS

#### Treatment table

a list of drugs used to treat ITP and their possible side effects

#### Holiday factsheet

ITP information and patient emergency details with English translation: available in Dutch, French, German, Greek, Italian, Russian, Spanish, Turkish or Romanian

#### Pupil's factsheet

ITP information with space for child's emergency details and photo

#### Employer's factsheet

ITP information with space for employee's emergency details

### ALERT CARDS

#### ITP Emergency card £5.00

personalised with your essential details for emergency use. Credit card size, laminated in plastic. Request an order form from headquarters.

#### ICH alert card

an alert card demanding immediate medical

## Publications List cont...

attention if the holder shows symptoms of intracranial haemorrhage (listed on the card). Also has information for medics.

### FUNDRAISING & MISCELLANEOUS

#### Fundraising pack

suggestions for those interested in running a fundraising event

#### How does the Association use your donations?

an explanatory leaflet

#### About ITP and the Association

explanation about the condition and our work

#### Gift aid declaration form

tax payers can increase the value of their donations

#### Gift aid cards & envelopes

for donations collected at events, parties or funerals

#### Standing order form

for supporters wishing to make regular donations to the Association

#### Leaving a legacy

how to make a bequest to the ITP Support Association in your will

#### Collection box

rigid plastic, or pyramid foldable card, please state preference

### ARTICLES PUBLISHED IN PREVIOUS ISSUES OF THE PLATELET

1. Colds and 'flu
2. ITP and skin irritation
3. MMR vaccine and ITP
4. Needlephobia in children
5. Hayfever and ITP
6. ITP & school attendance
7. ITP investigation & treatment procedures
8. Insurance issues
9. Accessing drug information
10. Is drug treatment a risk worth taking?
11. The ITP pupil moving to senior school
12. Alert medical cards and jewellery
13. Healthy eating with ITP
14. H-pylori (stomach bacteria) & ITP
15. Causes of excess infections in ITP
16. A summary of low platelet disorders
17. Night calls - when to call the doctor
18. Service recruitment & ITP
19. Dentistry and ITP (questions & answers)
20. Women & ITP (questions & answers)
21. New insights on what causes ITP
22. Neonatal Thrombocytopenia
23. Post Transfusion Purpura
24. Must I mention my ITP at a job interview?
25. The versatility of platelets
26. How is ITP diagnosed?
27. ITP - in dogs!
28. Complications of ITP
29. Flying & ITP
30. Who needs Vitamin D supplements
31. Why don't we see an immunologist
32. What does the ITP Support Association do?
33. Sustained responses with TPO drugs
34. Is splenectomy still a valid treatment today?

## Publications List cont...

35. Where are we with ITP today?

36. Are young platelets better?

### AMERICAN PERSPECTIVES

1. A history of ITP
2. ITP in pregnancy
3. What is a platelet?
4. How is ITP diagnosed?
5. Non-intervention in childhood ITP
6. Activity restrictions in ITP children
7. How many platelets are enough?
8. Splenectomy and ITP
9. Can I die from ITP
10. The child newly diagnosed with ITP
11. Surgery in the patient with ITP
12. Are alternative & herbal remedies safe?
13. Use of steroids - a boon and a bane
14. Immunoglobulin - good and bad news
15. Intravenous Anti-D - another treatment
16. Chronic ITP - disease or risk factor?
17. Platelet counts - how useful are they?
18. ITP, sports, and sports injuries
19. After failure of splenectomy & steroids
20. ITP in the elderly
21. Rituximab for ITP
22. ITP and tiredness
23. Viruses and childhood ITP
24. Increasing platelet production
25. What happens to adults with ITP
26. ITP and 'cure'
27. What is a clinical trial?
28. The relationship between ITP and lupus
29. ITP in adolescents
30. The development of new ITP drugs
31. Menstrual periods in women with ITP
32. Coping with prednisolone - book review

33. Assessment of bleeding severity in ITP

34. Steroid side effects

35. Splenectomy for children with ITP?

36. What happens after a child recovers?

37. Prevention of infections in asplenic

38. Who cares for patients with ITP

39. Who needs the new TPO drugs for ITP

40. TPO drugs in children & adolescents

41. Platelets & walnuts (food intolerance case)

42. Let's let ITP kids be normal

43. Silent hemorrhage in ITP

44. When bad bleeding happens

45. How often does ITP occur

46. How do hematologists treat ITP patients

47. Low platelets in children- is it always ITP?

48. Low platelets in adults- is it always ITP?

49. ITP: It's not only about bleeding

50. Vitamins, alcohol & ITP

51. Familial (hereditary) thrombocytopenia

52. The full blood count - what does it tell us?

53. Abnormal blood clots in ITP

54. Treatment of ITP children; Who and when

55. Immuno suppressive therapy

56. Platelet counts during pregnancy

57. Vaccinations - An ounce of prevention

58. Spinal anesthesia, and childbirth

59. ITP and Depression

60. Adherence to ITP therapy

61. Bone marrow biopsy and ITP

62. Don't forget splenectomy (in adults)

63. Splenectomy for children with ITP

**To order any of these items (free to members), send a stamped addressed envelope to: The ITP Support Association, The Platelet Mission, Kimbolton Road, Bolnhurst, Beds, MK44 2EL.**

# MEMBERSHIP SUBSCRIPTION FORM:

PLEASE USE THIS FORM TO PAY BY CHEQUE, POSTAL ORDER OR STANDING ORDER

YOU CAN PAY ONLINE AT [WWW.ITPSUPPORT.ORG.UK](http://WWW.ITPSUPPORT.ORG.UK)

## SECTION 1: MEMBERSHIP DATABASE CONTACT INFORMATION *Please complete this section*

TITLE	<input type="checkbox"/> Mr	<input type="checkbox"/> Mrs	<input type="checkbox"/> Miss	<input type="checkbox"/> Ms	<input type="checkbox"/> Dr	<input type="checkbox"/> Other
NAME						
ADDRESS						
ADDRESS						
POSTCODE				TELEPHONE		
EMAIL						
Let us keep in touch	Opt in <input type="checkbox"/>	<i>Please tick the box</i>		<input type="checkbox"/> Email	<input type="checkbox"/> Post	<input type="checkbox"/> Phone

## SECTION 2: PLEASE INDICATE YOUR ITP STATUS *Please tick the appropriate box*

This assists us if we need to produce statistics about our membership for health organisations or pharma companies

- Person with ITP (ongoing or in episodes)     In remission from ITP     Parent of ITP child
- Family member of someone with ITP     Friend or other     Health Professional

## SECTION 3: PAYMENT *Please tick the appropriate box(es)*

- Please Gift Aid my payment (Please complete the gift aid form if you haven't sent us one before)
- I wish to pay by standing order (Please complete the standing order form)
- I wish to pay by cheque (Please complete the section below. We are grateful for added donations)

MEMBERSHIP	<small>*After 31<sup>st</sup> January 2020</small> <b>*£15 UK    *£20 Overseas</b>	FOR OFFICE USE
GENERAL DONATION		
RESEARCH DONATION		
TOTAL ENCLOSED		

Please return this form with your cheque or standing order form to:-  
The ITP Support Association, The Platelet Mission, Kimbolton Road, Bolnhurst, Beds MK44 2EL

The associations privacy policy is available at: [www.itpsupport.org.uk](http://www.itpsupport.org.uk)

Send this form to: The ITP Support Association,  
The Platelet Mission, Kimbolton Rd, Bolnhurst, Beds, MK44 2EL

