



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



ITP Support Association UK Convention London 2020



The **Platelet**

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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 NOVARTIS & AMGEN for grants to assist with the printing and distribution costs of The Platelet.



From ITP HQ

The ITP Support Association Convention 2020



Many of you will already have seen the details of our next convention #ITPLondon2020 on social media and our website, ticket sales have been amazing, with over 50% already sold. 2020 will be a huge milestone for the Association, it is not just the start of a new decade, but it will also mark our Silver Jubilee. In celebration of our 25th Anniversary our 2020 UK Convention will take place on 9th May 2020 (9:30am to 5:00pm) at the Royal College of Pathologists in their brand-new headquarters building in Alie Street, London. Further details about #ITPLondon2020 and how to book tickets are covered in the main Convention article within this edition of the Platelet. We are also pleased to welcome the sponsors of our 2020 UK Convention, as we go to press, they are:



Local ITP Support Group meetings

Our network of local support groups around the country continues to grow, a list of the meeting dates (as we go to press) is published in this edition of the Platelet. Please check our website for any additional meetings and new dates. There are also several new local groups in the pipeline, details will be made available once plans are firmed up. Numbers attending our Local groups varies by meeting. There can be 10 or 12 at one meeting and then 3 or 4 at another. Numbers help, but what is important is the fact that everyone who has attended one of these meetings feels that they have made a positive contribution to their wellbeing.

Updated international consensus report on the investigation and management of primary immune thrombocytopenia

Over the last decade, there have been numerous developments and changes in treatment practices for the management of patients with immune thrombocytopenia (ITP). This article is an update of the International Consensus Report published in 2010. A critical review was performed to

identify all relevant articles published between 2009 and 2018. An expert panel screened, reviewed, and graded the studies and formulated the updated consensus recommendations based on the new data. The final document provides consensus recommendations on the diagnosis and management of ITP in adults, during pregnancy, and in children, as well as quality-of-life considerations. The full report can be read on our website at www.itpsupport.org.uk.

New sponsor for the Platelet 2020



We are pleased to announce that Argenx have agreed to sponsor the Platelet during 2020, this sponsorship will commence with the March 2020 edition.

ITP Support Association Membership

The Associations membership rates have been the same for many years, during this time our operating costs (mainly postage costs) have increased. Therefore, the Trustees have agreed that there will be an increase in the membership rates from 31st January 2020. From that date membership rates will increase as follows, UK Members £15 and £20 Overseas Members.

Mervyn Morgan CEO

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Cover Photo: UK ITP Convention London 2020

The American Perspective

New Drugs for an "Old" Disease
- Spero R. Cataland, M.D.



I and more than 30,000 other doctors and researchers from around the world have all just returned from the 61st Annual Meeting of the American Society of Hematology in Orlando, Florida. This meeting brings together everyone in hematology annually to present research, discuss how this research might change the care of patients with malignant and non-malignant hematologic diseases, and to discuss and plan for future research studies. This year's meeting was as busy and exciting as previous meetings, with several interesting studies relevant to patients with ITP.

One of the newest treatment approaches for ITP is one that attempts to increase the break down of the IgG autoantibodies that increase platelet clearance from the blood and are at the center of the cause of ITP. In this study, the drug efgartigimod was given as a weekly infusion over 3 weeks to patients with long-standing ITP



who have had insufficient responses to prior ITP treatments or failed splenectomies. The study showed that the drug did, indeed, lower the IgG levels and result in meaningful increases of the platelet count in treated patients. There were also no significant side effects in treated patients although longer studies of this drug and the safety of lowered levels of IgG are needed. These results pave the way for future studies of efgartigimod in patients with ITP.

Another medication with a similar mechanism of action that attempts to decrease the levels of the IgG autoantibodies in patients with chronic ITP is called rozanolixizumab. In contrast to the previous study, the medication was administered subcutaneously over 30 to 90 minutes in single dose or as multiple doses each week. Similar to the previous study, reductions of the IgG levels and improvements in the platelet count were seen in treated patients. Mild to moderate

headaches were the most common side effect, but they did not lead anyone to discontinue the study. These encouraging results will be studied further in the upcoming phase III study that, if positive and with a continued reassuring safety information, could lead to this medication being available to patients with ITP.

In what is a very different approach to the treatment of ITP, the drug sutimlimab was studied in patients with chronic ITP. Sutimlimab is an antibody that blocks part of the immune system called the complement system. It does so by interacting with a very specific part of the complement system called the classical pathway. The complement system is a part of our immune system that helps to clear infections and damaged tissues among other roles. The complement system can become unchecked and this lead to certain conditions such as another rare blood disorder that you may have heard of before, atypical hemolytic uremic syndrome or aHUS. Previous studies in patients with ITP have shown that activation of the complement system occurs on the surface of platelets and may contribute to the destruction of platelets. Therefore, being able to block this pathway may increase the platelet count.

Sutimlimab (given subcutaneously) has been shown to be able to block the activation of the classical pathway of complement activation. The early results of this study showed a rapid increase in the platelet count (<24 hours) after the drug was given that was sustained with ongoing treatment with sutimlimab. As a part of the study, 4 patients stopped the medication with a plan to restart it if needed for a recurrent drop in the platelet count. Interestingly, in these 4 patients stopping the drug resulted in a recurrence of their low platelet count, and then again the recovery of the platelet count after

the drug was restarted. This aspect of the study helps to truly confirm that the increase in the platelet count is a result of the drug as opposed to a spontaneous recovery of the platelet count which can be seen in patients with ITP. Migraine-type headaches were the most common side effect noted in this trial among patients treated with sutimlimab.

While these data are encouraging, initial results from all of these studies will need to be confirmed in larger studies to ensure that the drugs are safe and effective in patients with ITP. Despite the remarkable progress in the development of treatments for ITP over the past several years, there is promise for the development of even more novel treatments that may someday benefit patients with ITP around the world.



Update on the UK Adult ITP Registry

By Haroon Miah, Research Coordinator / Data Manager at the Royal London Hospital

In the last year we have added 19 new sites to the 74 hospitals that already report their new ITP patients to the Registry. This is 69% of the acute non-specialist Trusts in the UK (based on 135 acute non-specialist Trusts in the UK). We have now recruited over 3780 patients and have clinical information on virtually all and DNA stored on over half. It has been estimated that over 2,000 patients are needed in any Registry to detect worthwhile trends and in a disease as diverse as ITP this may be more. We have however published some very important drug studies, as mentioned in the June edition of the Platelet. We have also in the past shown the major impact that steroid treatment has on patients and identified the increased risk of thrombosis in ITP despite the low platelet counts. We were also one of the first to show the impact of fatigue on quality of life in a study we performed in conjunction with the ITP Association.

Over the last 12 months we have undertaken some exciting studies and research into treatments used for ITP. The first of these was a report on the treatment patterns being used for ITP in the UK over the last 25-30 years. We have presented this in UK and European medical meetings and also at the UK ITP Assembly in May, organised by Dr Nichola Cooper. This generated a lot of discussion, in particular around how the treatment patterns have changed, using more medications such as eltrombopag and romiplostim with fewer splenectomies and the increased use of drugs such as Mycophenolate. In addition, we have also analysed rituximab treatment use in the UK, looking at high and low dose treatment in over 300 patients. These results will be published shortly but we have also presented the results at UK and international meetings. We are also collaborating on a laboratory project with Dr Quentin Hill at Leeds looking at what factors may affect response to treatment with rituximab and intravenous immunoglobulin.

We are very grateful for the ongoing support from the ITP Support Association for the Adult ITP Registry. It has allowed us to continue to develop

and expand the Registry, add the Pregnancy ITP Registry, with Dr Robinson from Guys and St Thomas', and continue to undertake research into the causes of ITP and outcomes of our patients in the long term. Without the patient involvement and the support from the Association we would not be able to do this – so THANK YOU!

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.



The ITP Support Association Convention 2020



Many of you will already have seen the details of our next convention #ITPLondon2020 on social media and our website, ticket sales have been amazing, with over 50% already sold.

There is still time to book your ticket, to book your place visit www.itpsupport.org.uk you can also order by post, send your details along with payment to our office (address on the back page) Tickets for the event are as follows:

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

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

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

Keynote Speakers



Professor, Medicine, Harvard Medical School
Imperial College London
Guy's and St Thomas' NHS Foundation Trust



Professor John Semple Dr. Henrik Frederiksen Dr. Vickie Macdonald

Lund University, Sweden Odense University Hospital, Denmark Barts Health NHS Trust

Medical Advisors attending



Chair of Trustees, ITP Support Association
Ex-Director of Pathology at Barts Health NHS Trust
Consultant Haematologist with the Health Service Executive of Ireland



Dr. John Grainger
Royal Manchester Children's Hospital

THANK YOU TO OUR LONDON 2020 ITP CONVENTION SPONSORS



Fantastic Fundraisers

Jimmy Gledhill's son (Jimmy 13) has been battling with ITP for over three years. One of Jimmy's old football coaches (Tom Mellor) arranged another charity match which took place recently at Curzon Ashton fc. We managed to raise a fantastic £660.00.



Fun day - we are very grateful for the £472.20 raised.

Ethan Turner raises £455

Ethan Turner - Says his mother "Ethan took up running in 2018 and due to his increasing ability and interest, he joined a running club this year. He decided to use the ITP support association as his motivation to train towards taking part in the Great East half marathon held in Ipswich on 22nd September.



Antony Nugent ran the Great Scottish Half Marathon and raised £385.75.

Anthony with his fiancée Fiona who has ITP



Another Scottish Half Marathon runner was Neil Crawford who managed to raise £391.25. Neil was very happy with his 1 hour 55 min completion time!



Ethan Turner in action!

Despite Ethan's little sister, Freya, now in remission following her diagnosis 6 years ago, the Support Association continues to be dear to us, not least because we have a friend whose ITP journey has continued. I'm delighted to say that Ethan raised £455 and came a respectable 20th out of 4,000 runners in the Great East Run!" Well done for raising £455!

Stephane Mouilleron, who has had ITP for 3 years took part in the Ealing Half Marathon and raised £311.25.

Avicenna Pharmacy

The charity was delighted to have been nominated by employee Mima to benefit from the proceeds of the AMG Healthcare Ltd Charity

Fantastic Fundraisers

Natalie Bain and her daughter Amelia (aged 7) and not forgetting the family dog! walked 6 miles in the Dundee Kilt Walk. Natalie said "For Amelia to walk for a charity that helps people who suffer like her made me, her and dad and extended family so proud".



Natalie Bain with daughter Amelia and family dog who all took part in the Dundee kilt walk raising £1,448.89 (which included 40% top up donation from the Hunter Foundation).

A group of Evonik Goldschmidt UK Ltd employees participated in a fun run in aid of the association raising a total of £500.00. Thanks go to Amanda, Martin, Clive, Sue, Nisha, Mia, Julio, Shahid, Lloyd, Victoria, Christiane, Lewis & finally Liam.



Nevin Ibrahim, who herself has ITP, asked all school staff at Galliard Primary School to wear purple for the day. A big thank you to all having raised £190.00.

Nevin sporting her "wear purple for ITP"

Robbie Buchanan, a young lad who has ITP and is a regular fundraiser has sent a cheque for £180.00. Says his mother Ann, "Robbie has been doing more to raise awareness of ITP and has received a few donations along the way".

Condolences

Our thoughts are with the following persons families and friends. We are grateful to have received the following donations:-

£395.00 in memory of the late Mr Thomas Joseph

£117.35 in memory of the late Mrs Sandra South

Anna-Marie's husband died recently. The association received £270 in his memory from funeral collections.

Research Funds Appeal

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

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

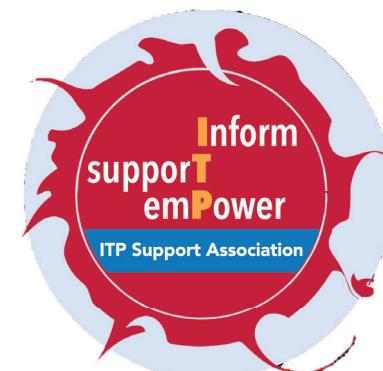
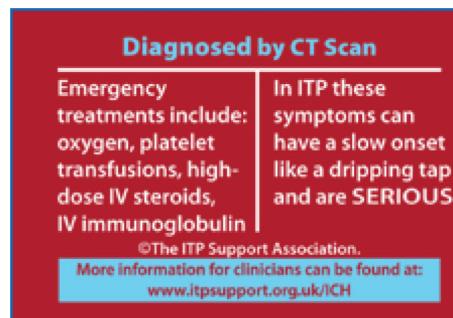
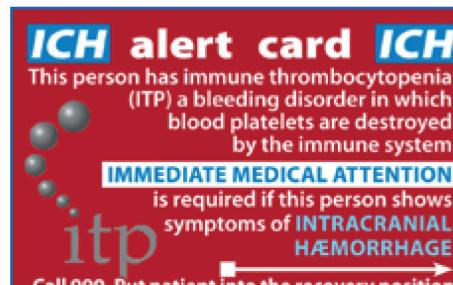
Order a free ICH alert card

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.



Patient Mentors for the ITP Support Association

The term Patient Mentor is a relatively recent one, the use of email has made a huge difference to ease of contact.

What or who is a Patient Mentor? Perhaps it is easier to answer what a Patient Mentor is not.

We do not give medical advice of any kind. That is for fully qualified medical professionals only. Any support we give will always come with the caveat that this should be discussed with your medical team such as your GP, your ITP Nurse, and, or, your Specialist team at your hospital.

A Patient Mentor is one who has experience of ITP and can chat things over with people who have concerns about any patient aspect of their diagnosis. This includes members of the family and of course, parents of children with ITP.

We are a listening ear for people who feel the need to discuss their worries and fears due to their diagnosis. We are also on email and you will see the box of 3 names and contact details, who are the current Mentors.

A Patient Mentor must be well informed about ITP and keep up with new treatments and research.

After each editions of The Platelet we usually get a flurry of contacts asking various questions. These

PATIENT MENTORS

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

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

David Farrow | Tel: 01664 852218
E-mail: davidfarrow40@yahoo.co.uk

can vary from quite simple to very complex, and sometimes research is required in order to be able to give the required information. Some emails can be quite long, and also phone calls, giving reassurance and friendly chat to help people overcome their shock and bewilderment at this surprising diagnosis.

We always suggest looking at the website and the lists of leaflets produced by the Association, in order to have the written material to hand. Some is useful to give to schools for their information, as we all know ITP is not your run of the mill condition, and it can be very perplexing for many people who have to deal with it in the workplace.

Generally speaking, queries fall into several categories. If it isn't a newly diagnosed patient, it is usually one of three things - despair because ITP hasn't improved, the complications of ITP running alongside some other disease, or asking should medical help be sought for some particular ITP problem.

I always think it is a privilege to touch people's lives in this way, and to be able to provide a supportive and friendly time for them to chat and have confidence to express their innermost anxieties. We are not counsellors, but in many ways, we do the same things that they do, such as listening very carefully and caringly. It is an invaluable resource provided by the ITP Support Association. [Editors note, support for those with ITP has taken another step forward with the introduction of local ITP Support Groups around the United Kingdom, details are in this edition of the Platelet] [We hope to have a new Patient Mentor joining the team early in 2020, details will be published in the March edition of the Platelet].

Rhonda Anderson

ITP Support Association Local Group Meetings

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

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

Scotland ITP Local Support Group Meeting

Next Meeting: Thursday 27th February 2020 1.00pm to 3.00pm
Venue: Cajystane Hall, Fairmilehead Parish Church, 1a Frogston Road West, Edinburgh, EH10 7AA.

South Wales (Pontyclun) ITP Local Support Meeting

Next Meeting: TBA
Venue: Bethal Baptist Church Centre, Heol Miskin, Pontyclun, Rhondda Cynon Taff, CF72 9AJ

South Wales (Maesteg) ITP Local Support Meeting

Next Meeting: 20th January 2020 TBC
Venue: TBA

Sussex ITP Local Group Meeting

Next Meeting: 14th March 2020 10:30am to 12:30pm (future meeting dates TBC 6th June, 10th October)
Venue: St Pauls Church Hall, St Pauls Church,

Churchside, Chichester, West Sussex, PO19 6FT

Devon ITP Local Group Meeting

Next Meeting: 7th February 2020, 11:45am to 1:45pm.

Venue: St Andrews Church Hall, Ashburton, TQ13 7DD.

Limited parking is available at the hall, if this is full then you can park on the forecourt of the residential home next door (St Andrews House).

East of England ITP Local Group Meeting

Next Meeting: Thursday 2nd April 2020 10:30am start

Venue: The Platelet Mission, Kimbolton Road, Bolnhurst, MK44 2EL

Limited parking is available at the Mission, if this is full then you can park on the road.

Bury St Edmunds ITP Local Support Group

Next Meeting: TBA
Venue: SAngel Hill Surgery, Angel Lane, Bury St Edmunds, Suffolk, IP33 1LU

Limited parking is available at the hall, if this is full then you can park on the forecourt of the residential home next door (St Andrews House).

Southport ITP Local Support Group

Next Meeting: TBA
Venue: Silocks Pier Family Restaurant, Promenade, Southport, PR8 1QX. Fish and Chips then a walk in the park.

Nottinghamshire ITP Local Support Group

Next Meeting: 28th January 2020 7pm to 9pm

Venue: Chesters, 72 Main Street, Balderton, Newark, NG24 3LL

Cheshire (Altrincham) ITP Local Support Group Meeting

Next Meeting: 31st January 2020 11am to 1pm

Venue: Altrincham Library (Room 1), 2 Pott St, Altrincham WA14 1AH

Worcestershire ITP Local Group Meeting

Next Meeting: 10th January 2020, 2:30pm to 4:30pm

Venue: Waitrose Community Room, 223 London Road, Worcester, WR5 2JG, On arrival please report to the consumer desk which is just inside the front entrance and give them your car registration number.

One off Local Meetings

ITP Support Group Meeting, Broomfield Hospital

Next Meeting: 15th January 2020 - 3pm to 5pm

Venue: Broomfield Hospital, Chelmsford, CM17ET

ITP Patient Research Evening - Queen Elizabeth Hospital Birmingham

Next Meeting: 28th January 2020 - 6pm to 8pm
 Please note you must register to attend this event, to register go to:

<https://www.eventbrite.co.uk/e/itp-patient-research-evening-tickets-80211616103>

Venue: Education Centre, Queen Elizabeth Hospital Birmingham, Mindelsohn Way, Birmingham, B15 2TH

PRN1008-010

ITP CLINICAL STUDY IS LOOKING FOR PEOPLE TO PARTICIPATE

To qualify, you must

- Be 18 years of age or older
- Have ITP with Platelets less than 30,000
- Had a response to at least one prior ITP therapy or a splenectomy

Study staff will also evaluate other criteria to make sure you qualify for this study

clinicaltrials.gov

PRINCPIA

BIO PHARMA

ITP AWARENESS - Looking forward to Rare Disease Day 2020

By Anthony Heard



The annual ITP September Awareness Campaign has now come to a close after a wonderful purple tinged month. With contributions from all corners of the globe we have once again drawn attention to ITP in spectacular fashion.

A huge thank you goes to every single person who took even the smallest action to spread awareness of our enigmatic condition. Whether it be writing a blog entry, an article, Tweeting or Facebooking about it or sporting Purple for Platelets, we have all done a fabulous job.

As a relatively rare illness we all know that ITP can easily be lost amongst so many other very worthy causes. So as we end the September awareness campaign we need to keep the focus on our condition. One major International initiative which can help us to keep the attention on our illness, as well as other rare diseases, is Rare Disease Day, held on the last day of February every year.

A rare disease is defined by the European Union as one that affects less than 5 in 10,000 people.

ITP is most definitely one of those rare diseases. There are between 6,000 and 8,000 known rare diseases and around five new one's are described in medical literature each week.

The vast majority of rare diseases will affect quite small numbers of people – some will touch only a handful of people, or even a single person in the whole of the UK. To put things in purple perspective, it is thought that there are about 4000 to 5000 ITP sufferers in the UK at any one time.

It is estimated that 1 in 17 people, or 6% of the population, will be affected by a rare disease at some point in their lives. This is about 3.5 million people in the UK and 30 million people across Europe.

We ITP sufferers know the frustrations and uncertainty around there being no cure for our illness, albeit we have numerous treatment options. We also understand the problems of diagnosis because ITP is diagnosed by exclusion where all potential causes for our reduced platelet count are ruled out before ITP is confirmed.

My ITP diagnosis took 8 hours on a worrying Friday night in my local A and E (Accident and Emergency) because the hospital did not have anybody on site with ITP expertise at the weekend. That is by no means as wretched as some other people's experiences, but it was still pretty harrowing, and it doesn't mean we shouldn't aim for improvement.

Rare Disease Day improves knowledge amongst the general public of all rare diseases while encouraging researchers and decision makers to address the needs of those living with rare illnesses.

So, although it may seem like a long way off, please do put a note in your diaries for Rare Disease Day February 29th, 2020. Check the websites listed below to keep in touch with plans for the event and do try to join in.

Rare Disease Day – Useful links

What is it all about - <https://www.rarediseaseday.org/article/what-is-rare-disease-day>

How to get involved - <https://www.rarediseaseday.org/article/get-involved>

Rare Disease UK - <https://www.raredisease.org.uk/about-us/>

In The ITP Blood

Angus Ogilvy, member of the Scotland ITP Local Support Group has written a poem called:

In The ITP Blood

Every so often there comes a warning
to stay off the hill lest my blood counts
plunge and I bleed into the rusting heather,
or can't be found in a camouflage of bruise.

But the uncaring hill I climb each morning
is my best way to go, I have no doubt,
whatever the state of the wind or weather.
At least, for now, that will be my excuse.

Lying in the sphagnum and the asphodel,
I'll watch the lace-work of the northern lights
as spiderlings encase me hair to toe.

Rain will stroke and kiss, but never tell;
I'll wait in the wool of the dewy night
till snow blows in to cover me from crows.

©Angus D H Ogilvy September 2017



INTERNATIONAL UPDATE for 2019

Derek Elston, Trustee

The last twelve months have been extremely busy with the association being involved in representing ITP patients not only within the United Kingdom, but also within Europe and beyond.

Whilst much of the involvement has been reported in previous editions of the Platelet, a recap of the year illustrates what is and has been happening around the world with which we have been directly associated. The adage of the world becoming smaller is well known, but it is certainly true with regard to ITP. With the advent of new drugs from various pharmaceutical companies in the pipeline, life is becoming very interesting.

The start was in January with a meeting in Amsterdam with UCB Pharmaceuticals Patient Council on ITP. This was the first meeting of the council and was attended by our CEO and other representatives of the European groups. In March I attended the annual meeting of the Protein Plasma Therapeutics Association, an organisation of which we are a stakeholder, The venue was Amsterdam. The main topic was the shortage of IgG and how it could affect ITP and neurological patients worldwide.

The beginning of April saw a close collaboration with Novartis and the first ITP convention to be organised in Ireland for many years. A successful meeting with a good attendance from both North and Southern Ireland. It is planned that this will be repeated next year.

Later this month saw a meeting in London under the name of the ITP Assembly. This was organised for ITP physicians and chaired by Dr. Nichola Cooper with ITP specialists from the USA, Europe and the United Kingdom.

May saw the annual European Haematology Association (EHA) meeting, again in Amsterdam. The attendees at this conference are from the world over and this year saw record numbers of 12,000 plus. I represent the European ITP groups on the patient's workgroup together with sixteen other medical conditions, both malignant and non-malignant. The workgroup is strongly represented on various committees of EHA and is becoming a much valued and important part of EHA. This year they were allocated a full day's conference facility and considered such diverse matters as T-cell replacement therapy. Whilst not being relevant to ITP, it proved a most popular presentation with an overflow of attendees into the emergency seating area.

The ITP groups attending included PDSA from the USA, and representatives from Finland; The Netherlands; Denmark and Italy.

EHA provided a booth for the patients in a prominent location and the literature which we and other groups provided was soon depleted. It proved a very good meeting and networking desk for the representatives and the clinicians. Incorporated within the conference was a meeting with the EHA policy committee.

Two weeks later, this meeting was followed by a committee meeting in The Hague at EHA offices considering the following years program.

The end of July saw the third meeting of the ITP International Alliance in Washington DC. A three-day conference attended by our CEO along with representatives from China, New Zealand, South America and Europe. It is hard to believe that this international group has grown at such an alarming

INTERNATIONAL UPDATE for 2019 cont...

rate since inception only three years ago following an initiative by PDSA and ourselves whilst at the EHA meeting in Copenhagen. With 32 country members from around the world and still growing. Collaboration is inevitable and extremely valuable. We learn so much about the problems encountered in other countries.

In September we were invited to a meeting in Brussels by UCB to attend the patient's council to consider further the development of their new drug. This meeting was attended by our CEO and myself together with representatives from the patient groups of Finland; Sweden; Denmark and Italy via telephone link. A very interesting and fruitful day for all concerned. We understand UCB derived considerable knowledge from this meeting which at times was lively. The following day I was attending a UCB new meds congress in Eindhoven, The Netherlands. I was addressing another group of medics and chemists telling them about ITP and the impact this condition has on its patients. At this meeting I met one of their employees who also suffers from ITP. Needless to say, we had a long conversation.

In October, UCB invited us to attend a meeting in Ghent, Belgium and provide a presentation to another division of UCB on how ITP affects its patients. This meeting was also attended by Dr. Nichola Cooper. Interestingly, neither of us were allowed to hear the others presentation. My presentation was to provide insight into ITP and the patients perspective. Dr Cooper was to talk about administration of medication and diagnosis.

At the end of October, I attended an EHA policy committee meeting in The Hague considering the further relationship of the patient's workgroup within

EHA. Coupled with an in-depth discussion into the relationship and the contributions patients have to offer to the medical profession and pharmaceutical companies alike.

In November Novartis organised an advisory board meeting in Madrid. I was extremely pleased to represent patients at this meeting. This was a truly international meeting of haematologists from Hong Kong, Canada, USA and Europe. I was supported by two patients from the Israel support group. My presentation was the patient's perspective in relation to tapering and discontinuation of medication.

In addition to the above, we have been involved in teleconferences at various times with all the pharmaceutical companies; organisations and other patient groups in varying parts of the world. A useful way in which to communicate and save on expenses but not always as beneficial as a face to face meeting.

The year has been very active and next year is looking very much in the same mode. I certainly have conferences booked in Berlin and Frankfurt. The international global alliance is proposed with a meeting in Italy in 2020 and we are already considering Poland for the following year. I feel sure that if anybody would like to attend either, they would be sure to receive a warm welcome.

As to the future, there will be closer co-operation between countries that is certain. Medication is improving as is the care afforded to patients. Far more is known now about ITP than has ever been known and I feel sure, knowledge will improve and expand and working closely as we are doing, can only be beneficial for patients.

Your Questions

Q

Question from Elisabeth Frost

We are heading to India and Nepal and have been advised that we need all sorts of jabs.

The CDC and WHO recommend the following vaccinations for India: hepatitis A, hepatitis B, typhoid, cholera, yellow fever, Japanese encephalitis, rabies, meningitis, polio, measles, mumps and rubella (MMR), Tdap (tetanus, diphtheria and pertussis), chickenpox, shingles, pneumonia and influenza. Shot lasts 2 years. I am also advised that I should take anti-malaria drugs.

Are all these compatible with ITP? I am currently taking Azathioprine but I expect people with other treatments would also like to know what can and cannot be taken. If some are a problem, what is the best solution? Can I still travel?

A

Dr. Jecko Thachil replied

Re: vaccinations -- Some vaccinations can worsen the platelet count. The updated ITP consensus document says "There has been anecdotal association between vaccination and ITP; a prospective case-control study found no increased incidence of ITP following vaccination. Acute viral infections and some vaccinations (with live attenuated virus) have been associated with (usually transient) thrombocytopenia." It is usually good practice to check the platelet count in the first week or so after the vaccinations to ensure no drop in the count.

Re: antimalarial drugs and azathioprine – several drugs are known to interact with azathioprine but the GP should be able to check this on a

medical interactions database. It is probably unsafe for patients who have had splenectomy to travel to malaria-endemic areas, however. It is generally recommended that if such patients find it necessary to travel to malaria-endemic areas, adherence to basic preventive measures and prophylactic regimens (eg; penicillin) is extremely important in addition to prompt diagnosis and treatment of suspected malaria.

Re: In any case of foreign travel, we recommend i) adequate travel insurance, ii) identifying hospitals (prior to the journey) in case of an emergency, and iii) keeping mobile on the flights to avoid risk of blood clots.

Q

Question from Maria

My 6 year old daughter has been taking eltrombopag for over a year, she was taking 50mg but side effects worsened (head aches, hair loss, leg cramps) so went back down to 25mg where side effects remain manageable and platelet count around 20-30 (whereas she would be single figures without eltrombopag).

Over the past year she has developed inner ear hearing loss in both ears. She has had tests done to try and determine reasons for this rather sudden and significant loss, however all tests to identify a cause have returned as normal.

Is there any known link between hearing loss in the paediatric population who take medication like eltrombopag?

Also given the above, on the medication and counts usually between 20-30 for over a year. I was wondering how often should she have blood

Your Questions cont...

tests now?

A

Dr. John Grainger replied

Hearing loss was not reported as a side effect in the paediatric Eltrombopag studies and has not been observed in any of my patients. Hearing loss can occur with iron chelating drugs which are used to treat patients on regular blood transfusions. Eltrombopag is a weak iron chelator so it is possible that this could be the cause if other causes have been excluded.

A platelet count >20 is safe for the majority of children whom are avoiding high risk activities. The frequency of blood tests would be determined jointly between the doctor reviewing and the family. It will be dependent upon factors such as the previous bleeding severity, response to emergency therapies etc. It is likely there would only be a change to treatment if there was a persistent drop in counts or actual bleeding.

Q

Question from Parisa

My name is Parisa. I'm 45 and I'm from Iran. I'm diagnosed with chronic ITP 16 years ago. Since then, I'm doing regular monitoring and platelet checks.

The first treatment was a surgery to remove my spleen and take a Prednisolone 5mg every day.

But two years after surgery doctors found out my platelet count falls to 18000. So my doctor changed my medications to boost my platelet. I started to take a new medication called Danazol. During the time that I was taking Danazol, my platelet increased to 80000.

But soon after that the doctors diagnosed that I have Anticardiolipin Antibody (ACL) so they changed my medication again to Prednisolone 5mg and Hydroxychloroquine 200mg.

During this period of monitoring, sometimes my platelet count falls below normal and because of that I've had IVIG injection as well as Dexamethasone injections to boost platelet.

Since then I'm still taking my medications (every day I'm taking Prednisolone 5mg and Hydroxychloroquine 200mg, Prograf [also known as tacrolimus Ed.] 1ml twice a day and folic acid 5ml) and do regular monitoring and platelet check, but every time I've checked my platelet count falls to 7000 and now it's dangerously low 7000.

I'm currently under emergency treatment which is transfusions of platelet concentrates. But Doctor said to me that is a temporary treatment and it's not going to work. I'm really scared. I have 6 years old son and I'm not going to die.

Could you please let me know is there any other treatment options or generic alternative to the medications that I'm currently taking?

I found out there is a new medication called Tavalisse [also known as Fostamatinib Ed] that FDA approved recently. I was wondering if you have information about this medication? I'm not sure how much is the cost and if there is a way for an international patient to buy it.

A

Prof. Adrian Newland replied

Thank you for your query. Most

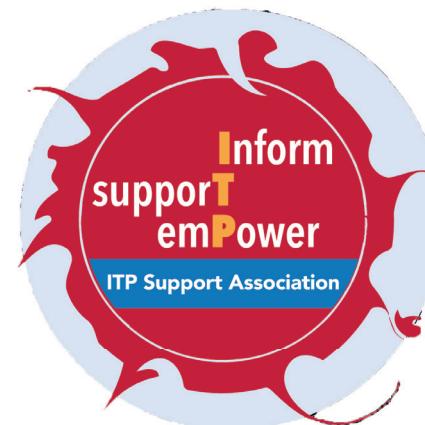
Your Questions cont...

haematologists have access to treatment Guidelines and therefore the approach to ITP is fairly universal around the world. The treatment that you have received is very standard and has clearly worked well for some years. The addition of Hydroxychloroquine is often added to treatment if the discovery of an Anticardiolipin antibody suggests a diagnosis of Lupus, although this is often not the case. The addition of Tacrolimus (Prograf) is used as an additional immune suppressive agent, this is not much used in the UK where we tend to use Cyclosporin or Mycophenolate but is well accepted for this indication although more widely used to prevent rejection following organ transplantation.

The question is what to try now that your platelet count is less than 10. You do not say whether you have any bleeding problems as we prefer to judge severity on whether there is bruising or bleeding rather than on the count alone, which at those levels may not be very accurate. The use of platelet transfusions can be helpful in an acute situation but should be avoided for more long term use as the body becomes resistant to them. Tavlisse (Fostamatinib) is now licensed for use but tends to be reserved at the moment for when other options have been tried and failed. Whether it is obtainable in Iran I do not know.

Our own policy at this stage would be to use one of the agents known as Thrombopoietin receptor agonists. The two most widely used are Romiplostim (Nplate) and Eltrombopag (Revolade), both are used extensively in the Gulf area and should be available. Both have very similar clinical effects but one is given by

injection and the other as a tablet and use would depend on availability and your doctor's experience. This would be the choice at this stage. I can assure you that the risks of dying from ITP are extremely low. The risk is greatest in those with extensive bleeding despite treatment or when there are additional medical conditions or medications that increase the bleeding risk.



UK ITP Support Association Convention 2020 Sponsorship Options

In celebration of the Associations 25th Anniversary we are also pleased to announce that the 2020 United Kingdom ITP Support Association Convention will be back in London for the first time since 2017. The UK Convention will take place on 9th May 2020 at the Royal College of Pathologists in their brand-new headquarters building in Alie Street, London. Sponsorship options for the 2020 Convention are as follows:



- Complimentary exhibitor table space
- Prime exhibitor table placement
- Logo placement 50% larger than Silver and Bronze Sponsors
- Company logo on convention programme distributed to potential UK & Overseas attendees
- Company logo on all convention pages on the website (up to 15,000 monthly visitors)
- Editorial recognition in all quarterly newsletter convention related articles (2,000 circulation)
- On-site signage with company logo and sponsorship level
- Company logo on convention program cover
- Acknowledgment in Special Thanks section of convention program
- Recognition during convention opening presentation
- Four full convention registrations and two exhibitor registrations



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EXHIBITS

Those attending the convention (Patients, caregivers and medical professionals) are continually seeking information about products and treatments that will help manage ITP and improve their quality of life. The exhibition area is strategically arranged for exhibitors to meet conference attendees. Located directly adjacent to the conference meeting space, exhibiting allows exhibitors to interact and network directly with target audiences and build brand recognition.

For further details or if you would like to discuss sponsorship for this event please email: mervyn.morgan@itpsupport.org.uk

Ways To Donate

Wonderful Organisation



The ITP Support Association are pleased to announce that due to the impending closure of BT MyDonate (end June 2019) we will be using the Wonderful Organisation for our supporters to make donations at <https://www.wonderful.org/charity/theitpsupportassociation>

Facebook



Towards the end of 2018 many friends of the ITP Support Association have used Facebook as a platform to help raise donations for the Association. This has raised almost £14,000 in support of the ITP Support Association in less than nine months. Facebook has 'no fees' which means 100% of the contributions are donated to the ITP Support Association.

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



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

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

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

Publications List

BOOKLETS

Know about ITP

core information booklet

Fatigue in ITP

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

What did you call it?

question & answers about adult ITP

What did you call it?

question & answers about childhood ITP

ITP 'n stuff

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

Drugs that cause or aggravate thrombocytopenia

drugs to avoid with ITP

Splenectomy

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

Holiday insurance & travel guide

advice on travelling, flying, vaccinations & insurance

Protocol for dentists treating patients with ITP

to give to your dentist

Guidelines for schools, clubs and playgroups

to give to a child's school

Choosing your sport

which sports are safe with ITP?

James/Jessica tells his/her story

a book about ITP for newly diagnosed children

'I have chronic ITP'

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

FACTSHEETS

Treatment table

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

Holiday factsheet

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

Pupil's factsheet

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

Employer's factsheet

ITP information with space for employee's emergency details

ALERT CARDS

ITP Emergency card £5.00

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

ICH alert card

an alert card demanding immediate medical

Publications List cont...

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

FUNDRAISING & MISCELLANEOUS

Fundraising pack

suggestions for those interested in running a fundraising event

How does the Association use your donations?

an explanatory leaflet

About ITP and the Association

explanation about the condition and our work

Gift aid declaration form

tax payers can increase the value of their donations

Gift aid cards & envelopes

for donations collected at events, parties or funerals

Standing order form

for supporters wishing to make regular donations to the Association

Leaving a legacy

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

Collection box

rigid plastic, or pyramid foldable card, please state preference

ARTICLES PUBLISHED IN PREVIOUS ISSUES OF THE PLATELET

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

Publications List cont...

35. Where are we with ITP today?
36. Are young platelets better?

AMERICAN PERSPECTIVES

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

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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

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