



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

Cover image Networking @ Convention 2023



The Platelet

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The ITP Support Association Team

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THE ITP SUPPORT ASSOCIATION HQ

The Platelet Mission
Kimbolton Road, Bolnhurst,
Beds. MK44 2EL (UK)
Tel: 01234 376559

Web: www.itpsupport.org.uk

E-mail: info@itpsupport.org.uk

Shirley Watson MBE Founder

TRUSTEES

Professor Adrian Newland CBE (Chair)
 Derek Elston
 Xenia Norman
 Colin Williams
 Anthony Heard (Patient Observer)

OFFICE

Chief Executive

Mervyn Morgan

Deputy Chief Executive

Dianne White

Office & Fundraising Administrator

Liz Gooch

VOLUNTEERS

Social Media

Anthony Heard

Mervyn Morgan

Group Liaison

Derek Elston

Patient Mentors

Rhonda Anderson

Derek Elston

Karen Smith

Website

Mervyn Morgan

MEDICAL ADVISORS (Adult ITP)

Prof. Adrian C. Newland CBE
 MA FRCP FRCPATH
 Dr. Drew Provan
 MD FRCP PRCPATH
 Dr. Jecko Thachil
 MRCP FRCPATH
 Dr. Will Lester
 MBChB(hons), BSc, MRCP, FRCPATH, PhD
 Dr. Nichola Cooper
 MA, MBBS, MD, FRCP, FRCPATH
 Dr. Gerard Crotty
 MB BCh BAO, FRCPATH, FRCPI
 Dr. Catherine Bagot MBBS
 Dr Vickie McDonald
 Prof. David Kuter
 Louise Taylor ITP Nurse Consultant

MEDICAL ADVISORS (Childhood ITP)

Dr. John Grainger
 MBChB MD MRCP FRCPATH
 Dr. Mike Richards
 MA BM BCh DM MRCP FRCPATH
 Dr. Cindy Neunert
 MD MSCS

AMERICAN PERSPECTIVE (Contributors)

Dr. Cindy Neunert
 MD MSCS
 Prof. Spero R. Cataland
 MA FAAP (USA)
 Dr. Adam Cuker
 MD MS
 Dr. Rachael Grace
 MD MMSc

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

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

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



From ITP HQ

In this edition of the Platelet you will see a report on our recent Annual ITP Support Association Patient Convention which took place at the Royal College of Pathologists in London.

If you could not make it to our Patient Convention, then you can still watch the presentations as all the talks at the Convention have been recorded and are free to view for members of the UK and Ireland ITP Support Association, if you are a member and have given your consent for us to email you (under GDPR rules) you would have already received login details. If you are a member but have not consented for us to contact you by email you will need to email us with your details, we will then arrange login details. If you are a member and have consented for contact by email but have not received your login details please check your junk mail folder before contacting the office on info@itpsupport.org.uk.

The Convention recordings can be found at www.itpconventionuk.org, just login with the username and password you would have received (if you consented to contact by email).

For those who are not members of the ITPSA you will need to join to be able to view all of the recordings. Visit www.itpconventionuk.org and click on membership.

The list of talks available to view are as follows:

How do I handle the patient with ITP – Dr Drew Provan
 What is the problem with Steroids? – Dr Quentin Hill
 The use of Rituximab – Dr Marc Michel
 Update from the Adult ITP Registry – Dr Vickie McDonald
 Shared Decision Making – Dr Cindy Neunert
 Viruses, immunisations, and ITP – Dr Sue Pavord
 Why do we get ITP – Prof John Semple
 What is new in ITP – Dr David Kuter
 The management of teenagers and young adults – Dr Nikki Cooper
 The wider use of Thrombopoietins – Dr Cindy Neunert

ITP Support Association 25 Years

Although we are now in the Associations 28th Year, due to Covid our 25th Anniversary celebration was postponed due to the restrictions in place at the time, however we are pleased to say that it finally went ahead on Friday 12th May at the Charterhouse in London. Those in attendance included the Trustees and board members, volunteers, medical advisors plus international guests. A report can be found in this

edition of the Platelet.

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

ITP Support Associations Platinum Sponsor for 2023.

We have been working with Sobi on a number of projects in recent years, these include the ITP Discussion Guide, details of which can be found in this edition of the Platelet. They also supported our activities during ITP Awareness Week 2022, and I am pleased to say that as part of this sponsorship we are also working on some very exciting projects for Awareness Week 2023.

Mervyn Morgan CEO ITPSA



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New Deputy CEO for the ITP Support Association

We would like to introduce you to Ms Dianne White, who is joining the ITP Support Association as cover and support for the CEO Mervyn Morgan.

Dianne has a wealth of experience as a patient with ITP and was first diagnosed in 1992, after remission in 1993, the ITP did not return until 2013.

As a patient at one of our major teaching hospitals Dianne was asked to sit on the Haematology Patient Panel and also Haematology Clinical Governance in 2018.

She has taken part in several initiatives since becoming a member of the ITPSA, running a patient support group in the Northwest, involvement in the Patient Discussion Guide preparatory work and also interfacing with Novartis, Sobi, Grifols and the James Lind Alliance on varying ITP related projects in the areas of Education, Patient Support and Research.

Recently she was the Patient Advocate on the NICE Committee Appraisal for the TPO RA Avatrombopag and is currently the ITPSA member liaison on the EurACT project (European Atlas on Clinical Trials in Cancer and Haematology) collecting data on PROs.

(Patient Response Outcomes) in Haematology and Oncology medical trials in UK and Europe.

Mervyn Morgan said, we are pleased to have Dianne on board, the work of the Association has grown so much in recent years with an international reach, with Dianne's input we will be able to continue this work and grow the Association further.



The ITPSA Annual Patient Convention

The ITPSA Annual Patient Convention – London 2023



The ITP Support Associations Annual Patient Convention took place at the Royal College of Pathologists in London on the 13th May 2023. This was our first in-person event post covid and despite the train strike, that put paid to the plans of many patients it was a great success.



The Convention brought together patients, haematologists, and other healthcare professionals from all over the UK and from around the world to discuss the latest news in the treatment and care of those with Immune Thrombocytopenia.

Here are some highlights of the Convention:

Patient involvement

The Annual ITPSA Patient Convention is unique in that it is focused heavily on patient involvement. Patients were invited to share their experiences with the healthcare professionals and give their

thoughts on how the condition effects their life. There was also an emphasis on Shared Decision Making with the treatment and management of ITP, this approach was refreshing, as it gives patients a voice and allows them to be active participants in discussions with their healthcare professional.

Networking opportunities



The Convention also provided excellent networking opportunities. Attendees had the chance to meet and connect with some of the leading healthcare professionals in the field from around the world. Plus, it was also an opportunity for ITP patients to meet other ITP patients.

Speakers

The ITPSA Annual Patient Convention, as always is blessed with an impressive line-up of speakers. This year the speakers giving talks were Prof David Kuter, Prof Adrian Newland, Dr Quentin Hill, Dr Vickie McDonald, Dr Drew Provan, Prof John Semple, Dr Cindy Neunert, Dr Sue Pavord, Prof Marc Michel and Dr Nikki Cooper.

All of the talks at the Convention have been recorded and are free to view for members of the UK and Ireland ITP Support Association, if you are

a member and have given your consent for us to email you (under GDPR rules) you would have already received login details. If you are a member but have not consented for us to contact you by email you will need to email us with your details, we will then arrange login details.



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Conclusion

Overall, the Convention was a massive success. It provided an excellent platform for patients, healthcare professionals, and researchers to come together and discuss various aspects of their condition. The focus on patient involvement was particularly refreshing and provided valuable insights into the challenges faced by patients. The networking opportunities and the impressive line-up of speakers made the Convention an excellent learning experience for all attendees. We look forward to the next Convention in 2024 and hope that it will be just as successful as this one.

Thanks as always to our Convention Sponsors



ITPSA Platinum Sponsor



Event Sponsors

ITP Support Association 25 Years

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Charterhouse is a building well worth visiting when in London, it dates back to 1371, for more information visit <https://thecharterhouse.org/>



Where would you like the 2024 Conference?

ITP Support Association - Annual Patient Conference 2024 - Which Location?

Every year the UK and Ireland ITP Support Association holds its Annual Patient Conference, this year the event was held in London, this was preceded by three virtual events (due to Covid), our last in-person Patient Conference (pre-covid) was held in Dublin, Ireland.

Have your say, Your feedback will help us decide our 2024 Patient Conference Location.

To take part in the survey please use this link: <https://www.surveymonkey.co.uk/r/WKPJN32>

A graphic for a survey. On the left is a red circular logo with a jagged, sunburst-like edge. Inside the logo, the text reads 'Inform support emPower' in white and yellow, with 'ITP Support Association' in white on a blue background at the bottom. To the right of the logo, the text 'ITP Support Association Annual Patient Convention' is written in white. Below this, the year '2024' is displayed in white. At the bottom right, there are seven question marks '???????' in white.

ITP International Alliance Meeting

The ITP International Alliance held their first business meeting of the year in London in May as part of the ITP Support Associations Annual Patient Convention which was held at the Royal college of Pathologists.

Members from around the world (North and South America, Australia, and various European Countries) attended the meeting to discuss the future structure of the organisation which now consists of over 30 Associations worldwide.

For more information about the ITP Global Alliance please visit www.globalitp.org



Virtual Group Meetings

Virtual Group Meetings to resume shortly

We put virtual patient meetings on hold earlier in the year when Mervyn had a short stay in Hospital, we are now looking to resume our virtual meetings in the next few months, please keep a lookout on our social media channels and email newsletters for dates

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

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



PATIENT MENTORS

Rhonda Anderson

Tel: 0208 504 2688

E-mail: rhonda.anderson@virgin.net

Derek Elston

Tel: 0151 625 8213

E-mail: derek.elston@itpsupport.org.uk

Karen Smith

Tel: 07521 279565

E-mail: k.smith01@btinternet.com

New Medical Advisors



We are pleased to announce two new Medical Advisors have joined the ITP Support Association, both of whom will already be known to our members.

Dr Vickie McDonald

Dr Vickie McDonald is a consultant haematologist at the Royal London Hospital, UK. Her main interests are disorders of coagulation, including ITP. She looks after patients with inherited and acquired disorders of clotting. She is the current lead for ITP services at the Royal London Hospital, the Chief investigator of the UK adult ITP registry and CI for several clinical trials for patients with ITP in the UK. She is an honorary senior lecturer at Queen Mary University of London and deputy director for clinical research for Barts Health and Queen Mary University London.

Dr McDonald has supported the Association in a number of its Zoom patient Meetings in recent years and has also been active at our virtual and in-person patient conferences.



Professor David Kuter

Professor David Kuter is a haematologist and medical researcher who specializes in the study and treatment of blood disorders, including immune thrombocytopenia (ITP). He is currently a faculty member at Harvard Medical School and has served as the director of the Haematology Division at Massachusetts General Hospital. Professor Kuter has conducted extensive research on the use of thrombopoietin (TPO) receptor agonists as a treatment for ITP and has contributed significantly to our understanding of the underlying mechanisms of the disorder. He has also been recognized for his contributions to medical education and has received numerous awards and honours for his work.

Professor Kuter has presented at a number of the Associations Patient Conferences over the years and has been a good supporter and friend of the Association.

Living life feeling like a pioneer! By Sue Weall



My ITP journey began in February 2021 with my first Astra Zeneca covid vaccination. I felt unwell 10 days later and after a phone chat with my GP, I shared photos of my mouth blisters and went for a blood test. Results showed my platelets were at 6 and I was swiftly

admitted to Poole hospital. My reaction to the vaccine was yellow carded in March 2021. Weekly care for my ITP has been from Poole Hospital, University Hospitals Dorset NHS Foundation Trust (UHD), my Haematology Consultant Dr Ram Jayaprakash and my team of a specialist pharmacist, nurses, and phlebotomists.

After initial local hospital interventions in 2021 and my introduction to steroids, I started Eltrombopag. This did not last long as I experienced headaches and severe nose bleeds after less than a week, then was changed to Romiplostim. I had increasing doses of Romiplostim from April 2021 – February 2023, initially at Poole hospital for 10 months then self-administered at home but with many side effects, including granular dermatitis over half my body. Dosage was increased incrementally whenever platelets fell dramatically. Side effects increased to a level which I was finding difficult to live with, including muscle & joint pain, low moods.

Dr Jayaprakash referred me to Dr Nichola Cooper (Imperial College Healthcare NHS Trust) later in 2021 and I first saw Dr Cooper at her ITP Clinic (Hammersmith Hospital) in January 2022, and now every 6 months.

Dr Jayaprakash and Dr Cooper agreed in February 2023 to try me on 100g twice daily on a drug new to the UK, Fostamatinib. My blood pressure gradually increased over the next month and reached 210/110. Then blood ulcers appeared in my mouth and nose bleeds started daily. I felt unwell with a sore throat but tested covid negative with lateral flow test at home. Went to Poole Hospital for a blood test, found my platelets had fallen to 7 and I was surprised to be positive for covid when tested for admittance to a ward.

I was the first person in Dorset to take Fostamatinib and few people in the UK are on the newly licensed drug. So, I feel like a cross between a pioneer, and a guinea pig, as consultants and teams increase their clinical experience. I have never met someone with ITP, face to face and it is quite an isolating disease as so rare. When you can try a new treatment, you become the local patient expert. I am hoping to get to the ITP Support Association Convention in 2024, Online was a valuable learning experience for me in 2022.

After in-hospital treatment March 2023 with covid isolation including steroids, blood pressure medication, I gradually recovered from Covid. Restarted Fostamatinib once daily 150mg (rather than twice 100mg) from early April. Some symptoms, side effects but other meds were, in the mix, and weaning off steroids. Platelets rose whilst on steroids but afterwards, kept falling even with Fostamatinib so weekly doses of Romiplostim added back in but only 200mcg/0.4. Combination not great to live through most weekends but hopeful things will improve. Ongoing experiment to find a balance and by mid-May my platelets had gone up to 215.

Diarrhoea was a problem by end of April, five or six times a day, and diarrhoea relief medications made me feel very dizzy, headaches, and generally unwell. So, a short break from Fostamatinib, but continued with Romiplostim and then reintroduced Fostamatinib at a low dose of one 100mg in the evening rather than the morning. Ongoing experiment, ongoing pioneer but seeking a balance in my life so that I get the freedom to leave home and engage with family and friends more consistently. Small victories and achievements count much more than in the past. I'm hopeful that things will stabilise soon.

For all of you and your ongoing treatment, surround yourself with people who will encourage and support you, try to understand your unpredictable life filled with numbers that rise and fall, lift you up when it gets hard and have fun together whenever possible.

My story goes on, and perhaps from where I was in February 2021 that is my success story!

Sue Weall, 67 years old, Poole, Dorset, UK

A is for Anxiety, P is for Peace

If A is for Anxiety and P is for Peace, how do we get from A to P?

This is not an easy question to answer and everyone will have their own ideas and ways of doing this. Sadly, some will struggle to achieve peace of mind, but on this journey of life, we encounter many things that give us anxiety or peace, and everything in between.

Imaging a scale of zero to ten, with zero not at all, and ten extremely high, where do you score yourself on the Anxiety scale? Where do you score yourself on the Peace scale? I doubt anyone scored themselves either zero or ten, although it doesn't matter, as it is just an indication to yourself of how anxious you are, or how peaceful you are. Most would probably wish to be less anxious and more peaceful. However, you may be very happy with where you are.

Anxiety, like stress, is a normal part of human nature, part of our inbuilt survival kit. Even if you experience it, and it impacts your life, it can usually be managed. Having a long term condition such as ITP, can cause anxiety and stress. The pandemic has left a lot of people fearful and anxious about even going outside their own homes, let alone mixing with anyone.

If you feel your anxiety is unmanageable, then you should seek professional help, especially if you feel like hurting yourself or others, and if you are suicidal.

I am not medically qualified, but I offer you some ideas that have helped me, and others that are known to assist.

During Mental Health Awareness Week this May, the emphasis was on Anxiety as a mental health condition, and there have been many radio programmes and much media coverage on that topic, I have especially heard some on the BBC. It is great to hear that you are not alone and hearing others' experience can be very helpful and supportive. Do look them up for excellent interviews with doctors and people with lived

experience of this condition.

Stress and anxiety are different. Stress has a definite cause, such as going to the dentist, you know what it causing it, and once the event is over the stress dissipates.

Anxiety has less defined causes. Often people have distinct physical symptoms, especially before they experience a Panic Attack. These feelings can be overwhelming with rapid heart rate, dry mouth, sweaty palms, feeling faint, difficulty breathing, talking and making sense, and overwhelming feelings of doom.

How can we deal with these feelings of anxiety before they get too serious?

I offer you some ideas below.

The top tip from health professionals was to Breathe. This may sound silly, of course we all breathe, but anxiety can disrupt breathing, we tend to hold our breath, and breathe shallowly. Concentrating on your breathing has beneficial effects on your brain systems and helps to calm you down. It is the one thing to remember as a method to help yourself if you begin to feel overwhelmed by Anxiety.

If you are tempted to use alcohol, smoking, recreational drugs and over eating as ways to combat Anxiety, please think again. Many of these things can actually exacerbate the condition.

Distraction is a great way to make your mind think of something else. Concentrating on something pleasant and interesting, that you can lose yourself in, helps the restless mind. Do a course on something creative such as cooking, or many other things that are on offer and above all, that you enjoy. Get friends to share ideas with you on anything they are good at and share back again.

Physical exercise, walking, gym classes, sport and gardening are some things to consider. You will know what interests you and your loved ones and your capabilities. Being physically active aids good

A is for Anxiety, P is for Peace Continued...

sleep. If Anxiety disrupts your sleep, ask your GP or Pharmacist for help. Do use some of the ideas here too, as they may help with sleep.

Cultural activities such as music, art, museums, and theatre are the interest of some people and all of this can be very enjoyable, and you also learn things from them. Art therapy can be very useful for some people. Others enjoy adult colouring books for relaxation. Then you have a coloured picture to display.

Social interaction with others is good for you, phoning a friend, going out, having a coffee, seeing a film, or eating a meal together, out, or at home. Keep it simple.

Learn something new. A game, dancing, pottery, sewing, knitting, crochet, a sport, a language, an instrument.

Join organisations such as u3a, The University of the Third Age, which is for over 50s and everyone gives their expertise for free. Some groups also do holidays.

The Arts Society, or any other organisation that will suit you such as a tennis club, a social club, or a film club. There are many rewards from volunteering, and helping others is a great way to give your time and feel given to. Everyone loves volunteers.

Mindfulness and Meditation are lovely calm ways to relax and feel better in yourself, deep down. Many free Apps are available and some online groups.

Writing a diary or making notes or letters can be a very useful way of getting feelings out of your head. No one else needs to see them. Writing a gratitude diary can help to give the realisation of all the good things in our lives that we can be thankful for. This gives a more positive attitude and then you may begin to look out for the things you are grateful for, to note down. This time of year gives us a huge riot of colours and sweet smells from the flowers which seem to be especially beautiful this year. I love seeing the cygnets and ducklings on our walks to

local parks. It really does lift my spirits to see them swimming around with their vigilant parents.

One University is giving Lego to students to help them combat exam anxiety. We might in fact call this stress as we know what is causing it and there is an end to it when the exams are over and the results come out. However, if you feel constructing with Lego, (I hesitate to say 'playing'), will help you, there are plenty of Lego stores and online sellers who will be delighted to take your money. In fact, you may have some Lego your children used at home. Go on a Lego hunt in the loft or cellar, or in the toy boxes when you visit the grandchildren. They do now sell very expensive sets to construct space stations, Land Rovers, all kinds of machinery and items and it is called Adult Lego. Have a go! It is very good for us to make something and see an end product, it gives great satisfaction and helps allay anxiety. Make something today!

You may be fine, but someone close to you may need support with their anxious feelings. Here are some ideas that may help you find a way to support them.

Ask them how you can help.

Don't only focus on anxiety, encourage them to explore support. This may be from family and friends, or from health professionals.

Encourage them to take daily exercise of their choice. Very mild and then building up. This may seem a chore at first, but it does become more enjoyable as it develops into a looked forward to daily habit, especially if accompanied by family or friends.

Be reliable and be there for them.

Encourage them to try something new. We are fortunate to have a lot of awareness now about the need for support and even the local library may have things to do and join, from Knit and Natter, to Book Groups and talks on varied subjects. My library even has an adult games group. That sounds a bit ambiguous doesn't it!!!

In summary, a healthy life style helps us to help ourselves. Eating a balanced diet with good hydration and weight control, avoiding alcohol, smoking and recreational drugs, getting daily exercise, a good night's sleep and doing enjoyable things, all adds together to aid getting from A to P.

I hope this article has given you some ideas that you feel drawn to try, to take you on your journey from Anxiety to Peace. Good luck and Bon Voyage!

Rhonda Anderson May 2023

The following information may be of some help, please remember the ITPSA does not have any control over the content of these website.

This link below is particularly helpful on the NHS site and really goes into some good detail about where to go and what to explore.

<https://www.nhs.uk/mental-health/feelings-symptoms-behaviours/feelings-and-symptoms/anxiety-fear-panic/>

MIND

<https://www.mind.org.uk/>
0300 123 3393

The Mental Health Foundation online

<https://www.mentalhealth.org.uk/>

Anxiety UK

<https://www.anxietyuk.org.uk/>
03444 775 helpline
07537 416905 text service helpline

Young Minds (for children and teenagers/young adults)

<https://www.youngminds.org.uk/>
020 7089 5050

Royal British Legion for any serving/ex serving or connections with Armed Forces

<https://www.britishlegion.org.uk>
0808 802 0282

Plus, don't forget you can always contact your GP and request a referral to Talking Therapy" in your local area

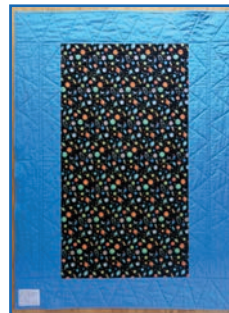
Books that might be of interest (available on Amazon):

Eat Yourself Healthy - Dr Meghan Rossi (regularly presents on television)

Happy Mind, Happy Life - Dr Rangan Chatterjee (again, regularly hosts broadcast programmes on Health)

Overcoming Anxiety - Helen Kennerley (A prize winner in the British Medical Awards)

Our Senior Rhonda Anderson has always said doing something creative can also help with one's mental wellbeing, looking at this quilt she made for her Grandson Wilbur she is right. It is just wonderful.



Experience of Roger Woodward

Experience of Roger Woodward, Sevenoaks, Kent – October 2020 – February 2023

It all started when I got an enormous bruise on my chest (the size of my whole hand) after catching it on the top corner of the car door in a tight car park. I didn't think anything of it at the time but noticed that I was getting bruises easily and after a week or two I started getting blood blisters in my mouth and black spots on my tongue. My GP sent me for a blood test, and I was immediately called in the hospital where I stayed for a week. After various steroids (Prednisolone) and an immunoglobulin infusion I was released when my platelets were in the teens. Two weeks later I got more black spots and red spots on my shins and was back in hospital again for eight days. The same procedure, except this time, I had a bone marrow biopsy taken which showed that I was producing my own platelets. I was started on Romiplostim injections the dose of which was increased, and this worked for a few weeks and then suddenly crashed at the same time as I had a sinus infection. I was back in hospital for two days and put onto Eltrombopag that never worked even after the dose was increased. I had several more emergency hospital admissions with blood platelets below 5, several immunoglobulin infusions, and short courses of steroids. and eventually, after nine months, was given four Rituximab infusions. After a few weeks, the platelet count started rising from single figures (two) through the teens to about 50 after a month, then to around 300 after another month. Two weeks later, they were 298. I have had no more spontaneous, bleeding in my mouth or bruises elsewhere since then.

I found the whole period very stressful. All the blood testing was done at a local hospital which didn't have booking facilities, so I was going there four times a week for either blood tests or Covid tests or treatment at the Haematology centre,

sometimes waiting for treatment up to 4 or 5 hours each week. From day today, I lived in fear of blood, blisters, bruises, et cetera leading to yet another hospital admission. I never felt particularly ill but out it really affected mentally. I was unable to travel or do anything really. Since I live on my own, this was particularly difficult to cope with. The ongoing Covid situation didn't help and on one of my emergency admissions. I had Covid myself being in hospital was a horrid experience on that occasion.

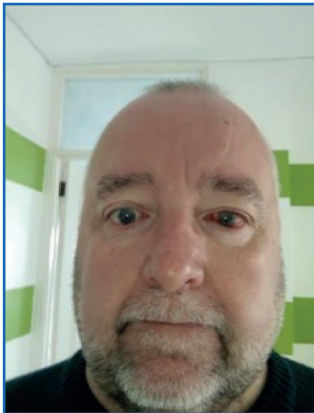
Following the rituximab infusion, I developed swelling in my lower legs, with a tenderness and rash. My GP seemed baffled by this, and I never really got an answer or resolution. This together with pain from arthritic knees, made walking extremely difficult. This seems much better after six weeks or so. The steroid treatment also made me put on a lot of weight and not being able to exercise it's very difficult to lose it.

My initial treatment was by admission at Tunbridge Wells Hospital, the second and subsequent times were all at Maidstone hospital, each time requiring a lengthy assessment period in A&E of course. My Haematology specialist at Maidstone eventually after a second opinion from specialist at Bart's in London, but the rituximab treatment was authorised and carried out at Maidstone. I only got a call from the doctor at Barts after that had been completed. I'm expecting another call in April.

I am delighted at being able to stop to get back to a normal life. I've even booked a short overseas trip in two months' time and possibly a longer cruise in six months' time but I'm a bit worried about getting insurance*.

*Editors note regarding Insurance, many ITP Patients have found companies such as Staysure offer travel insurance coverage at reasonable rates.

Patrick Doyle's ITP Journey



My journey with ITP started in 2010 with a subconjunctival bleed which covered 3/4 of the white of my eye. I saw my GP and had blood tests. These were repeated at closer intervals until my GP phoned to say he had been consulting with haematology at my local hospital. He was in the process of writing a letter for me to take to A&E where they would organise a bed for me. My platelets were at 8 with no visible symptoms and I was started on 100 mg IV steroids for 2 days then discharged on 90 mg oral for two weeks then reducing. Thankfully this put me into remission although the side effect was horrid. I was told if I was clear for ten years it wouldn't return. Imagine my surprise when twelve years later I found a mouthful of blood blisters and the following day petechiae all over and bruising. Off to A&E platelets at 3 started on steroids no effect. Got to 7 had IVig and bag of platelets. Next day was at 0. No more platelets given but had second IVig. Eltrombopag was given at 50 mg and a slow increase

in platelets began and 4 infusions of Rituximab began. After the first of which I reached 67 and after 17 days in hospital I was discharged. My numbers have remained in the 200s. I am not on any medication at the moment and am hoping remission will be confirmed soon.

We need to be aware that this disease not only affects our physical health but our mental health too. Compared to many sufferers I am very lucky, but it has messed with my head leaving me anxious about its inevitable return.

Editors note, there is an excellent article in this edition of the Platelet by Rhonda Anderson covering Mental Health, the article also contains a number of very useful links to help people find support.



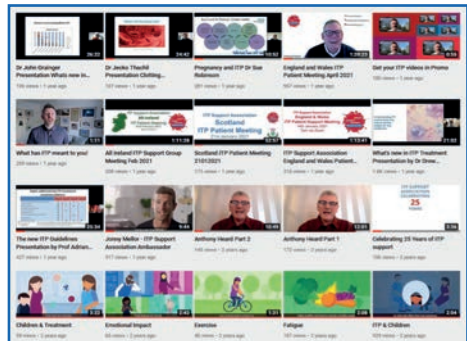
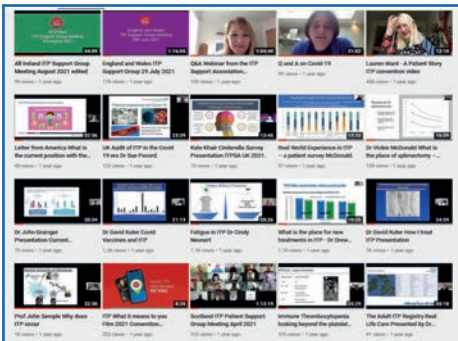
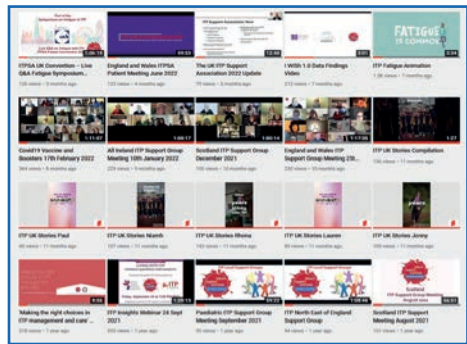
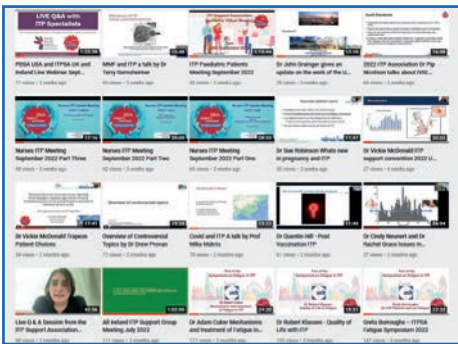
Visit Our Youtube Channel

Visit the ITP Support Association YouTube Channel

We have our own YouTube Channel with numerous helpful, informative & interesting videos covering a wide range of ITP related issues - <https://www.youtube.com/channel/UCRkHwFvYAAIKKajFI4L37g/videos>

or go to our website at www.itpsupport.org.uk and click on the YouTube Social Media icon under the top menu. We have over ninety ITP related videos available and are adding more all the time.

Please subscribe to the channel.



My ITP Story by Simon Edwards



I'd start at the beginning if I knew exactly when that was; in late 2020 I started to show some bruises after doing DIY and only now two and a bit years later do I have some slight suspicion that it is linked to my official ITP diagnosis made in July 2021. Since

my diagnosis I've thrown a great deal of effort into building a timeline - I have been playing detective at times as I don't normally keep a journal of everyday events; so receipts, emails and photos have all been very useful to piece things together, as well as talking to people who may have noticed anything but didn't mention it to me at the time...

I now know that my first sign was at the very end of May 2021 when my dental hygienist noticed excessive bleeding, the same day that I had been for my second Covid vaccination. Then over the weekend I noticed faint red spots on my arms and legs. Petechiae, I discovered after a few web searches, but I still can't pronounce it! I'll not mention too much about my experience with my GP surgery; whilst knowing my symptoms were quite serious, and despite my efforts to communicate this, to be seen and get a successful blood test, it was not until the first week in July that I was officially diagnosed with ITP. Meanwhile in June I had raised my own Yellow Card report with the Medicines & Healthcare products Regulatory Agency for my Petechiae as a suspected side effect of the Covid vaccine and my research had led me to believe that I had ITP. In hindsight I'd have been better ringing NHS 111 to start with...

When I did finally get a Full Blood Count done it was the morning of the fifth of July 2021 and late that evening NHS 111 instructed me to go to Accident & Emergency immediately as my platelet count was nine. After a couple of days of being monitored at the Leicester Royal Infirmary, as well as a CT scan and a few other tests, the Haematology department put me on 70mg of Prednisolone for a fortnight. It was noted by registrars and consultants that the onset of ITP and the timing of my vaccinations were most likely related. However, never one to leave any

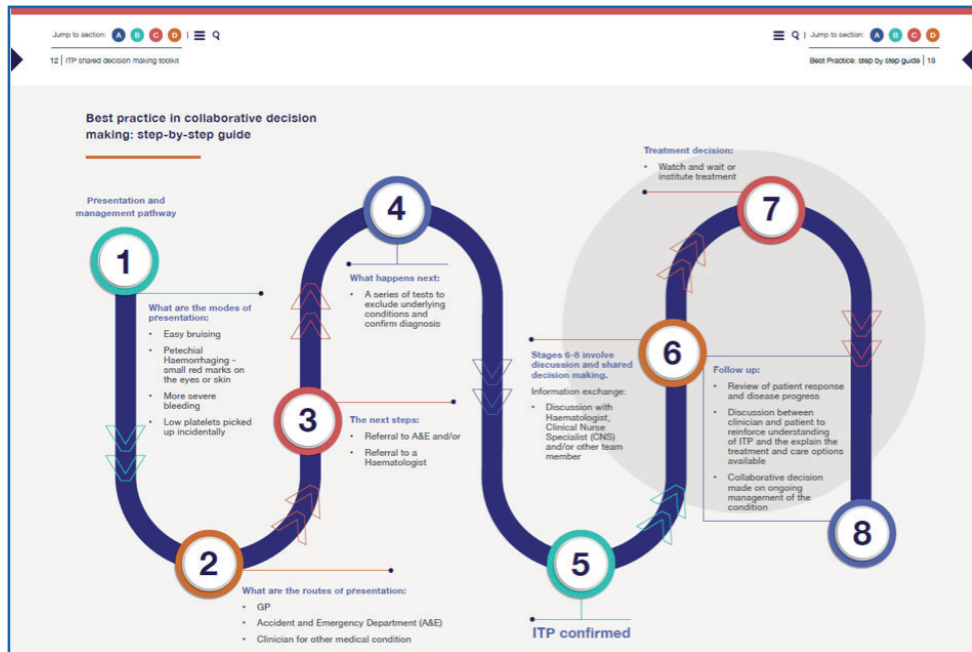
stone unturned, I have had my domestic water supply tested as for excessive lead content and searched for any research mentioning lead or any other chemicals in the home that are linked to ITP. Since my admission I've also had a trephine of my hip bone, my marrow is functioning OK, and a Helicobacter Pylori breath test which was negative too.

Only a high dose of Prednisolone has any noticeable direct effect on my count, as I write this after eighteen months on steroids my count was fifteen last week with slight Petechiae and feeling rough at times. I had been tapering my dose down to 5mg every other day whilst also on 2000mg of Mycophenolate Mofetil daily, so that wasn't working at all. On average over my ITP history my count has been about thirty but dipping to nine on occasion. I am asymptomatic at anything above about a count of twenty. I am currently waiting for a delivery of Doptelet (Avatrombopag) and I have high hopes as this is a Thrombopoietin (TPO) drug to boost platelet production rather than another immunosuppressant. Trying something new and being free of steroids will be something to celebrate. It isn't a cure, but a stable platelet count at about fifty will be a daily joy as well as improving my confidence to travel again.

Previous to my ITP Story I often wondered whether some of my other ailments were related to Lupus, tests have said not but I'm still keeping an open mind on this. Speaking to my father who is now in his mid-eighties I have been noting his references to bleeding and bruising and so I am trying to encourage him to have a Full Blood Count, even though he has had surgeries etc in the past without issue. If there is a factor of inheritance then again, more confidence comes from knowing he has lived to that age otherwise unaware of ITP!

Everyone has a different mean baseline platelet count and we know that viruses and vaccinations of all kinds can lower platelet counts temporarily; I do wonder how many people in the world with mediocre baselines are asymptomatic and unaware of any problems even when they have an infection or injection; and how many people with slightly lower baselines are sent to A&E because of their signs and symptoms after similar health issues. Afterall, the difference for me between being oblivious of my condition and being in some danger is just a platelet count of ten.

Shared Decision Making Document available in Six Languages



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

To download the English Language version click this link: [Making the right choices in ITP management and care.](#)

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

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

Shared decision-making toolkit developed for people with Immune Thrombocytopenia (ITP) - a rare autoimmune blood disorder that causes a

shortage of platelets and bruising.

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

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

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

The toolkit is a response to the results of a patient

survey made by the ITP Support Association in 2020. The survey highlighted inconsistencies in the diagnosis and management of ITP – which can negatively impact patients.

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

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

This toolkit is ground breaking in that it is one of the first haematological conditions to develop specific guidance in response to National Institute for Health and Care Excellence (NICE) recommendations for shared decision-making practices to be implemented across all conditions. The toolkit is endorsed by the Royal College of Pathologists, Royal College of Physicians, The British Society for Haematology, and the Genetic Alliance UK.

The ITP Expert Working Group and partners are calling for this best practice guidance to be adopted across all healthcare settings in the UK. Professor Adrian Newland, Chair of the ITP Support Association, said:

“Following our recent patient survey, the ITP Support Association identified significant disparities between patient experiences of care and whether individual preferences were considered in care management plans. We decided that we should bring together a group of

haematologists with a particular expertise in ITP to develop this toolkit that, we hope, will empower patients to hold collaborative and honest discussions with their clinician which in turn will result in better outcomes and quality of life.”

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

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

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

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



ITP Patient Explainer

Make the most of your appointment with your care team, using the **ITP Discussion Guide** For people living with ITP



NP-23508 | Date of preparation: September 2022

ITP Patient Explainer Cont...

What is the ITP Discussion Guide?

The ITP Discussion Guide is a tool that can help support focused discussions with your care team about your ITP care goals, needs and preferences.

Highlight what matters most to you and discuss it with your care team to make a joint decision about your care plan.

How do I use the ITP Discussion Guide?

- 1 Complete your personal ITP Discussion Guide** by answering questions about your last month managing ITP
- 2 Highlight your top care priorities** based on your answers, so that you can remember what you want to discuss at your next ITP appointment
- 3 Bring your completed guide** to your ITP appointment
- 4 Use the guide to help structure a discussion with you care team** about what's most important to you in your daily life with ITP

Scan the QR code to complete your own
ITP Discussion Guide

You don't need to register to use the ITP Discussion Guide.
None of your data is stored, tracked, shared, processed or saved.



NP-23508 | Date of preparation: September 2022

ITP Patient Explainer Cont...

Why highlighting what matters most to you with your care team is important

While controlling your bleeding is essential, maintaining your health is also about your ability to enjoy and get on with life.

When you and your clinician understand what's important to each other, you can make decisions about your care together. Your clinician can then design your care plan with your personal needs, preferences, and goals in mind.

Top tips for using the ITP Discussion Guide for your next consultation

- Usually, our first reaction is the most accurate, so don't spend too much time thinking about your answers, just go with your gut
- Remember that each response will be individual to you, so there is no right or wrong answer
- Use the guide ahead of each appointment to track any changes over time, and let your care team know if your priorities have changed since your last appointment
- Ask for an explanation of anything you don't understand or feel unsure about
- Refer to the guide if you feel like your care priorities aren't being heard
- Don't be afraid to say if you feel like your goals, needs and preferences are not being taken seriously

NP-23508 | Date of preparation: September 2022

ITP Discussion Guide



Your ITP Discussion Guide

This guide is designed to help you have more focused discussions about your ITP care needs and preferences with your carer / care team

- 1 **Reflect on your last month managing ITP** and note down what matters most to you. You do not need to complete everything: focus on the elements that are most important to you.
- 2 Once completed, **tick the stars next to the questions that are most important to you.**
- 3 **Bring your completed guide to your next appointment** and discuss it with a member of your care team:
 - Use the guide to outline your top care priorities and go through your other issues in turn
 - Help your care team to understand your goals and what's most important to you in your daily life.
- 4 **Make a joint decision** on your future care plan.

Today's date:

Note down today's date so you can look back and track how you're feeling over time.

____ / ____ / ____

My goals

First, write down your short-term goals; the things that are most important to you right now (this week / month).

For example, having a nice walk with the dog this week.

Then, write down your longer-term goals; the things that are most important to you in the future (next 6 months).

For example, going on a cycling holiday in three months.

Living with ITP

Living with ITP can affect your wellbeing and how you cope with everyday activities. **Use the scales below to rate how ITP affects your day-to-day life. Circle the score that best reflects how you feel.**

Coping with ITP symptoms

How have ITP symptoms impacted your daily life in the last month (including fatigue, bleeding, bruising, etc.)?

☹️ 1 2 3 4 5 ☺️ ★

Feeling on top of things

Do you feel able to carry out everyday tasks like washing yourself, dressing up, cooking, DIY, doing household chores and shopping?

☹️ 1 2 3 4 5 ☺️ ★

Having emotional wellbeing

Do you feel positive (in control of your thoughts and feelings), or more negative (anxious, upset or depressed)?

☹️ 1 2 3 4 5 ☺️ ★

Pursuing hobbies

Do you feel you can pursue the activities you enjoy the most?

☹️ 1 2 3 4 5 ☺️ ★

Spending time with friends and family

Do you feel you can spend time with or care for family and friends in the way you want to?

☹️ 1 2 3 4 5 ☺️ ★

Performing well at work or school

Do you feel you can excel in your work and/or studies?

☹️ 1 2 3 4 5 ☺️ ★

Taking part in sports and exercise

Do you feel you can reach your sport and exercise goals?

☹️ 1 2 3 4 5 ☺️ ★

Use this space to write down further details about how ITP affects your day-to-day life.

ITP Discussion Guide Cont...

Managing ITP effectively

To enable you to live your life the way you want to, it's important to work with your care team to find a treatment that works well for you. **Use the scales below to rate how you feel about your ITP treatment. Circle the score that best reflects how you feel.**

How well does your ITP treatment help you to manage / prevent your symptoms (including fatigue, bleeding, bruising etc.)?

1 2 3 4 5

How satisfied are you that your treatment maintains or increases platelet production?

1 2 3 4 5

How satisfied are you with how often you take your treatment?

1 2 3 4 5

How satisfied are you with the number of blood tests needed to check your platelet count due to treatment?

1 2 3 4 5

How satisfied are you with the way your treatment is administered?

1 2 3 4 5

How easy is it for you to fit your treatment intake into your usual daily routine? (For example, commuting, working, eating, sleeping)

1 2 3 4 5

How easy is it for you to take treatment when your routine changes? For example, when on holiday?

1 2 3 4 5

Overall, how satisfied do you feel with your treatment and/or care?

1 2 3 4 5

Notes:

Use this space to write down further details about how your treatment and care impacts your daily life, or any wishes you would like to share with your care team.

ITP treatment and your goals

Does ITP or ITP treatment currently affect your ability to pursue your personal goals?

YES NO

Use this space to write down how ITP affects your personal goals.

Priority discussion points for your next consultation

Look back over the questions and tick the stars highlighting the elements that are most important to you.

Use this space to write down the 1-3 most important topics you would like to discuss at your next ITP appointment.

And finally...

- Don't be afraid to say if you feel that you're not being heard, or your issues aren't being taken seriously
- Ask for an explanation of anything you don't understand

Fundraisers & In Memoriam

Fundraisers



Marie Price and four other family members completed the Yorkshire Three Peaks challenge and raised £507.50. Marie's daughter, 8 year old Layla has ITP. We are extremely grateful for all Marie's hard work in doing this mammoth climb.

Picture shows Layla holding the cheques, £507 for the ITPSA and £507 for Coeliac UK.

The Sisterhood of Hope Baptist Church Cross keys donated £100.00 in May.

£133.00 from Atlas Trading Limited - they have a collection box for ITP.



Luke Whitaker participated in a charity boxing match in aid of ITP! He has ITP himself "He spent most of his life as a child in hospital and eventually had his spleen removed". Luke decided on raising funds through boxing. He has raised £60.00 through JustGiving.



Thanks to Tony and the brethren at the Warwickshire Freemasons for their wonderful donation. The Cheque was presented to the Associations Trustee Derek Elston at a recent meeting of the lodge.

In Memory:

£252.65 in online and cash donations was raised in the memory of Lynn Thome. We send our deepest condolences to family and friends.

The association received an anonymous donation in May of £489.36.



Leaving a Legacy



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

There are 3 main types of gift you can make:

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

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

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

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

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

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

make a new will.

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

Suggested wording for making your gift to the ITP Support Association

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

Wording for a residuary gift

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

Wording for a gift of money or an item

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

Note

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

Buzzy

Information on the Buzzy® Kits for Paediatric ITP Patients.

WHAT IS BUZZY?

BUZZY® is a small vibrating bee with blue ice-pack wings. He helps block sharp pain and provides distraction when giving injections or other medical procedures.

Just like cool running water soothes a burn, Buzzy® uses a combination of cold and vibration to replace pain with temperature and movement.

Buzzy® confuses your body's own nerves and distracts attention away from the pain, thereby dulling or eliminating sharp injection pain. In the same way that rubbing a bumped elbow helps, or cold running water soothes a burn.



BUZZY® was invented by Pediatric Emergency Doctor and Pain Researcher Amy Baxter. She invented Buzzy® to help her children overcome their fear of needles.

Buzzy® is now used in medical practices, vaccination clinics, hospitals, dental practices, and homes by both adults and children. Over 20 independent clinical trials prove Buzzy® works!

HOW DOES BUZZY WORK?

Gate Control Theory of Pain

The gate control theory is the basis for the design of Buzzy®. The premise is that when nerves receive non-painful signals such as vibration or cold, the brain closes the gate on pain signals. For example, if you hit your finger with a hammer, you might instinctively begin to rub it, shake it, or run it under cold water. You are sending non-pain signals through your nerves to close the gate on the pain signals.

Descending Inhibitory Controls

The second part of Buzzy efficacy, and the reason it can help even when distant from the site of procedural pain, is something called Descending Noxious Inhibitory Control, or DNIC. While gate control happens locally (confusing nerves right where the pain happens) another effective mechanism of pain control uses the brain's ability to dampen out unwanted signals. Instead of happening right where the nerves are, though, an intense degree of cold can work anywhere on the body.

The idea is like putting your hand in a bucket of ice water. Whoa, it's cold! But you can handle the amount of cold initially. Studies have found that when someone's hand is in ice water, they can handle more intense pain everywhere else in the body, probably because the sensation of ice is so intense it doesn't leave as much room for the brain to notice pain as sharply other places.

It is as if when one sensation is very intense, the brain turns the volume down on sensations anywhere in the body. In scientific terms, intense cold activates a supraspinal modulation raising the body's overall pain threshold.



ITPSupport.org.uk

Buzzy Cont...



Helping to take the sting out of ITP.

HOW TO USE BUZZY?

Step 1 - Freeze the Ice Wings

Wings will stay frozen 10 minutes at room temperature. For best pain relief, the wings must be frozen solid to avoid absorbing vibration.

Step 2 - Attach Wings to Buzzy

Slide the ice wings through the elastic strap on the back of Buzzy.

Step 3 - Place Buzzy

For injections, place Buzzy on the injection site for 30-60 seconds. Then move Buzzy up and secure there during the injection. Buzzy must be placed proximal to the pain to be most effective. Buzzy goes between the pain and the brain.

Step 4 - Turn Buzzy On

Once Buzzy is being held in place either by a comfort strap, tourniquet, or by hand, press the button or switch on the top of Buzzy. Hold Buzzy in place for a minimum of 3 minutes.



WHEN CAN BUZZY BE USED?

Buzzy can help in a range of areas. Some of these can include:

- Immunisations
- Blood tests
- Finger sticks
- IV lines
- Insulin injections
- Glucose tests
- Dentistry treatment
- First aid at home – including removal of splinters, bee stings
- Medical treatments (cancer patients)
- Flu injections
- Injected medicine
- Wart treatment
- Biopsies
- Cannula changes
- Juvenile Arthritis
- Travel immunisations
- Beauty therapy procedures
- Lumbar punctures

ABOUT THE ITP SUPPORT ASSOCIATION

The UK and Ireland ITP Support Association is a registered charity for those with ITP, it was formed in 1995 and was the first ITP Support charity in the world.

With the help of its team of medical advisors and volunteers it has since grown into one of the leading ITP patient support organisations in the world and is proud to have been a founding member of the International ITP Alliance.

The organisations funding comes from a variety of sources but mainly from charitable events that patients and their carers undertake, donations and from unrestricted grants from pharmaceutical companies. The organisation is not dependent on funding from any one company. If you would like to make a donation to the ITP Support Association please visit justgiving.com/itpsupportassociation.



Buzzy Cont...



ITP Buzzy Kits Request Form

ITP Warrior Name: _____

ITP Warrior's DOB: _____

ITP Warrior's Address: _____

Parent's Name: _____

Your Name: *(if different from above)* _____

Your Address: *(if different from from above)* _____

When was your ITP Warrior diagnosed ITP? _____

Tell us about your ITP Warrior's ITP Journey

How will a Buzzy help your ITP Warrior?

What's next?

In addition to the completed Request Form, please send us a letter which includes the contact details of your healthcare professional, the child's diagnosis and date of diagnosis.

Please forward the completed form and letter to info@itpsupport.org.uk

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.



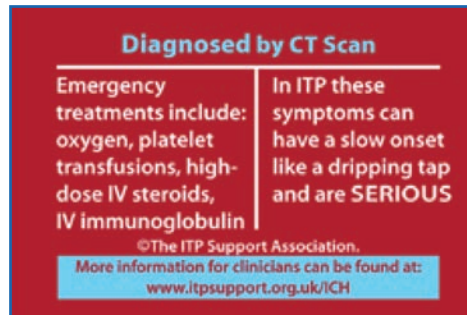
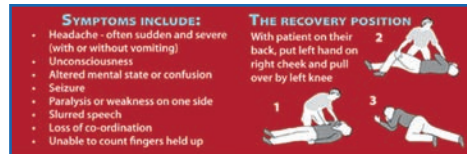
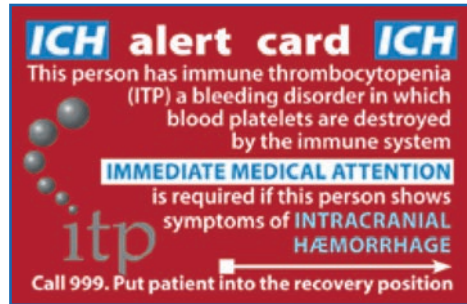
Order a free ICH alert card

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

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

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

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



Ways To Donate

ITP Support Association switches to JustGiving.com

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



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

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

Facebook



Towards the end of 2018 many friends of the ITP Support Association have used Facebook as a platform to help raise donations for the Association. This has raised almost £14,000 in support of the ITP Support Association 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

Shared Decision Making 'Making the right choices in ITP management and care' – A ground-breaking booklet mapping the process from diagnosis to treatment. This document has been endorsed by a number of Royal Colleges and the BSH.

ITP Discussion Guide – produced in conjunction with Sobi, this is a questionnaire type guide that you complete prior to your clinical appointment, helps you ask the right questions during your appointment.

ITP Discussion Guide patient explainer – helps you understand the ITP discussion guide.

ITP Discussion Guide Clinician explainer – take a copy with you for your Doctor or Consultant.

Know about ITP - core information booklet.

Fatigue in ITP - about this hidden symptom of ITP with suggestions on how to cope.

What did you call it? - question & answers about adult ITP.

What did you call it? - question & answers about childhood ITP.

ITP 'n stuff - question & answers about ITP for teenagers.

ITP and pregnancy - what to expect with a low platelet count in pregnancy.

Drugs that cause or aggravate thrombocytopenia - drugs to avoid with ITP.

Splenectomy - About open and keyhole surgery, indium labelled spleen scan, and aftercare.

Holiday insurance & travel guide - advice on travelling, flying, vaccinations & insurance.

Protocol for dentists treating patients with ITP - to give to your dentist.

Guidelines for schools, clubs, and playgroups - to give to a child's school.

Choosing your sport - which sports are safe with ITP?

James/Jessica tells his/her story - a book about ITP

for newly diagnosed children.

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

FACTSHEETS

Treatment table - a list of drugs used to treat ITP and their possible side effects.

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

Pupil's factsheet - ITP information with space for child's emergency details and photo.

Employer's factsheet - ITP information with space for employee's emergency details.

ALERT CARDS

ITP Emergency card £5.00 - personalised with your essential details for emergency use. Credit card size, laminated in plastic. Request an order form from headquarters.

ICH alert card - an alert card demanding immediate medical attention if the holder shows symptoms of intracranial haemorrhage (listed on the card). Also has information for medics.

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. - e 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)

Publications List cont...

21. New insights on what causes ITP
22. Neonatal \rightarrow thrombocytopenia
23. Post Transfusion Purpura
24. Must I mention my ITP at a job interview?
25. \rightarrow e versatility of platelets
26. How is ITP diagnosed?
27. ITP – in dogs!
28. Complications of ITP
29. Flying & ITP
30. Who needs Vitamin D supplements
31. Why don't we see an immunologist
32. What does the ITP Support Association do?
33. Sustained responses with TPO drugs
34. Is splenectomy still a valid treatment today?
35. Where are we with ITP today?
36. Are young platelets better?

AMERICAN PERSPECTIVES

1. A history of ITP
2. ITP in pregnancy
3. What is a platelet?
4. How is ITP diagnosed?
5. Non-intervention in childhood ITP
6. Activity restrictions in ITP children
7. How many platelets are enough?
8. Splenectomy and ITP
9. Can I die from ITP
10. \rightarrow 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. \rightarrow The relationship between ITP and lupus
29. ITP in adolescents
30. \rightarrow 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 haemorrhage in ITP
44. When bad bleeding happens
45. How often does ITP occur
46. How do haematologists 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. \rightarrow 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
64. I have ITP. Should I be taking this blood thinner?
65. ITP, Platelet Counts, and Pregnancy
66. ITP and New Treatments: The view from your side of the pond
67. New Drugs for ITP- Why wait?
68. How do ITP patients know what's the right thing to do?
69. Understanding the Immune System
70. New Drugs for an "Old" Disease
71. Different Bleeding Symptoms Despite Similar Platelet Counts
72. COVID-19 and ITP
73. Teaching a New Dog a New Trick
74. COVID-19 Vaccination: What you Need to Know
75. Participating in Research in ITP
76. What is vaccine-induced immune thrombotic thrombocytopenia (VITT) and is there a connection with ITP?
77. Are people with ITP immunocompromised?
78. Revisiting Splenectomy for Treating ITP
79. Fatigue

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

MEMBERSHIP SUBSCRIPTION FORM:

PLEASE USE THIS FORM TO PAY BY CHEQUE, POSTAL ORDER OR STANDING ORDER
YOU CAN PAY ONLINE AT WWW.ITPSUPPORT.ORG.UK

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

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

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

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

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

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

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

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

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

The associations privacy policy is available at: www.itpsupport.org.uk

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

