



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



The  
**Platelet**

JOURNAL OF THE ITP SUPPORT ASSOCIATION

**JUNE 2019**

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Charity Registration No. 1064480

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

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

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



# From ITP HQ



Things have been extremely busy since the last issue of the Platelet. We had more Local ITP Support Groups started up around the country, plus the Association also organised a very successful ITP Patient Day in Dublin, a full report of the Dublin Patient Day is in this issue of the Platelet.

In 2018 we started planning a project called 'ITP on the road', as the planning developed this changed into the Local ITP Support Groups that we see today. This was thanks, in the main, to the response the association had to its appeal for volunteers that went out towards the end of 2018.

In order to organise and run Local ITP Support Groups we need a local volunteer to step forward who can find a suitable venue and get things moving at the local level. We currently have 6 Local ITP Support Groups running from Edinburgh in the North, Cheshire in the North West, Nottingham in the Midlands, East Anglia, West Sussex and all the way down to Devon in the South West. We would love to have more groups running but to do so we need volunteers at a local level. If you would be interested please email [platelet@itpsupport.org.uk](mailto:platelet@itpsupport.org.uk) with your details and we will get back to you.

In this issue our Chair of Trustees Prof. Adrian Newland has written an excellent article on the Associations position with regards to research and the support we are giving the ITP Registries (Adult, Paediatric and Pregnancy Registries). We also have details of more 'fantastic fundraisers' who have gone that extra mile for ITP.

The eagle eyed amongst you would have noticed that the association has a new logo, a big thank you to the design team responsible, we hope you all like the new look.

If you would like a question answered by one of our medical advisors please email [platelet@itpsupport.org.uk](mailto:platelet@itpsupport.org.uk) or write to Mervyn Morgan (Question) The Platelet Mission, Kimbolton Rd, Bolnhurst, Beds MK44 2EW.

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## ITP Patient Day – Dublin April 2019

Earlier in 2019 the ITP Support Association was asked if it would be able to organise an ITP Patient Day in Ireland, the Association had previously held one of its early conventions in Ireland around 15 years ago. We said yes and after a hectic period of planning the result was a fantastic ITP Patient Day held at the Ashling Hotel in the centre of Dublin. Over 50 ITP Patients and family members were in attendance. Our thanks must be extended to Novartis Ireland who supported the event with a generous donation.

The event would not have been possible without the contribution of the Patients attending and some wonderful speakers:

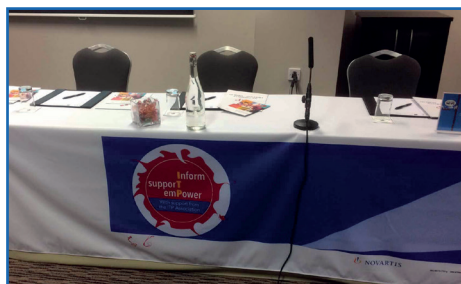
From Ireland, Dr. Gerard Crotty, Haematologist and Health Service Executive, gave a presentation on the 'Treatment of ITP, Practical Aspects', Nichola Harten, Clinical Nurse Specialist, gave a presentation titled 'Managing symptoms' and Rachel Fox, Clinical Nurse Specialist was on hand for a brilliant and well supported Question and Answer session.

From the United Kingdom, Prof. Adrian Newland CBE, Professor of Haematology and ITP Chair of Trustees, gave a talk on 'ITP Management & Treatment options'. Mr Derek Elston, ITP Trustee and Vice Chair, gave a presentation covering 'Living with ITP' and finally Mervyn Morgan ITP CEO gave a presentation, for the formal launch of the 'ITP Pocket Log App' in Ireland.

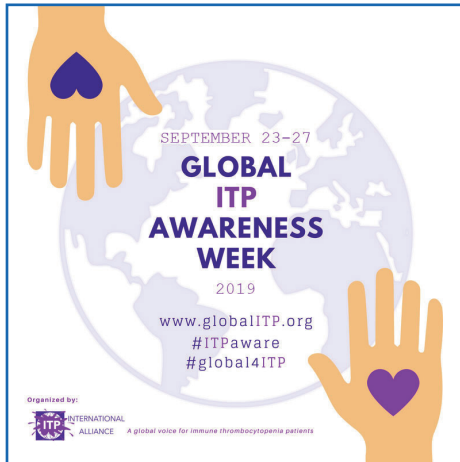
These are just a few of the comments received after the Dublin Patient Day:

- Some very useful information, I have learned more here than from my Doctor in 2 years.
- Very informative, I am a Staff Nurse in Haematology, I have come away with much more knowledge about this condition.

- This was a fantastic event. The information provided will be invaluable to me in managing my condition going forward.
- A huge thank you to all involved in setting up and delivering this Patient Day.
- An excellent and informative day, good panel of speakers, the event was well organised.
- Very well supported and covered many aspects of the condition, Excellent!
- It was a fantastic day, lots of information.
- Very informative, would love this every year and be able to share ITP questions.
- Very helpful advice, it was nice to be able to connect with others who have this condition.
- Thank you for your hard work for ITP Patients and thank you for coming to Ireland.



# Global ITP Awareness Week



**September 23-27, 2019**

## 4th Annual Global Event

Since the 2010 designation of September as National ITP Awareness Month in the United States, immune thrombocytopenia patients and support organisations from around the world have celebrated the month with awareness-raising events and Sport Purple for Platelets Day (the last Friday of September) to promote public awareness for the most common autoimmune bleeding disorder unknown to most - ITP.

In 2016, these organisations united as the International ITP Alliance to create a global voice for ITP patients and invite you to join the week-long celebration again this year to create a deeper understanding of ITP around the world.

As you join the global movement and paint social media purple this September, don't forget to use #ITPaware and #global4ITP!

## 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.



# Fantastic Fundraisers

**A big thank you to Atlas Trading Ltd** - We have received £97.40 this year from the ITP collection box at their premises.

**Anne King** (whose youngest son was diagnosed with ITP over ten years ago) says " We shall never forget the support and advice we received from the charity. As I am taking early retirement it seemed fitting to kindly ask for donations rather than a gift. Despite being a very small group, I was staggered and amazed at the total raised." £230.00



**Sara Adam** - In March 2018 Sara's middle daughter, Gracie, had a nosebleed that took them to A&E where ITP was finally diagnosed. "Gracie had to stay in at playtime at school and her gymnastics has had to be put on hold for the time being. It's hard when you are an energetic eight-year-old who loves

dancing and gymnastics but it could be much worse".

Sara decided to fund raise by taking part in the Meadows Half Marathon as well as holding a cake bake sale. She raised a fantastic £230.00 (including gift aid).

**Kieron Stokes** - Kieron's son Brodie was diagnosed with ITP two and half years ago. Says Kieron "To look at him he is absolutely fine. Despite no yard play, no riding his bike and any other normal kid activities he never moans about it so me and Sarah try not to either, but telling a 6 year old he can't join a football club ect sometimes takes its toll."

Kieron and his friend Ryan undertook the mammoth mission to climb Ben Nevis and fund raise for the association raising £368.00 including Gift Aid.



**West Denton Primary School** raised £307.64 following a non uniform day. This is in memory of Oly Fickling.

**Lynn Cox** of Anaesthetics Department Peterborough City Hospital nominated the charity and raised £100.00 in collections.

**Harrison Campbell** - The family of 5-year-old Harrison Campbell, who was diagnosed with ITP in 2015, held a Charity Night, which included a Raffle and a Disco with DJ's George Bowie and Stevie Brennan. The family would like to thank all the local companies who donated the food, items for the raffle and all the family and friends who helped to raise a fantastic £1,120.



Harrison's Mum Kara said, "there were so many companies who supported the event, without their help this would not have been possible, a big thank you".

# Condolences

## Jim and Dawn Horn. Happy memories.

Mum has had ITP for many years and with her platelet levels still up and down, it was only 2 last week, her team have tried various treatments and she currently injects her latest treatment weekly. Dr Grace and his team at Eastbourne Hospital are so supportive, kind and reassure her all the time.

Although stress is not thought to be an influence on platelet counts mum's levels have been low since losing my Dad at the end of January. Dad died at home, which was his wish, having been diagnosed with an aggressive brain tumour only last September.

Mum was his main carer and provided 24-hour care and support throughout his illness. She was amazing.

Dad's wish was that after his funeral donations went to 2 charities. We were so pleased that we raised £510 for The ITP Association from donations plus a further £100 from online donations.

We all hope this helps to find reliable treatments for people like my Mum in the future.

lots of love Mum from Nicola and Fiona



## Condolences

We Are extremely grateful for donations received in memory of loved ones and send our deepest sympathy to their family and friends.

Mrs McNeil sent a cheque to the value of £200.00 raised from the Hawick Angling Club's dart tournament in memory of her late husband Billy McNeil.

£150.49 in memory of James Collins.

The late Mrs Sybil Moen - Sybil was a supporter for many years and we thank her friends/family for donations totalling £110.00.

The late Mr James William Horn - £610.01 raised in his memory. The family are supporters of the charity and we send our condolences at this sad time.

A donation of £200.00 made from three of the late Margaret Lowrie's neighbours. Says one neighbour "Maggie as she was affectionately known, was a good friend and contributed greatly to the well-being of the community".

## 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](http://www.itpsupport.org.uk) or through Facebook at [www.facebook.com/ITPSuppAssocor](https://www.facebook.com/ITPSuppAssocor).

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

# My ITP Story

## My ITP story by Dave Barnes



A year ago, I was in the Royal London Hospital being treated for ITP. I was given various treatments such as steroids and the complete replacement of my platelets. This was done by an amazing machine which separates your blood and platelets and then returns it into your body with new platelets. None of this seemed to work for me and my doctors described me as a very interesting (i.e. difficult) case. Talking to my daughters and friends after I came out, they all seemed to think I was going to die. During my 7 weeks stay in hospital I lost count of the number of blood and platelet transfusions I had and one day I counted the number of tablets being given to me. It was 35. In the end the doctors decided to remove my spleen, an operation that required a lot of blood and platelets being used. Interestingly my operation was conducted by an all-female

surgery team. A spell in the high dependency unit and lots of scans later I was allowed home. I felt that my active life might be restricted but my doctors would have none of this. I was encouraged to gradually get back to an almost normal lifestyle.

A year later and my platelet count is that of a normal, elderly adult and I am now considered to be in remission. The point is that you should never give up even when things look bleak. In July I am going to California for 2 weeks with my doctors blessing, something I could not have imagined a year ago. I am so grateful to all the brilliant staff who have treated me, in particular my wonderful, caring consultant. Above all it reinforces my belief that the NHS is one of the greatest health services in the world.

## Dave Barnes



**The ITP Support Association**  
The UK Charity supporting those affected by ITP



# Diagnosis of ITP

## Diagnosis of ITP by Maggie Casey

My name is Maggie Casey and I always considered myself a fit and healthy 71-year-old. However, in January this year, I developed three small rashes on three areas of pain on my legs. The one I was concerned about was close to a scar where I had a grade 1 skin melanoma removed a few months previously.

For this reason, only, I made an emergency appointment that evening with my GP, who to my surprise referred me immediately to the local hospital, with instructions to take an overnight bag and make sure someone drove me there. It was then discovered that my platelet levels were a measly 4. The normal levels are over 150.

After double checking this, I was admitted to an assessment ward and given 70mg of the steroid Prednisolone, plus Tranexamic Acid and Lansoprazole. In myself I felt a little bit of a fraud as I did not feel at all ill, just a little washed out, plus the rash was starting to disappear.

The following morning, my platelet levels were 8 and I was discharged that afternoon when they reached 13. I was also given a follow up appointment with the Haematology Team at Princess Royal Hospital, Telford, within four days.

At this appointment the diagnosis of ITP was patiently explained to me. I must admit it was a condition that I was totally unaware of. I had no other symptoms other than the rash and a few very small bruises.

It soon became apparent that this was not going to be a quick fix, I would need to take the massive dose of steroids for a few months and

that I would be needing weekly appointments to see how I reacted to these.

In the long term it became obvious that the steroids were having little effect and a decision was taken to give me an Ivig infusion followed by four weekly infusions of Rituximab. My platelet levels fluctuated throughout this five-week period. However, good news after the last infusion, they had reached safe levels of 160. I am now waiting to see if this stabilises, but at least have been able to start reducing the Prednisolone down to 40mg. This at least makes me feel as if I have a little more control.

The only downside to my treatment is that two days after the Ivig infusion, I developed lower back pain, which unfortunately over the weeks developed into quite excruciating pain. I was unable to walk or use stairs. My doctor believes this may be from the infusion and is hopeful that this will work its way out of my system within a couple of more weeks. I hope he is correct as it is very debilitating.

I can only praise all the staff within Haematology at both Telford and Shrewsbury Hospitals, for their knowledge, kindness and assistance. It has been invaluable to me in understanding this condition and accepting the treatment offered.

I am aware that there are other drugs available, should these be required and that I will probably be monitored for a while yet.

The motto of my short story, is that if you feel something is not quite right, make a medical appointment as soon as possible and don't just ignore it.

*Maggie Casey*

## Your Questions...

**Q** I have a lupus type ITP diagnosed last year. (But not actual lupus)

Initially, I was treated with a high dose of prednisolone which was reduced quickly when the platelet count didn't rise above 9. I am now on Mycophenolate Mofetil twice daily. The initial dose was 500mg. This was reduced to 250mg twice daily when I got increasing pains in both legs.

I haven't taken any steroids since just before Christmas. My platelet count continues to rise. It is now 182. I am 73. Prior to problems with ITP I did exercises and a fair amount of walking which helped with osteoarthritis. I haven't felt well enough to do this whilst I was on the steroids. Now I want to get going again but am finding it very difficult. I take paracetamol during the day, and 2 co-codamol at night.

### *Prof Newland Replied*

**A** I am sorry to hear about the problems you have been experiencing but pleased that your platelet count has responded well.

From what you say when your ITP was diagnosed, they found an abnormality in the blood called the 'lupus anticoagulant'. This is found in up to 30% of people with ITP but only very rarely is associated with the condition of lupus. It will have no impact on your response to treatment.

It was quite right to tail off the steroids when you didn't respond as we find these are associated with many problems. It is encouraging that you

have responded so well to the Mycophenolate but a shame that you have been limited by the pains in the legs. While most drugs are associated with side-effects this is not one that I am aware of with Mycophenolate and the company do not report it as a possible problem that they are aware of either.

It is right, however, that the dose has been reduced and depending how long you have had your response your doctors may want to try and reduce the drug further. Exercise is certainly good for helping arthritis and I would encourage you to continue to try and get back to it in a gentle way. When there is a background of arthritis this may often get worse when steroids have been discontinued and it may take some while to settle down so gentle exercise plus the pain relief that you are taking is the best way forward. When you next see your haematologist, you should discuss this and see what they suggest regarding the treatment. I hope things settle and you get back to your old active self.



**The ITP Support Association**  
The UK Charity supporting those affected by ITP

## Research and the ITP Support Association

The Association is a registered charity whose aims are to promote and improve the general welfare of patients and their families. It does this in a number of ways, by providing written information, support through the website, access to experts, mentors and other patients, and through the Conventions and small group meetings which allow patients to meet others with similar problems to discuss and share their issues.

The Association also has an important role highlighting the disease regionally, nationally and internationally through links with Societies and specialist groups, by organising medical seminars and by communicating with the regulators, commissioners and various NHS bodies. We have also been active in linking in with other patient groups and have strong links with the PDSA in the States and with a number of the European groups. Through the latter we have been pushing recognition of ITP, as a bleeding disorder, on a wider scale.

With these initiatives we also hope to encourage the development of research into ITP and have been particularly successful in our links with pharma in supporting clinical trials. The Association is also keen to directly fund research projects but as a small organisation needs to use its resources wisely and not compete in areas where funding is available from other sources. We have achieved this in two ways; by supporting individual research projects and by funding the Adult and Paediatric Registries.

The Registries have been particularly successful and have proved real value for money. Studies through the Paediatric group have led to both

romiplostim and eltrombopag being made available to children with ITP. The Adult Registry showed the increased incidence of thrombosis in ITP, identified the degree of fatigue patients suffered and demonstrated the long term sustained response following cessation of the thrombopoietins in adults. More recently they have presented data on the use of rituximab in over 300 patients using either low or high dose treatment. Their data on spleen scanning and platelet survival in predicting response is now well established and they will be presenting data on both the numbers and results of splenectomy over the last 3 decades shortly. Together the Registries receive support of £40,000 per year.

With regard individual project support the Association has provided funding of more than £250,000 over the last few years. All projects have been carefully scrutinised and although not all are successful that is the nature of research. Of particular note the study on food, allergy and ITP conducted at Addenbrookes showed no association, which is an important finding. This demonstrates that while there may be occasional (although rare) reactions diet is not a major issue. We also supported a 1-year pilot study on ITP in pregnancy carried out by Dr Angharad Care based in Liverpool at a cost of £16,000. She published the data and also reported it in the 'Platelet' in June 2017. This confirmed the increased risk of severe post-delivery haemorrhage and the importance of specialist care. From these findings we have decided to support a Pregnancy in ITP Registry at a similar annual cost. A final important study worth highlighting is one looking at microbleeds into the brain in patients with persistently low

## Research and the ITP Support Association cont...

platelet counts. These are bleeds that do not cause any clinical problems but may lead to longer term disability. This was developed by Dr Nikki Cooper at Imperial College. Funding for this was £20,000 for the pilot study and she is now seeking funding for a much larger study with the support of the Association. This was presented by Nikki at one of the patient days that we hold and was also published in the 'Platelet' in September 2018.

Such recent expenditure has reduced the Associations reserves, but we remain committed to supporting such projects. As a short term measure, we have decided to continue to fund the Registries. The two established ones are long term established projects with important ongoing data collection, while the Pregnancy Registry is getting underway and promises much. The latter will also benefit from the support of the Adult Registry infrastructure, which was one of the requirements of the grant. Support for these three will require between £50-60,000 per year.

We have temporarily suspended funding for individual projects while rebuilding our reserves but hope to recommence next year. We will be looking to support pilot studies at around £20,000 per project. This will not commit us to longer term expenditure and will allow us to be aware of our commitments. We hope that by supporting the provision of early results from these studies applications to larger grant giving bodies will be facilitated.

The Association has always been grateful to its members for their enthusiastic and imaginative fund raising and from the extraordinary generosity of all concerned. We are determined that the money should be used carefully and focussed on the support and care of patients with ITP, fulfilling the broader aims of our charter.

*Professor Adrian Newland CBE  
Acting Chair of the Trustees  
The ITP Support Association*

**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

# ITP Support Association Local Group Meetings

Since January 2019 we have been rolling out Local ITP Group Meetings around the country. These local groups are an opportunity for ITP patients, their family and friends to meet in an informal setting over a cup of tea/coffee and an opportunity to chat and talk about each other's experiences with ITP.

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

The latest dates of our local ITP Support Group meetings are published on our website at [www.itpsupport.org.uk](http://www.itpsupport.org.uk) and listed on our Facebook page [@ITPSuppAssoc](https://www.facebook.com/ITPSuppAssoc).

As this edition of the Platelet goes to press the latest dates are as follows:

## Cheshire ITP Local Group Meeting

Next Meeting: Friday 21st June 11:00am to 13:30pm De Trafford Arms in Alderley Edge  
Venue: De Trafford Arms in Alderley Edge

## Devon ITP Local Group Meeting

Next Meeting: September / October (Date to be confirmed)  
Venue: St Andrews Church Hall, Ashburton, TQ13 7DD.

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

## Scotland ITP Local Support Group Meeting

Next Meeting: Thursday 3rd October 1.00pm to 3.00pm

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

## East of England ITP Local Group Meeting

Next Meeting: Wednesday 3rd July 2:00pm 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.

## Nottinghamshire ITP Local Support Group

Next Meeting: Tuesday 25th June 7pm start  
Venue: Grange Hotel, 73 London Road, Newark, NG24 1RZ

## Sussex ITP Local Group Meeting

Next Meeting: 31st August 10:30am to 12:30pm  
Venue: St Pauls Church Hall, St Pauls Church, Churchside, Chichester, West Sussex, PO19 6FT



**The ITP Support Association**  
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# Health & Wellbeing



You may have seen a Health and Wellbeing banner around in many places recently. It is the latest buzz in health circles. A lot of money is going into local libraries and within health Trusts, GP surgeries, and elsewhere to promote the

idea. The health service is overburdened in all sorts of ways, and if people who end up being patients can take care of themselves, it should, in theory, release money and time for professionals to deal with the necessary work instead of the unnecessary, or the elementary.

You may have noticed that I have a different photograph in this edition of *The Platelet*. The previous one was from my 60th birthday and the new one from my 70th birthday, this year in January. After 10 years I thought I should update, and it gives me an opportunity to reflect on the last 10 years of my life in the light of health and wellbeing. When we get to the zero birthdays I think we all have a feeling of moving on in life, and it is a good point to reflect about the past and the future.

I don't think I have changed much, although you will have to be the judge of that! 10 years is quite a long time and in family terms we now have 2 married children and 2 grandsons. Importantly my ITP is well controlled, and although one can never probably say one is cured, this being an autoimmune disease, I consider myself as good as cured with platelet counts of around 350. I am not on any medication for ITP, but had a splenectomy in 2000.

I am on the Patient Participation Group, (PPG), at my GP practice and some room at Reception became available, so we have taken it over as a Health and Wellbeing area to display notices on a board and provide leaflets in racks and on a table. This is not without its pitfalls and we have to be very careful not to be too specific, such as giving information on specific cancers, although we have made an exception with Bowel Cancer, as this is the most undiagnosed cancer of them all, Macmillan tell us. Otherwise we provide general information on cancer and information for carers to get support locally. We cannot advertise, but have found out that the NHS

endorses Slimming World, so information about local groups can go on the board, and Slimming World can be done on referral from your GP.

We are keen to support mental health, and this is very wide in scope. We are looking into having a Local Events heading so that we can give exposure to local groups, such as the monthly WEA Film Club and other social events that people may wish to attend. Being socially active is a good marker of your mental health, and mixing with others and sharing conversation and stories, can be very beneficial for isolated and lonely people, or indeed anyone.

Health and Wellbeing books on prescription and Reading Well schemes, at the library are a government initiative and Councils have to provide resources. I have been instrumental at my library in getting the books moved to a more prominent position, and also asking for more appropriate books for the demographic of our area. Much information on this can be found on the net. See what your local library has to offer.

Bereavement information is also provided. Dying Matters, the title of some talks, is something that we do not readily want to discuss, but it is important as we will all die one day, and facing up to the preparation for this can be very healthy, but not many of us want to go there for many complex reasons. As the years roll by we do think more about our mortality, but on a positive note, it is worth looking at your lifestyle to see if you are in the best place, looking after your health by having a balanced diet, keeping to a steady, healthy weight, stopping smoking, drinking in moderation and having a daily exercise programme. You may think this sounds familiar, and it is, as it comes around regularly as the way to keep healthy in mind and body, and often seems to be the cure all in the popular press.

This is a huge topic which used to be called Health Education. It is notoriously difficult to influence people to change their lifestyle. Keep an eye out for Health and Wellbeing events in your local area and see what you think of them. Are they helpful, and how would you improve them?

*Rhonda Anderson - June 2019*

# 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](http://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.

# New Christmas Cards



## New Christmas Cards for 2019

Our new Christmas Cards for 2019 are £3.00 for a pack of 10 cards with envelopes.  
To order go to [www.itpsupport.org.uk](http://www.itpsupport.org.uk)

We also have lots of ITP branded items available on our on-line shop at [www.itpsupport.org.uk](http://www.itpsupport.org.uk)



# 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.

# Publications List Cont...

## ICH alert card

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

## FUNDRAISING & MISCELLANEOUS

### Fundraising pack

suggestions for those interested in running a fundraising event

### How does the Association use your donations?

an explanatory leaflet

### About ITP and the Association

explanation about the condition and our work

### Gift aid declaration form

tax payers can increase the value of their donations

### Gift aid cards & envelopes

for donations collected at events, parties or funerals

### Standing order form

for supporters wishing to make regular donations to the Association

### Leaving a legacy

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

### Collection box

rigid plastic, or pyramid foldable card, please state preference

## ARTICLES PUBLISHED IN PREVIOUS ISSUES OF THE PLATELET

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

# Publications List Cont..

35. Where are we with ITP today?

36. Are young platelets better?

## AMERICAN PERSPECTIVES

1. A history of ITP

2. ITP in pregnancy

3. What is a platelet?

4. How is ITP diagnosed?

5. Non-intervention in childhood ITP

6. Activity restrictions in ITP children

7. How many platelets are enough?

8. Splenectomy and ITP

9. Can I die from ITP

10. The child newly diagnosed with ITP

11. Surgery in the patient with ITP

12. Are alternative & herbal remedies safe?

13. Use of steroids – a boon and a bane

14. Immunoglobulin – good and bad news

15. Intravenous Anti-D – another treatment

16. Chronic ITP – disease or risk factor?

17. Platelet counts – how useful are they?

18. ITP, sports, and sports injuries

19. After failure of splenectomy & steroids

20. ITP in the elderly

21. Rituximab for ITP

22. ITP and tiredness

23. Viruses and childhood ITP

24. Increasing platelet production

25. What happens to adults with ITP

26. ITP and 'cure'

27. What is a clinical trial?

28. The relationship between ITP and lupus

29. ITP in adolescents

30. The development of new ITP drugs

31. Menstrual periods in women with ITP

32. Coping with prednisolone - book review

33. Assessment of bleeding severity in ITP

34. Steroid side effects

35. Splenectomy for children with ITP?

36. What happens after a child recovers?

37. Prevention of infections in asplenic

38. Who cares for patients with ITP

39. Who needs the new TPO drugs for ITP

40. TPO drugs in children & adolescents

41. Platelets & walnuts (food intolerance case)

42. Let's let ITP kids be normal

43. Silent hemorrhage in ITP

44. When bad bleeding happens

45. How often does ITP occur

46. How do hematologists treat ITP patients

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

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

49. ITP: It's not only about bleeding

50. Vitamins, alcohol & ITP

51. Familial (hereditary) thrombocytopenia

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

53. Abnormal blood clots in ITP

54. Treatment of ITP children; Who and when

55. Immuno suppressive therapy

56. Platelet counts during pregnancy

57. Vaccinations – An ounce of prevention

58. Spinal anesthesia, and childbirth

59. ITP and Depression

60. Adherence to ITP therapy

61. Bone marrow biopsy and ITP

62. Don't forget splenectomy (in adults)

63. Splenectomy for children with ITP

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

# MEMBERSHIP SUBSCRIPTION FORM:

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

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

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

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

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

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

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

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

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

MEMBERSHIP	£10	FOR OFFICE USE
GENERAL DONATION		
RESEARCH DONATION		
TOTAL ENCLOSED		

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

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

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

