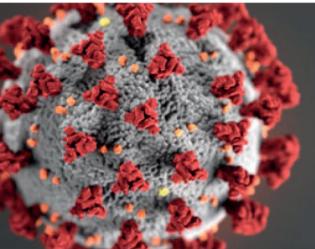




ITP news, patient stories, advice & more...



ITP Support Association
UK Convention - London 2020



Coronavirus
COVID-19

ITP Patient Day #ITPCork2020



The
Platelet

MARCH 2020

JOURNAL OF THE ITP SUPPORT ASSOCIATION

The ITP Support Association Team

Charity Registration No. 1064480

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

OFFICE

Chief Executive
 Mervyn Morgan
Office & Fundraising Administrator
 Liz Gooch

VOLUNTEERS

Social Media
 Hayley Howie
Group Liaison
 Derek Elston
Patient Mentors
 Rhonda Anderson
 Dave Farrow
 Derek Elston
 Karen Smith

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

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

The Platelet is the quarterly journal of The ITP Support Association. The Platelet is copyright and may not be copied, quoted or reproduced without written permission of the ITP Support Association (copyright holder). Articles in The Platelet represent the opinion of the writer, or writers, and not necessarily those of The ITP Support Association. Whilst every effort is made to ensure the accuracy of information, responsibility for omissions or errors cannot be accepted by The ITP Support Association, its personnel or medical advisors since circumstances and particulars vary from person to person. The Platelet is available free of charge to all to members of The ITP Support Association. It may not be sold.

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

UK ITP Convention #ITPLondon2020 – Change of Date

Following a meeting of the UK ITP Support Association Board, we have made the decision to postpone our UK ITP Convention, which was due to take place in May. The event will now be held on Saturday 10th October (same times, same venue), Royal College of Pathologists, 6 Alie Street, London, E1 8QT.

For those who have purchased tickets please note your ticket will be good for the new date, if you are unable to attend on the new date and would like a refund please email info@itpsupport.org.uk with your booking details.

This edition of the Platelet

The March edition of the Platelet Journal is packed with news of our latest events including the UK Convention in London and just announced, our Patient Day in Cork, Ireland in June.

In addition, this edition includes Prof. Newlands article on the Coronavirus plus his excellent summary of the new ITP Guidelines. All of this is in addition to the favourites such as the American Perspective, which is an excellent article on 'Different Bleeding Symptoms' by Rachel Grace MD.

Local ITP Support Group meetings

A few years ago, the ITP Support Association launched a project 'ITP on the road', after a few meetings the project was revamped to give it more of a local focus, although we still took every opportunity to support requests for meetings in Hospitals!

As a result, we now have an ever-growing number of 'Local ITP Groups' around the United Kingdom, each having regular meetings throughout the year. These 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.

By the close of 2019 we had held in excess of 20 meetings in places as far apart as: Edinburgh, Dublin, Bedfordshire, Nottinghamshire, Cheshire, South Wales, Devon, West Sussex, Suffolk, Essex.

We had a total of over 300 people attending these meetings held during 2019, we fully expect this figure to rise as we roll out our schedule for 2020.

In 2020 we have already had 6 meetings with a further 12 already scheduled between February and September. In addition, we have just published the date for a new group in High Wycombe, (first meeting in July). Planning is also underway for new groups in North London, Surrey, Birmingham, Bristol, Cardiff, Milton Keynes and possibly the North East.

Each of the local ITP Groups is run by a local volunteer who organises the venue and any refreshments, the Association carries out the advertising, provides resources to be made available at the meetings. The ITP Support Association CEO attends as many of these local meetings as possible, plus some of the Associations Trustees also attend when they are available.

Mervyn Morgan CEO

Contents

- 4** Coronavirus
- 5** UK Convention London 2020
- 7** ITP Patient Day – Cork, Ireland
- 8** Local ITP Group Meetings
- 10** American Perspective
- 11** Patient Mentors
- 12** ITP Treatment Guidelines – Summary by Prof Adrian Newland
- 14** Fantastic Fundraisers
- 14** Condolences
- 15** Leaving a Legacy
- 16** Please sir can I have some more!
By Anthony Heard
- 18** Dealing with difficult emotions after ITP Diagnosis by Rhonda Anderson
- 22** Your Questions
- 23** I have ITP but it doesn't have me
by Dave Farrow
- 24** Ways to Donate
- 2** Publications List
- 28** Membership Form

Coronavirus (Covid-19)



The type of viruses known as coronavirus are common throughout the world, although the current infection, from China, (now known as Covid-19) is caused by a new strain for which the population will have no underlying immunity.

Like the common cold, coronavirus (COVID-19) infection usually occurs through close contact with a person with the virus via coughs and sneezes or hand contact. A person can also be infected by touching contaminated surfaces if they do not wash their hands. Typical symptoms of coronavirus include fever and a cough that may progress to a severe pneumonia causing shortness of breath and breathing difficulties. To suspect the diagnosis, at the moment, not only should suspected cases have the symptoms but also a travel history, or contact with someone who has recently returned from suspect areas.

At the moment around 5% of those infected appear to develop a more critical illness. This is, however, a fast moving picture and the virus appears to show different ranges of severity, although this probably reflects the variable quality of data from the different countries where it has been reported. Currently it is estimated that 1% of those infected might die. To put this in perspective in the influenza pandemics the rate was 0.25% and in the Spanish Flu epidemic in 1918 it was 4%.

One aspect noted from the Chinese is that so far only 2% of cases occur in the under 19 age group, with it being more severe in those over 70. Generally, coronavirus can cause more severe symptoms in people with weakened immune systems, older people, and those with long-term conditions like diabetes, cancer and chronic lung disease. Patients with an autoimmune condition, such as ITP, will not automatically be at increased risk but, just as with infections in general, they may be more susceptible if they are taking steroids, immune suppressant drugs or have had a splenectomy.

The current position is changing rapidly and the government is publishing up-to-date data daily at 2.00pm on its website. As of 3/3/20 there were 51 identified cases in the UK although this is bound to increase. At the present time it is recommended that the public read, understand and abide by the advice issued on behalf of Public Health England on the UK Government website, which is being regularly updated.

<https://www.gov.uk/guidance/coronavirus-covid-19-information-for-the-public>

Although the risk level has been raised to 'moderate' and the likelihood is that the virus will spread further, all the current government advice is to go about your business as usual.

The important advice is to maintain a high level of personal hygiene, including thorough washing of hands and use of alcohol-based hand sanitizers, especially before eating. Use disposable tissues and, once used, dispose of them hygienically and then immediately wash your hands. In particular, avoid touching your eyes, nose and mouth with unwashed hands.

It is perhaps obvious but if you are feeling unwell with flu-like symptoms or indeed anything else that might be passed on to others, then you should avoid attending any gatherings (including work and travel) until you are given a clean bill of health. If in any doubt then use the NHS hotline (111) and self-isolate. This is very much for the benefit of the population in general, as well as that of the individuals concerned.

The ITP Support Associations Website at www.itpsupport.org.uk keeps its Coronavirus page updated with links to the latest advice.

Professor Adrian Newland 3/03/2020

The ITP Support Association Convention 2020



Following a meeting of the UK ITP Support Association Board, we have made the decision to postpone our UK ITP Convention which was due to take place in May. The event will now take place on Saturday 10th October (same times, same venue), Royal College of Pathologists, 6 Alie Street, London, E1 8QT.

For those who have purchased tickets please note your ticket will be good for the new date, if you are unable to attend on the new date and would like a refund please email info@itpsupport.org with your booking details.

There is now even more time to book your ticket, remember we are already 70% full so don't delay, 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 10th October* 2020 (9:30am to 5:00pm) at the Royal College of Pathologists in their brand-new headquarters building in Alie Street, London.

***Please note the revised date for this event**

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 David Kuter
Professor, Medicine,
Harvard Medical
School



Dr. Nichola Cooper
Imperial College
London



Dr. Sue Robinson
Guy's and St Thomas'
NHS Foundation
Trust



Professor John Semple
Lund University,
Sweden



Dr. Henrik Frederiksen
Odense University
Hospital, Denmark



Dr. Vickie Macdonald
Barts Health
NHS Trust

Medical Advisors attending



Prof. Adrian Newland CBE
Chair of Trustees, ITP
Support Association
Ex-Director of
Pathology at Barts
Health NHS Trust



Dr. Drew Provan
The Royal London
Hospital



Dr. Gerard Crotty
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



GOLD SPONSOR



SILVER SPONSORS



BRONZE SPONSORS





ITP Support Association UK Convention - London 2020



1995 – 2020 25 Years of ITP Support

The ITP Support Association is pleased to announce that its 2020 UK ITP Convention will take place on Saturday 10th October* 2020 9:30 to 17:00hrs in the Elizabeth Room at the Royal College of Pathologists, 6 Alie Street, London, E1 8QT.

***Please note the revised date for this event**

For tickets go to www.itpsupport.org.uk

Programme

Dr Vickie Macdonald, Barts - Treatment changes over the last 25 years; Adult ITP Registry

Dr Henrik Frederiksen, Denmark - Fatigue in ITP

Dr Nichola Cooper, Imperial - Is bleeding a problem in ITP?

Dr Sue Robinson, Guys - Pregnancy and ITP; the new Registry

Professor John Semple, Oslo, Sweden - Why does ITP occur?

Professor David Kuter, Boston, USA - Guidelines or new advances in ITP

The ITP Patient's journey (patient's stories)

Question Forum

Breakout Sessions

Prof. Adrian Newland, Dr. John Grainger, Dr. Drew Provan, Dr Gerard Crotty & Dr. Quentin Hill

This event is supported by:

GOLD SPONSOR



SILVER SPONSORS



BRONZE SPONSORS



For tickets go to www.itpsupport.org.uk

The ITP Support Association, The Platelet Mission, Kimbolton Road, Bolnhurst, Bedfordshire, MK44 2EL

Web: www.itpsupport.org.uk Email: info@itpsupport.org.uk Tel: 01234 376559

Registered Charity Number 1064480

ITP Patient Day - Cork



ITP Patient Day - River Lee Hotel, Cork Ireland

Following on from our successful ITP Patient Day in Dublin in April 2019 we are pleased to announce that we are planning to hold a further ITP Patient Day in Ireland. Please put 20th June 2020 in your diary, we are planning to hold the event at the River Lee Hotel, Cork, Ireland. Booking details will be published on our website at www.itpsupport.org.uk in the next few weeks.

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

1. Contact Give a Car on 020 0011 1664 or 'http://www.giveacar.co.uk/how-it-works' and say you wish to donate your scrap car in aid of ITP. It takes a couple of minutes to get your details and answer questions. Once they have your approval, a collection agent will call you in order to arrange a convenient pick-up time.
2. Your car is picked up. A tow truck usually arrives within 1 to 3 days to pick up your car, though in a few rare cases it may take up to 10 days.
3. Your car is sent to scrap or auction. Give a Car then donate all the proceeds, after administrative costs, to the ITP Support Association. Within 6 weeks you will receive a receipt for your donation, and so will we.



ITP Support Association Local Group Meetings

We have several 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

High Wycombe ITP Group Meeting

First Meeting: Saturday 25th July 10am to Noon

Venue: Wycombe Museum, Priory Avenue, High Wycombe, Bucks, HP13 6PX

This is a new group, the first meeting is being organised by Daniel Tavener-Smith, all welcome

Sussex ITP Group Meeting

Next Meeting: 14th March 2020 10:30am to 12:30pm (future meeting dates 6th June, 10th October)

Venue: Venue: St Pauls Church Hall, St Pauls Church, Churchside, Chichester, West Sussex, PO19 6FT



South Wales (Pontyclun) ITP Group Meeting

Next Meeting: Monday 23rd March 2020 2.00pm



to 4.00pm

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



Nottinghamshire ITP Support Group

Next Meeting: 31st March 2020 7pm to 9pm

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



East of England ITP 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.



Greater Manchester & Cheshire ITP Group Meeting

Next Meeting: TBC 3rd April 2020 11am to 1pm

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



Worcestershire ITP Group Meeting

Next Meeting: 24th April, 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.



Devon ITP Group Meeting

Next Meeting: 5th June 2020, 11:45am to 1:45pm

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

Scotland ITP Group Meeting

Next Meeting: Thursday 24th September 2020 1.00pm to 3.00pm

Venue: Caiystane Hall, Fairmilehead Parish Church, 1a Frogston Road West, Edinburgh, EH10 7AA.



Planning for new groups

We are also in the early stages of planning for several other local groups in Bristol, Northumberland, Yorkshire, Birmingham, Milton Keynes and North London.

Patient Meetings at Hospitals

In the past few months, we have also held ITP Patient meetings at Broomfield Hospital Chelmsford, Hammersmith Hospital London and the Queen Elizabeth Hospital Birmingham. We plan to hold more in the future, keep checking back to our website and social media pages for updates.

American Perspective

Different Bleeding Symptoms Despite Similar Platelet Counts Rachael Grace, MD

I have often wondered with other hematologists why bleeding symptoms can be so different between patients with the same platelet counts. For example, with a platelet count of 10k, one patient may have no bleeding whereas another may have extensive nosebleeds or blood in the urine. What causes this difference? Even with individual patients, I am often tricked into thinking the platelet count must be increasing when they were previously covered in bruises and petechiae and now those symptoms have completely resolved, only to find that there is actually no change in the platelet count. If not the platelet count, then what else changed so that these symptoms spontaneously resolved? In addition, if we knew what else caused patients to have bleeding, it would perhaps help us to be able to predict future bleeding. If a low platelet count alone doesn't always correlate with bleeding symptoms, how else can we predict future risk?

For some individuals with ITP, there are clear factors which contribute to bleeding differences. Some patients with ITP require other medications which can cause the platelets not to function as well or impact other parts of the blood needed to form a blood clot. Although many of the medications that cause these side effects are known to the patient, it may be less clear that other medications, vitamins, or supplements alter platelet function. For this reason, it is important to make sure you tell your physician about all medications and supplements that you take. Age is also linked to bleeding symptoms, in



which older individuals, such as the elderly, are more likely to have bleeding symptoms than younger individuals with ITP.

Platelets are just one part of the system that helps our bodies to form a blood clot. Our body also has a lot of other proteins (called factors) that must act together to help us stop bleeding. This is called the coagulation system. Baseline coagulation and clotting differ among individuals and likely vary among people with ITP. One example could be differences in von Willebrand factor, a clotting protein that binds to another coagulation factor (factor VIII) and platelets in blood vessel walls to help form a platelet plug during the clotting process. Von Willebrand levels vary in the general population and, therefore, also vary in individuals with ITP. Low von Willebrand levels affect 1% of the population, and people with Type O blood also have lower von Willebrand levels than non-Type O blood. Individuals with ITP and more bleeding symptoms may have lower von Willebrand

levels than those with fewer symptoms. Other variability between individuals may be due to differences in platelets. Platelets contain granules and substances that make them sticky enough to function. Patients can have variability in these granules, baseline platelet function, or the amount of circulating platelet derived microparticles, small fragments of the platelet surface (outer shell) which circulate and help the blood to clot.

How strong blood vessel are may also vary between individuals and even within an individual over time. If our blood vessels are weaker then we may have more bleeding. Some individuals with ITP have an improvement in bleeding symptoms with treatment with corticosteroids despite no change in the platelet count. We believe that the corticosteroids may increase the strength of blood vessels and decrease bleeding symptoms.

In addition to these differences, there are likely differences in the underlying biology of ITP which affect bleeding symptoms. Certain ITP-associated antibodies not only affect the platelet count but also affect platelet function. These antibodies attach to specific receptors on the platelet surface. Because these receptors help platelets to interact with the other coagulation factors and to activate, they can cause the platelets to not work as well in addition to causing thrombocytopenia. If differences in platelet function could explain some of the differences we see in bleeding symptoms, could we measure this difference and potentially use it to predict future bleeding? One major challenge is that it is not possible to measure platelet function clinically in individuals with low platelet counts. Current tests rely on a near normal platelet number to measure platelet function. However, research testing using flow cytometry, a technique that examines properties of individual cells, allows researchers to measure platelet function in individuals with ITP and low platelet counts. We are currently studying this to better understand differences

in bleeding and possibly predict future bleeding.

We know that individuals with ITP and low platelet counts have a higher risk of bleeding than those with higher platelet counts. However, despite low platelet counts, episodes of bleeding with ITP in general are lower than in other types of low platelet disorders. This is likely due to a high amount of young platelet production from the bone marrow, the factory where the platelets are made. The amount of these young platelets, called immature platelets, may be different in patients with different degrees of bleeding. Hematologists would like to understand what predicts the variability between patients with ITP who have different bleeding symptoms but identical platelet counts. This understanding could lead to better ways to identify risk for future bleeding, and thereby direct treatment.

Update on Patient Mentors for the ITP Support Association

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

PATIENT MENTORS

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

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

ITP Treatment Guidelines

A Summary of the new ITP Guidelines by Prof. Adrian Newland

TREATMENT GOALS

1. Treatment goals should be individualized to the patient and the phase of the disease.
2. Treatment should prevent severe bleeding episodes.
3. Treatment should maintain a target platelet level greater than $20\text{-}30 \times 10^9/\text{L}$ at least for symptomatic patients (because risk for major bleeding increases below this level).
4. Treatment should be with minimal toxicity.
5. Treatment should optimize health-related quality of life (HRQoL).

RECOMMENDATIONS FOR INITIAL TREATMENT OF NEWLY DIAGNOSED PATIENTS

1. Corticosteroids are the standard initial treatment for adults with ITP who need treatment and do not have a relative contraindication: prednis(ol)one at 1 mg/kg (maximum dose 80mg, even in patients weighing greater than 80 kg) for 2 weeks, to a maximum of 3 weeks, or dexamethasone 40 mg/d for 4 days, repeated up to 3 times.
2. If a response is seen (e.g., platelets above $50 \times 10^9/\text{L}$), the prednis(ol)one should be tapered, aiming to stop prednis(ol)one by 6 weeks (maximum 8 weeks), even if the platelet count drops during the taper.
3. If there is no response to the initial dose within 2 weeks, the prednis(ol)one should be tapered rapidly over 1 week and stopped.
4. Longer courses of steroids should be avoided, although occasional patients may benefit from continuous low-dose corticosteroids (e.g., no more than 5 mg/d). This type of ongoing low-dose corticosteroid treatment should be based on the



individual patient's needs, prior therapies, and so forth.

5. Use of IVIg (1 g/kg on 1 or 2 consecutive days or 0.4 g/kg per day for 5 days), or IV anti-D (50-75 mg/kg once) where available, may be appropriate in patients with bleeding, at high risk for bleeding, who require a surgical procedure, or who are unresponsive to prednis(ol)one. If using anti-D, consideration needs to be exercised over potential triggering of DIC or hemolysis. Steroid premedication should be considered for anti-D to minimize acute infusion reactions (e.g., headaches, fever-chills, and/or intravascular hemolysis).

6. Certain patients may have relevant contraindications to high-dose corticosteroid therapy (e.g., insulin-dependent diabetes, uncontrolled diabetes, psychiatric disorders, active infection) and may be managed with only IVIg or IV anti-D as initial therapy.

7. TPO receptor agonists (TPO-RAs) and rituximab are not considered initial therapies but may be sometimes used earlier on, or in combination with initial therapies in controlled or trial settings.

THERAPIES FOR THE TREATMENT OF ITP

CLINICAL SITUATION

Therapy option Initial treatment of newly diagnosed ITP

- Corticosteroids
 - Dexamethasone
 - Methylprednisolone
 - Prednis(ol)one
- IVIg
- Anti-D (licensed and available for ITP in only a few countries)

Subsequent treatment; Medical therapies with robust evidence

- Rituximab
- TPO-RAs:
eltrombopag,
avatrombopag,
romiplostim
- Fostamatinib

Medical therapies with less robust evidence

- Azathioprine
- Cyclophosphamide
- Cyclosporine A
- Danazol
- Dapsone
- Mycophenolate mofetil
- TPO-RA switch
- Vinca alkaloids

Surgical therapies

- Splenectomy

Treatment of patients failing multiple therapies

- Accessory splenectomy
- Alemtuzumab
- Combination of initial and subsequent therapies
- Combination chemotherapy
- Clinical trials
- HSCT
- Splenectomy, if not already performed
- Supportive care

RECOMMENDATIONS FOR SCHOOL AND PARTICIPATION IN SPORTING ACTIVITIES FOR CHILDREN WITH ITP

1. Children and adolescents 5 to 18 years old need 60 minutes of physical activity per day, 3 d/wk. This should include exercises or sports to promote strong muscles and bones (Grade C recommendation).

2. Normal attendance and play at kindergarten, school, or college, depending on age, is essential. The risk of bleeding and information about ITP should be provided to the school in a way that facilitates inclusion, not isolation (Grade C recommendation).

3. Active participation in low-risk activities should be maintained, irrespective of platelet count and

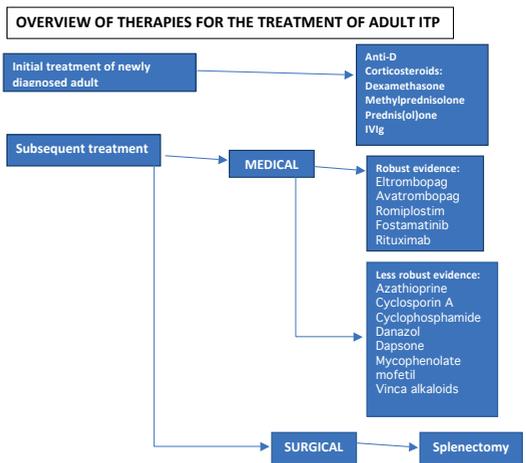
treatment (Grade C recommendation).

4. Participation in non low-risk activities must be discussed with the family, school, and coach. A number of factors must be considered prior to participation, including age of the child, platelet count, bleeding history, and physical nature of the activity (Grade C recommendation).

5. Participation in high-risk activities (including BMX racing, boxing, American football, ice hockey, lacrosse, motorcycle riding, motocross racing, power lifting, outdoor rock climbing, rodeo, rugby, snowmobiling, trampoline, and wrestling) should be discouraged unless the patient has a near-normal platelet count on a consistent and stable basis. Alternatively, treatment should be administered to provide a safe platelet count during the activity (Grade C recommendation).

6. Intermittent or continuous treatment may be given to cover activities with appropriate discussion of risks vs benefits of the activity and treatment, with emphasis on psychological well-being and risks for injury, despite treatment (Grade C recommendation).

7. Choice of treatment and target platelet count must be carefully evaluated based on extensive consultation with the family and consideration of the specific activity desired and the bleeding tendency of the child (Grade C recommendation).



Fantastic Fundraisers



Sally Rhodes and her daughter Laura Carson raised £100.00 collectively. Laura has collected donations from her local Weight Watchers group and Sally has received collections from the local Devon meeting group.

Pauline Chalk - £130.00 raised from ITP collection tin in her shop Chalk in Southfields London.

Kayleigh Shaw- nominated the ITP Support Association through her company, Three. We were thrilled to receive a cheque for £500.00

Ben Pentney - did a 10-hour bike ride as a member of his family has been diagnosed with ITP.

Team Leeds Beckett Gymnastics Club - "Three thousand skills in an hour. We chose this charity as back in February 2019 our current Captain developed ITP which caused him to step away from exercise. As we perform this fundraiser, we would like to say thank you to all those this charity has helped, and with this event we hope to help many more." They raised £115.75

Condolences

£100.00 received from Mr Robson in memory of his late wife Rosemary Dobson

£308.00 received from Lynda Allen as her mother had passed away and wanted donations sent to the association instead of flowers.

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/ITPSupportAssocor.

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!

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.

Please sir, can I have some more?

Food Glorious Food and ITP - What can we eat and what should we avoid?

As always in the first quarter of every year after a holiday season of overindulgence and with New Year resolutions to change things, it got me thinking about food, nutrition and ITP.

It is a subject which is raised regularly on the various ITP social media platforms so clearly it is something that occupies the attention of many of us purple people.

The power of a healthy lifestyle is undeniable for anyone. Although there is no single diet or regimen that will completely relieve the symptoms of ITP, you can support your immune system by making your lifestyle healthier. Even making small adjustments can have a dramatic impact.

So here are ten simple suggestions. I have included some things that we definitely cannot eat, and the list includes very big smattering of common sense.

1. Eat a good, fresh, well balanced diet as it gives your body the best chance to fight fatigue. It also helps your body in so many other ways too.
2. In a balanced diet, it is important to eat a healthy mix of protein, carbohydrates, fresh fruit and vegetables. We are all different and may have a variety of other medical issues to consider in addition to our ITP. So, it is important to discuss your diet and any changes you might make with your doctor or specialist.
3. With ITP we should avoid quinine, aspirin, ibuprofen and any products containing them. You'd be surprised at how many products do

include these things, so read labels carefully. Good examples to be aware of are cold remedies which often contain aspirin and soft drinks like tonic water, bitter lemon contain quinine.

4. Generally, eat less salt, lower fat and reduce sugar intakes. If eating readymade meals check very carefully the levels of salt, fats and sugars included as they can be surprisingly high.
5. Drink plenty of water. This is absolutely vital as dehydration is a major cause of many health problems including kidney stones, kidney infections, urinary tract infections. Dehydration will make us feel lethargic, tired, fatigued and listless. The suggested intake of water per day is 1.2 litres (somewhere between 6 and 8 glasses). During hot weather we should drink even more. Gulp!!!!
6. Avoid too much caffeine. Remember that caffeine is in many drinks, not just coffee & tea. It is in cola, and many soft /energy drinks. Caffeine keeps us awake and also prompts us to urinate more so dehydrating our system. It is also a stimulant and increases the heart rate amongst other things.
7. Being overweight increases fatigue/tiredness and has many other health risks like the possibility of developing heart disease and cancer. Avoid snacking and too much sugar. Cut down on fats and processed food like ready meals, take away foods like burgers, pizza, fried chicken. We can still eat these things, but they should only be an occasional "treat" option. Eat more fresh fruit and vegetables.
8. Cook your own meals. This sounds a bit trite, but it really is important. In cooking and preparing your

own food YOU know what is going into it. YOU can control the amount of fats, sugars, salts that you are eating by measuring how much of it you are putting in your food.

9. Greens Greens Greens.... For us ITP folk, green vegetables and fruits are essential. Consuming spinach, kale, cabbage, lettuce, broccoli, apples and pears is very helpful in boosting the health of our immune system. Greens contain plenty of Vitamins A, C, E, and K. (they help in the clotting process).

10. Alcohol - having ITP does not preclude us from drinking alcohol but the best advice is definitely to avoid over indulging and certainly do not binge drink.

The problems with drinking excess alcohol are pretty well known. But for us ITP sufferers specifically, it most importantly impacts on our liver function amongst many other negative things.

Now the liver is a very resilient organ but for us ITP folk the health of it is hugely important. Our liver controls the production of a substance called thrombopoietin which regulates platelet production. So if we damage our liver, it will have a negative effect on thrombopoietin production and hence the platelet count is likely to suffer.

Useful further links to articles on nutrition and ITP -

- The PDSA - Platelet Disorder Support Association in the USA - <https://www.pdsa.org/diet-lifestyle.html>
- The ITP Support Association in the UK - <https://www.itpsupport.org.uk/index.php/en/12-itp-research/26-can-itp-be-caused-by-something-you-eat>

On the issue of alternative, herbal medicines or things like aloe vera juice or papaya leaf extract there is absolutely no evidence whatsoever that taking them will increase the platelet count at all.

Some people may well believe that they have had successes with them, but we cannot really know if a response in platelet count is to the actual remedy or if the count would have increased naturally anyway. There just isn't any definitive research. Basically, there is no evidence and no real understanding of what is going on or how much any dosage should be.

So do not take any of these things without a full discussion with your specialist. If it were that simple to increase the platelet count, then sadly it would have already been done. I regret to say that it is wishful thinking, though I would never criticise anyone for holding out hope!

As a final reminder - PLEASE discuss your diet and any changes you might make with your doctor or specialist. The same goes for changes you may make to your exercise regime or if you are thinking about trying alternative medicines. Talk it through with your specialist before you do anything!

If anyone wishes to read my regular ITP blog, please feel free to have a browse at the following link....

My Purple Patch - Living with ITP -

<http://myownpurplepatch.simplesite.com>

I welcome any feedback or suggestions of topics that people may wish me to cover but the aim is always for positivity please!

Anthony Heard

Dealing with Difficult Emotions after ITP Diagnosis

The diagnosis of a long term condition can be devastating, and a whole new mind set has to be found to cope with this life changing news.

This is a general article for those of you who are feeling distressed about your diagnosis of ITP. We can often feel anxious, stressed, low, blue, distressed and worried about many things that touch our lives. That is exactly why the ITP Support Association was set up, to help you.

If you are feeling suicidal, or wanting to harm yourself or another person, you must seek professional, clinical help at once.

It is normal to feel down at times, we cannot feel on top of the world every day. Life is made of black and white and at least 50 shades of grey! A surprise diagnosis, of a long term condition, that we have never heard of before, can be a devastating shock. Fortunately, ITP is not usually a fatal disease, although rarely it can be. It is not something you should worry about unduly. This could blight your life, worrying about what might never happen. Don't let this worry ruin your life.

In answer to a patient's query in the ITP Journal, December 2019, page 20, our Medical Advisor, Professor Adrian Newland, wrote, "I can assure you that the risks of dying from ITP are extremely rare."

It is important to develop a good relationship with your medical team. Our Advisors suggest that the patient and their symptoms should be treated, not just the platelet count. This, and any other issues, such as drug treatments, need to be discussed and negotiated with your clinicians.

It is wise to have a few strategies worked out, to combat worry. You are your own best resource

because you know yourself better than anyone else. When you are feeling less stressed, think about what you can use to help yourself overcome your anxiety. Fear of the unknown can be very distressing. You have made the first step by reading this ITP journal, The Platelet, to inform yourself about ITP. The Publications List is very useful. Knowledge is power, power over worry. Information gives you confidence and understanding about your condition, and demystifies it.

The annual ITP Convention is a marvellous resource and the next one is on 9th May, in London, more details in this edition. Do try to attend if you can. Over twenty ITP Local Group Meetings have taken place and been extremely well received. Details of these are also listed in this edition. Patients welcome the opportunity to meet others with the same condition, in an informal setting to discuss problems, solutions and generally make friends. Many are surprised to find others have the same problems and worries, and airing them really relieves their anxiety.

Anyone living with ITP can usually lead a fully active and happy life. You are living with your condition, not suffering from it. Accommodate your lifestyle to it and in most cases there will be very little, if any, change needed.

Although you may not feel it helps to know this, there are many millions of people all over the world who are just like you, learning to live in harmony with their long term condition that may be limiting. Some of the greatest people who ever lived, have had to change their attitude to themselves and their condition, to achieve a happy and fulfilled life.

What pleases you and helps you to relax? If you have interests that you enjoy doing, then make

time, and go ahead and do them. Unless they are very dangerous like bungee jumping, weight lifting or contact sports, you should be able to do most things. If you are unsure, ask your GP or hospital medical team. In the end it will be your choice, and any sensible person will not take undue risks.

Having hobbies and interests is important and can be very relaxing and sociable. There are many clubs and groups around to join. Enjoying life and perhaps retirement, is important. Organisations like WI, U3A, Arts Society, Sporting clubs, book clubs, Ramblers, quilting groups, luncheon clubs, and many more, that you can think of and name, provide an excellent programme of events for people to enjoy. Some groups even do day trips, outings and holidays.

Phone a friend and be a friend by socialising with people. This need not cost a lot, it just takes a little effort to organise. A cup of coffee at a favourite venue can be a lifeline if you are feeling down. Sharing your worries with people and getting out to do something in a change of scene, can be a real morale boost. It can be your own talking therapy.

Try to smile, even if you don't feel like it. Speak to a stranger, just say, 'Good morning'. Do a good turn, such as giving way to traffic. You'll be surprised how good it makes you feel. No matter how stressed you get in a traffic jam, it won't change the situation, you will still be late, so put on the radio, listen and relax into the moment. The same for your ITP. No matter how much you rail against it, it will still be there to worry you. Learning to live with a long term condition can be a challenge. Distractions help.

Mindfulness, meditation and prayer appeal to some people. Some courses are free. Many people find taking time out from the bustle and noise of life for a short time every day, is very beneficial. Lots of churches have social groups such as luncheon

clubs, and bereavement support groups. Often you do not need to be a church goer or member to attend.

Your diagnosis may have been the tipping point, and there may be other issues in your life, that you need to sort out, which are adding to your stress. They may have been there before your diagnosis, but now they magnify because you are concentrating more on yourself and how you feel. As the majority of patients with ITP are over 60, many people live with other long term conditions such as arthritis, heart disease, chest conditions and diabetes, to name a few of the more common ones. You are not alone with health worries. What is important is how you deal with them.

The Expert Patient Programme (EPP), which I have written in detail about in this column before, is a course for people living with long term conditions, to support them in coping with their health situation. All participants benefit. Find out if you can attend the 6 session course in your area.

The boring, mundane chores of life, need to be punctuated with little treats. We all have things we have to do, but put a time limit on these, such as a 15 minute timer to do chores, such as cleaning the bathroom. When that is done, have a break, make a cup of tea and listen to relaxing music. Then tackle another 'must do' and you will get through the list quicker and feel energised instead of overwhelmed. If you get snowed under, make a little list. Then choose one thing to do every day that will release some of your anxiety. Lists can be made and remade. It is a great feeling of satisfaction to cross off things on the To Do List. If lists are not your thing, find an alternative to get through the things that are stressing you. Call in some help from family and friends. It is never one thing, such as your diagnosis of ITP, that is stressing you.

Dealing with Difficult Emotions after ITP Diagnosis cont...

Research has shown that time spent in nature is good for health and wellbeing, as seen on TV, Trust Me I'm a Doctor. There is now a new term, 'forest bathing' which means taking time out to go for a walk and be in a natural setting, such as a forest, park or other outdoor place, for at least one hour a week. The health benefits are remarkable on blood pressure, for example, and feelings of wellbeing.

Have a routine, so you sleep well, eat well, and have regular exercise every day. Having a companion to do these things with can be helpful to you both, through socialising and keeping each other going, especially in the winter when a lie in, and no activity, can be very appealing. Some local authorities have regular group walking schemes. Many people have a dog who keeps them company and gets them out for the daily 'walkies'.

By helping others we can help ourselves as a volunteer. This is the feel good factor that the brain switches on when we do pleasing things.

Writing your feelings down in a diary or journal can help. Maybe write a book about your experiences, poems, or your memoirs. Art journaling is very therapeutic, doodling and drawing in a specific book. Research your family history which can become an absorbing interest.

Write down, or think about, at least one thing that you are grateful for each day. Some lovely little things happen, that can lift our spirits. What lifts yours? This time of year, it is a joy to see the various spring flowers coming up. Look out for them, take notice of them, and enjoy them. Simple pleasures can be joyful. 'Every day is a gift' is the message written on a painted stone I have on my dressing table. A lovely, happy thought.

If you feel you cannot be bothered to do anything like this, and just want to stay in all day, on the couch resting, or in bed, eating chocolate biscuits, then it is time to seek professional help. Saying poor me, and why me, will not help. Changing your attitude will. No one can do it for you, only you can do it for yourself. My daughter has lived with depression for many years. When I was very distressed about it, and wanted to help her, she said, 'Mum, I am the only one who can do it. I have to make up my own mind, and do it myself!' That is one of the most profound things anyone has ever said to me. You are the controller of your own destiny. Make it a good one.

Concentrate on what you can do, not what you can't do. You may not be able to run a marathon, but gentle, regular exercise might be possible. Build up your goals gradually. A walk around the block can become a walk to the shops, or the cinema, or further afield to visit a friend. Howard and I are not natural athletes, but we have, over the last 2 years, built up our walking and exercise. I enjoy classes such as Yoga and Stretch at the gym.

Social media can be supportive, but be aware of the fact that some people are not qualified to give sound advice. Beware of internet sites that promise cures, expensive treatments, and other such things. Always make sure that the information you are sourcing is genuine, and not after your money, or written by people with outlandish views.

Self help books can be useful and positive. Libraries have books on prescription which are there to support health and wellbeing. Some outline CBT and other therapies, and have workbook exercises for you to follow. It is worth remembering that just reading the book will not do it for you. You have to

make the changes yourself.

If you have queries about your treatment plan, side effects of medication and other worries that need a doctor's advice, please make contact with the relevant authorities and agencies. Mental Health services are experiencing a great deal of over stretch and appointments are delayed, but try and help yourself in little ways each day, and see if you can lift your spirits and feel more positive about your diagnosis of ITP.

In conclusion, it can be helpful to consider a few previous points.

- The boring mundane chores of life need to be punctuated with little treats.
- Don't worry about what might never happen.
- Worry will not change the outcome of the inevitable, it will just make you feel worse.
- You are your best resource.
- Find out everything you can about ITP and attend the Convention and Local Group

Meetings.

- Treat the patient, not the platelet count.
- Get all the help you can.
- Phone a friend and be a friend.
- Use your friends and family to help and support you, and do the same for them.
- Have a plan for every day.
- Volunteer to help others and yourself.
- Think positive thoughts and do positive things. Ditch the negative.

"If you can't fly then run, if you can't run then walk, if you can't walk then crawl, but whatever you do you have to keep moving forward." Martin Luther King.

Please tell me what you think of these ideas and if they have helped. Also your own strategies for dealing with difficult emotions. Thank you and good luck.

Rhonda Anderson

rhonda.anderson@virgin.net

**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

PRINCIPIA

B I O P H A R M A

Your Questions

Q *In early December 2019 Katy Okwe-Pearson wrote:*

I have had ITP since being a child, episodic following splenectomy. It dipped a bit during recent pregnancy and my son is now 10 weeks. He has been affected by my antibodies and still has a count of 43. They did early immunoglobulin infusions which temporarily raised it in first couple weeks of life, but now are waiting to see if it goes up on its own. I just wondered if you could link me into any research about this. The haematologists at our hospital said it can take this long for my antibodies to clear, but they haven't ever seen it take so long before. I wondered about whether antibodies can cross through breast milk, I've been told not but I don't know if there is enough research to say this for sure? I could only find one v small study which said it was possible but doesn't seem to have been replicated.

Any information or link in with someone else who has experienced this would be very gratefully received.

This question was sent to Dr John Grainger Consultant Paediatric Haematologist at the Royal Manchester Children's Hospital.

The antibodies can last up to 12 weeks although most commonly clear in 6-8 weeks. Antibodies can cross in breast milk at small amounts and enough to bind to baby's platelets. At a platelet count in your boy of over 30 I would not be concerned nor advice to stop breast feeding. If the count is dropping, then you could try expressing for a few days to see if that helps the count come up but

might need to omit breast for a week. Usually I would only advocate stopping breast feeding if persisting severe thrombocytopenia.

A *Katy Okwe-Pearson sent the following thank you to Dr. Grainger and the ITP Support Association*

I would like to send a huge thank you to all at the ITP Support Association and to Dr John Grainger for supporting me with my recent ITP concerns regarding my son. I have had ITP since I was a child and had low platelets only periodically following a splenectomy in my late teens. During my pregnancy it flared up and my son was born with low platelets that persisted much longer than they had predicted at our hospital. As a new Mum I felt really at sea and much more worried about his platelet count than I had ever been about my own- making me a lot more aware and sympathetic to the stress it must have given my own Mum when I was younger! I felt worried that my breast milk might be compounding the issue and worried every time I fed him that I was inadvertently making it worse. I contacted the ITP Support Association late at night when I was sleep deprived, feeding and feeling full of worry and guilt. I felt so reassured and supported by the prompt response and the information Dr Grainger gave. This made me feel more confident to continue to breastfeed given the count my son had. I am delighted that at his blood test last week, at 4 months old, my sons count had rocketed to 200. We are hugely relieved and so appreciate the help we were given.

I Have ITP- but it doesn't Have Me.

By **Dave Farrow**

I developed ITP and neutropenia (loss of some white cells) way back in 1993.

Over the years I've had most treatments available including a splenectomy which did not work. Twenty-seven years later I still have the two conditions lurking in the background somewhere but thanks to treatment with various doses of Mycophenolate and a caring Haematologist that I can talk to, my counts have remained stable for several years now.

However, I have had to help myself too. In the early days I was stressed out and often looking for new bruises that were not always there. The large doses of prescribed steroids were driving me crazy and my loss of white cells made me vulnerable to infections. I knew that I had to somehow take charge and develop some coping strategies. I thought it time I shared some of these with others.

I was not feeling well and had been in and out of hospital during my first year, but I thought it important to learn all I could about the Immune system and the enemy within that was sometimes attacking my platelets. The immune system is complicated, so I tried to keep to the basics at first. I sought information from books and explanations from health professionals. I never really met another person who had ITP in those days. The ITP support organisation didn't exist in 1993. I was one of its early members. Later it became a great source of information and of course much more is known about ITP nowadays.

At first, I was stressed out by it all but after a while I thought it best to become a patient, patient! As all patients know we spend a lot of time waiting to see Doctors and others. I go prepared with

something good to read. I get to know staff and other patients. I became patient about results too. I learned not to expect rapid, long lasting, positive results from treatments.

I have practiced yoga, relaxation and a little mindful meditation over the years. I think controlled gentle breathing helps me relax and forget about ITP. Maybe my immune system somehow becomes aware of the calmness and as a result refrains from killing my healthy platelets for a while. The causes of stress and depression are often within us. They consist of negative thoughts about situations, events and illnesses, etc. Such thoughts as 'I will never get better.' 'These new tablets will never work.' 'I can't live as I want to because of my ITP.' 'It will kill me in the end.' Such thoughts trigger mood changes. I try to challenge such thoughts and either reject them entirely or modify them in some way. Then maybe replace them with a positive thought such as 'I will get better - at least enough to live and enjoy life as best I can.' It is good to notice how that thought feels.

So, I am using a cognitive behavioural approach to coping with my ITP. Now I can say, 'Yes I have ITP, but it doesn't have me.' I invite others to give it a try if they haven't already. Learn all you can. Become a partner in your care rather than a passive receiver.

And watch out for those negative thoughts.

There is lots of help out there. There are CBT counsellors and masses of books on the subject. I recommend 'The complete CBT guide for Depression and Low Mood.' Leon Brosan and David Westbrook.

Dave Farrow trained and worked as a mental health nurse, teacher and counsellor. He is an ITP friend/mentor

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 asplenic
38. Who cares for patients with ITP
39. Who needs the new TPO drugs for ITP
40. TPO drugs in children & adolescents
41. Platelets & walnuts (food intolerance case)
42. Let's let ITP kids be normal
43. Silent hemorrhage in ITP
44. When bad bleeding happens
45. How often does ITP occur
46. How do hematologists treat ITP patients
47. Low platelets in children- is it always ITP?
48. Low platelets in adults- is it always ITP?
49. ITP: It's not only about bleeding
50. Vitamins, alcohol & ITP
51. Familial (hereditary) thrombocytopenia
52. The full blood count - what does it tell us?
53. Abnormal blood clots in ITP
54. Treatment of ITP children; Who and when
55. Immuno suppressive therapy
56. Platelet counts during pregnancy
57. Vaccinations – An ounce of prevention
58. Spinal anesthesia, and childbirth
59. ITP and Depression
60. Adherence to ITP therapy
61. Bone marrow biopsy and ITP
62. Don't forget splenectomy (in adults)
63. Splenectomy for children with ITP

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

MEMBERSHIP SUBSCRIPTION FORM:

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

YOU CAN PAY ONLINE AT WWW.ITPSUPPORT.ORG.UK

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

