



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



The Platelet

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

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

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From ITP HQ



Local ITP Support Group meetings

Our network of local support groups around the country continues to grow, a list of the meeting dates (as we go to press) is published in this edition of the Platelet. Please check our website for any additional meetings and new dates. The number of local meeting groups now stands at eight, which includes the addition of our South Wales Support Group which is due to hold its first meeting on 7th October. There are also several new local groups in the pipeline, details will be made available once plans are firmed up. Numbers attending our Local groups varies by meeting. There can be 10 or 12 at one meeting and then 3 or 4 at another. Numbers help, but what is important is the fact that everyone who has attended one of these meetings feels that they have made a positive contribution to their wellbeing.



New Medical Advisor – Dr. Gerard Crotty

I am pleased to announce that we have a new Medical Advisor joining our long list of ITP experts, a big welcome to Dr. Gerard Crotty, Consultant Haematologist with the Health Service Executive (HSE)

of Ireland. Some of you will recall Dr. Crotty supported the Association at its ITP Patient Day in Dublin earlier in the year.

American Perspective is back – with a new team



Dr. Adam Cuker MD

Dr. Rachael Grace MD

Other good news is that the American Perspective Articles are back and thanks to some great work by Dr. Cindy Neunert, two new contributors to the American Perspective articles have joined Dr. Neunert and Prof. Spiro R. Cataland, they are Dr. Adam Cuker, Associate Professor of Medicine at the Hospital of the University of Pennsylvania and Dr. Rachael Grace, Assistant Professor of Paediatrics, Harvard Medical School. The latest American Perspective 'Understanding the Immune System' by Dr. Cindy Neunert can be found in this edition of the Platelet.

The ITP Support Association Convention 2020

A huge milestone will take place in 2020, it is not just the start of a new decade, but it will also mark the Silver Jubilee year of the ITP Support Association. In celebration of our 25th

Anniversary we are also pleased to announce that the 2020 UK Convention will take place on 9th May 2020 at the Royal College of Pathologists in their brand-new headquarters building in Alie Street, London. Planning for this event is in the very early stages but we have already lined up a virtual 'who's who' from the world of ITP. Details of how to book your place at the 2020 UK Convention will be published on the ITP Support Associations website at www.itpsupport.org.uk followed by publication in the December edition of the Platelet.

Mervyn Morgan CEO



Royal College of Pathologists

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Cover Photo: International Alliance Meeting, Washington

American Perspective



Understanding the Immune System

Dr. Cindy Neunert MD

Columbia University Medical Center

The immune system is an important part of the body. It works to keep our body safe from things that should not be there like bacteria and viruses. In ITP the immune system has become confused and is now treating the platelets as something that should not be there leading to them being cleared from the body. We don't know exactly what causes the immune system to act against the platelets and it may be different for each patient. However, based on our understanding of the immune system, many of the drugs that we use try to adjust the immune system by reducing or changing the action of certain cells. There are many cells in the immune system and each drug may act on a different one and some even act on more than one. Having knowledge about these different cells may help you understand how a specific medication is working.

In general, when a foreign substance (antigen) invades the body, there are several cells that work together to remove that antigen. A main defender of our immune system are the T-cells; they are called this because they start in the bone marrow but then grow up the thymus. While growing up in the thymus, they are trained to learn the difference between normal (self) and abnormal (non-self). During this process, T-cells that recognize the self as abnormal are eliminated. There are several different types of T-cells. Helper T-cells do just that—they help. They are the coordinators of the immune system. They assist other cells in the immune system to recognize antigens and stimulate other cells to be active. One of the cells they help are the killer, or cytotoxic T-cells. These cells go straight to the source of infection and destroy infected cells. Lastly, we have regulatory T-cells. These cells help to make sure that the immune system knows when to shut down and not “overreact”. They serve as the thermostat for the immune system, keeping it balanced. There are no T-cell specific drugs used in the treatment of ITP; however, some immune suppressive drugs such as sirolimus seem to have effects on T-cells more so than on other cells in the immune system.

We also have B-cells that grow up in the bone

marrow. The B-cells are responsible for making something called antibodies that float in our blood. Each antibody is an exact match for a specific antigen and they fit together like a lock and key. Antibodies do not directly kill what they are locked on to, but simply serve as a red flag that the rest of the immune system should react. They are like a sticky note that attaches to the antigen and flags it to be removed from the body. While they are growing up in the bone marrow, the B-cells learn to not make antibodies against our own body. Once a B-cell encounters an antigen, it begins to replicate itself into plasma cells and memory cells. Plasma cells begin to make a lot of antibodies and release them into the body. Memory cells help us fight an infection faster the second time by remembering that it is foreign and being prepared. Rituximab, used for the treatment of ITP, works by trying to reduce the number of B-cells. It identifies the B-cell marker CD20 on the outside of the cells and attaches to it to break down the cells.

They are a few other cells that are less common in the blood. One type is called natural killer cells. These cells also grow in the bone marrow; however, unlike B cells, they directly kill cells that are infected with viruses. They do this by placing substances in the cell that cause it to be destroyed, destroying the virus at the same time. Another cell is the macrophage. Macrophages sit in important organs like our liver and spleen and wait for foreign substances to pass by. When they encounter a foreign substance, they ingest it and break it down. They also present the digested parts to other immune cells and also produce chemicals that help regulate the immune system. Other cells called dendritic cells can detect even small amounts of antigen in the blood and present them to other cells of the immune system to activate them. The new medication, fostamatinib, works by blocking the ability of the macrophages to ingest things. This drug blocks an important enzyme in the macrophages (spleen tyrosine kinase or Syk) and prevents the shape change needed for macrophages to work.

As you can see, the immune system is very complex, but this certainly does not even fully detail all the interactions that occur to keep our bodies safe from antigens. As we learn more about the immune system in ITP we can hopefully develop newer treatments and perhaps learn what treatments will work best in each patient.

ITP International Alliance Meeting



The International ITP Alliance Meeting 2019

The International ITP Alliance symposium 2019 on July 25th took place in Washington, DC, USA hosted 18 delegates from 12 countries: Argentina, Australia, Brazil, China, Denmark, Finland, Israel, Italy, Netherlands, New Zealand, United Kingdom, and United States. There were representatives from 6 Industry Partners including Argenx, Momenta, Novartis, UCB, Amgen and Rigil.

The symposium provided the opportunity for ITP Alliance Ambassadors from around the world to present developments, achievements and current objectives from their respective organizations and groups. Industry partners listened in awe of the many achievements accomplished by global ambassadors who attain so much despite the absence of financial resources and assistants.

Thanks to Nancy Potthast, PDSA USA for the report.

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 donation of £300.00 was received from the Inner Wheel of Carlton - Ms Crosby nominated the charity as her friends daughter and a friend of Ms Crosby both have ITP.

Mrs Connor of Glasgow sent the association a cheque for £500.00 raised in lieu of gifts for their Ruby Wedding Anniversary.

Atlas Trading Group Limited - £75.50. Another large sum to have been raised from the collection box inside the shop!

In addition, we continue to have some fantastic donations via our Facebook page, a huge thank you to everyone for taking the time to raise funds on our behalf.



Frances Connor and husband at their Ruby Party

Condolences

£597.50 in memory of the late Murray Cleghorn. Murray had been involved in fundraising for ITP over the years as his grandson has ITP.

£225.00 raise in memory of the late Terry Carter who had ITP. This was collected in lieu of flowers at the funeral.

£417.50 in memory of the late Malcolm Akerman from the beautiful county of Cornwall, Malcolm had been a friend and supporter of the charity for a number of years.

£216.53 in memory of the late Douglas Todd.

£200.00 in memory of the late Christine Fletcher. Christine had been a supporter of the charity for many years.

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!

My success with MMF



As I approach my thirteenth ITP Birthday on July 28th, I can reflect upon plenty of incidents during ITP years. It hasn't been a picnic by any means. I have been through the Prednisolone ringer five times, Rituximab twice and a horrible week or so with Azathioprine (I could not tolerate it all and withdrew from it within ten days).

I am one of those ITP sufferers who have been fortunate to respond well to Prednisolone and Rituximab. With the steroid, I have obtained about 6 months remission every time that I went on it and with Rituximab, I got about 2 years and 8 months remission both times that I had it. But in February 2016, I relapsed from the Rituximab remission that I had enjoyed since Summer 2013.

So, at that point my specialist suggested that we try Mycophenolate Mofetil (MMF). He was reluctant for me to undergo a third round of Rituximab treatment. Although I had responded well to it twice already (2010 & 2013). He felt that the long-term damage that it could potentially do to my immune system was not worth the risk. More long stints with Prednisolone were also ruled out. Although I responded well to it, the problems that it caused every time that I had used it on 5 occasions already, would just not be bearable again.

Most ITP sufferers will be familiar with the horrible side effects that Prednisolone can

sometimes inflict on the patient, so I will not dwell on them further here, suffice to say that I was not willing to put myself through them again. In addition to the wretched side effects, long term steroid usage is also damaging for us in several other ways, not least in weakening our joints and bones. So MMF seemed to be a very attractive option back in 2016.

For those not familiar with it, MMF like Prednisolone, Rituximab and Azathioprine is another immune suppressing drug which raises the platelet count by slowing down the destruction of platelets. It hopefully achieves this by suppressing the immune system and its' penchant for incorrectly attacking and destroying our platelets. It has the added benefit in most cases, of fewer nasty side effects.

As usual we must emphasise that we all respond differently to all these treatments and all encounter different side effects to varying degrees. MMF is a drug which is most commonly used by patients who have been given an organ transplant as it works to prevent any rejection of the new organ by the patients' immune system.

A key point to make about MMF is that like Rituximab it can take 2 to 3 months to impact on the platelet count. So, I was put on a fairly low, yet gradually reducing dosage of Prednisolone initially, just to get my platelet level up and hold it whilst MMF was introduced. I reluctantly accepted that I'd have to go back on the steroid for what turned out to be six weeks. Once my platelet count was back to normal levels, MMF was introduced at a dosage of 750mg's twice per day. It has subsequently been reduced to

My success with MMF cont...

500mg twice per day and that is my current dosage. I take no other drugs.

After six weeks of tapering down the steroid and getting MMF on board, my system responded well and since February 2016 MMF has been my constant companion. My platelets have settled at normal levels and even reached the low 200's, quite regularly. I could not be more delighted. The only side effects I get from MMF are a little nausea, usually first thing in the morning, but it is not too problematic. I don't encounter any other issues at all.

Some ITP sufferers have had equally positive responses from MMF but as ever all I can say is that like all treatments, responses vary. I continue to have excellent platelet numbers, but I also keep a watchful eye out for any unprovoked bruises and am always wary about any signs of over tiredness. You have to keep a secret service like watch out for any ITP warning signs. That is the daily routine of any ITP sufferer, so nothing new there.

One very important thing to mention about MMF, is that like all immune suppressing drugs it does reduce our ability to fight off infections, viruses, bugs, colds, flu's etc. So, we are more vulnerable to illness than we otherwise might be. Like any treatment, it is a matter of measuring risk versus reward in all these things. We have to weigh up the side effects, potential problems (both short and long term) against keeping our platelet levels as high as possible and at consistent levels.

A further thing to keep in mind about MMF is that it also makes us more vulnerable to skin cancer and therefore I always wear a hat in the

sun and always use Factor 50 sunscreen lotion. It is common sense for anyone anyway, but when taking MMF it is a necessity.

As I approach my thirteenth ITP Birthday, I can definitely confirm that MMF is the drug that best suits me. I am aware that I will likely as not, always be taking MMF from now on. However, I am grateful and realise how fortunate that I am to have found a drug which maintains my platelets at normal levels, without any of the nasty side effects. I fully understand how tricky getting the right drug for each individual ITP sufferer can be. I went through 10 years of some pretty nasty times, but I am thankful to have come through them.



Been there, done that, got the T shirt or Jonah or Jynx - By Steve Syddell



Editors note, a long but well written and at times heart wrenching account of Steve's ITP journey with all the ups and downs that entails.

My childhood more or less followed what could be described as the 'norm', although my father's drinking caused my parents to split when I was 16. I spent time alternately with both, until I met my future wife and moved to her grandparent's home, to be closer to her.

Apart from the usual ups and downs, we had a very happy marriage until Glenda died of ovarian cancer after 29 years together. Some while later I met Mandy and remarried. After she suffered a heart attack, her personality changed, and we drifted apart. Things finally came to a head after 12 years and we sensibly agreed to an amicable divorce.

At that time, I was looking into my family history and often corresponded with Sandy, a lady online, who was undertaking similar research. It transpired that she had become widowed after a fairly loveless marriage, at about the same time of my divorce. We eventually met and formed an instant attraction to each other and, to save a long story, we were together for 16 very happy years. I had previously been in 'poor me' mode but she soon cured that.

After surviving breast cancer in 2002, fairly soon after we had met, she passed away in 2016, from multiple organ failure and I was devastated. Sandy had been my rock, my love and my whole reason for living.

Some years earlier, along with others, I lost my job,

due to a takeover by another company. Based on my prior experience, I then had a spell at running my own business, but after an encouraging start, the bank foreclosed on a client who owed me a healthy sum of money. It was not just me who suffered as there were many similar companies and individuals. The knock-on effect meant that I lost my house and my whole way of life. And, I think, my second wife!

I was forced to take stock of my situation and face realistic possibilities for the future. At 56 years of age I found it very hard to even get job interviews and ended up using my only asset, my car, and undertook some minicab work. I developed friendships with many clients and one passenger asked me if I wanted a proper full-time job and offered me a driving position for a television program, The Big Breakfast. It was a fantastic job transporting the rich and famous to and from the studio, or those with an interesting tale to tell. The programme, however, was not one that really appealed to me. The ratings began to drop, and Channel 4 eventually pulled the plug after I had given 5 years of service. It ended on a Good Friday and on the Easter Sunday, I had a heart attack. Lewisham Hospital were outstanding in their treatment and I spent a month there as an in-patient.

During my initial examination session, I was asked to go for a chest X-ray as a matter of procedure. After being photographed I took the results back to the doctor and whilst looking at the X-ray he calmly said, "I have some unwelcome news for you"! I immediately thought that the X-ray has shown something sinister, but he then went on to say, "I am afraid your blood test shows that you are diabetic, and that is possibly why you had the heart attack".

I was so relieved that I replied "Oh, that's all right then". Seeing the look on his face I explained that

Been there, done that, got the T shirt or Jonah or Jynx - By Steve Syddell cont...

Glenda, my late wife, had had severe diabetes type 1 since her 19th birthday and I was fully used to being around the condition. I am only type 2 and well controlled now. Although she suffered greatly from time to time with many side effects, it did not really hold any great fears for me, compared to the cancer I thought he was going to tell me about. Happily, I have never had another heart attack, since the original in 2002. The doctor since agreed to change his bedside manner!

Then we move onto the next drama. One day in 2011, I had a telephone call from my doctor. He explained that my platelets were decreasing each month or so and that they had picked this up from my diabetic blood tests. He advised a consultation with the Haematologist at the Lewisham Hospital. You can guess the rest.

Just like many members' reviews that I have read in 'The Platelet', I then tried various tablets and treatments, without success, mainly the well-known ones. At times my level dropped to just 1 very lonely platelet, although I felt no obvious side effects. I had tried Prednisolone, Rituximab, Danazol, Mycophenolate, Romiplostim, Eltrombopag, with little, or no, positive results. I had IVIG for 2 consecutive days every 3 weeks. What an absolute trial that was, although essential. Bone marrow samples showed that I was producing adequate platelets, but then killing them off.

Fate then decided it was time to give me another nudge! I fell backwards onto the side of our bath and I was in a fair amount of pain. I slept on our sofa for a few weeks as getting back upstairs to bed was nigh on impossible. During this period, I was not able to attend hospital for my infusions, but one day I was determined to make the effort and steeled myself to resume contact. I got a cab to the hospital, and

whilst walking towards the building, fell again. Luckily, I was spotted on the CCTV, staff rushed out with a trolley and I was wheeled straight into A & E. IVIG treatment resumed and patient transport was used from then on.

I was diagnosed with a fractured spine from my earlier fall, with my mobility drastically reduced, even after rehab. My Partner, Sandy, was a great, and willing lady, and literally offered me all kinds of support over and above the call of duty. However, she gradually began to slow down, and things were beginning to become a burden for her. She was eventually admitted into hospital, where she passed away some 3 weeks later.

Now I was beginning to doubt myself even more than ever before, and was convinced that I was, somehow, personally responsible for all these dreadful events. I started fearing the future in very strong and frequent episodes. I wondered what would become of me in the fullness of time. How would I cope without my love, how would I find somewhere to live, how was I going to deal with all the regular hospital trips, as mentioned earlier?

Hospital visits, as you may know, only too well, can be very lengthy and very debilitating. In my case I now went by Patient Transport [a debt of thanks to the excellent G4S], had to wait for a porter, went to the treatment ward, had a six-hour IVIG transfusion, waited for another porter, then waited for Patient Transport again. Exhausting! And then it all happened again the next day. Another ten hours of hell.

They say that the death of a loved one, funerals, divorce and home moving are the four most stressful events for the average human being, and yes, I had experienced them all. I was diagnosed by my doctor with acute clinical depression and was admitted

into the care of the South London Mental Health Association, to whom I owe an enormous debt of gratitude. I was a voluntary in-patient with them for 4 months, as I could not face returning to my former partner's now empty home.

Gradually, they got me sorted out and suggested many positive ways forward, most of which I took on board and can now face the future with confidence and optimism again. I was fortunate to be offered a residential place by Abbeyfield Kent, which has now been renamed, in our area, by Rapport Housing & Care. They are a truly wonderful set of residents and staff, and all have become good friends. I purchased an electric wheelchair and can now go out and about again, to the shops or wherever I want, after several years of being totally housebound. The biggest boon of this is that it has cut down my time at hospital visits by anything up to 2 hours.

Finally, [about time I hear you say], my story gets even better. My consultant, the excellent Dr Naheed Mir, was concerned about my loathed and debilitating programme of IVIG sessions, consisting of two consecutive days, every three weeks. She decided to re-start an earlier course of treatment. Romiplostim had worked to a slight degree in the past, so she put me back on it with fortnightly injections of 500ml.

Guess what? No-one knows why, but it started working properly after a short while, and I was considered to be fairly stable and once more within the acceptable range [just] and possibly suitable for gradually transferring to oral medication. This could be obtained from the hospital pharmacy, thus greatly reducing the frequency of my hospital visits. Eltrombopag was then reintroduced and I have happily been taking it for a while now, with slightly reduced platelet levels, but still well within my target. At 79 years of age, I have had other issues too, but then so does everybody. I am sorry to have gone on for so long but wanted to impress on you that there is always hope, even if you do not immediately respond to treatment. When things seem at their

blackest, life can suddenly surprise you unexpectedly in positive ways too. Despite well publicised claims to the contrary, I have always found the NHS more than satisfactory, and their wonderful staff to be outstanding and dedicated professionals.

Like many others, I have been contacted to take part in the national survey currently being conducted throughout the UK, in an attempt to try and identify possible causes of ITP. The multi-page request covered many issues, but the one that concerned me was the data regarding pregnancy. So, as a 79-year-old male, I was alarmed at the possible side effects that ITP might cause me!

I even have the time and inclination now for assisting the local Talking Newspaper for the Blind by sourcing news and other stories from the internet, whether important or just of general interest, for them to read out in their weekly bulletins and I fill other spare moments by serving on the management committee of two football leagues. These pastimes are something that I enjoy enormously, and it gives me a chance to give something back for the numerous times I have received help and support in the past.

I am much happier now that I have been in many years and I am positive that you should be optimistic too. It does sometimes take a while to come to terms with everything that is thrown at you but stick with it and it can be worthwhile in the end.

Good luck to everyone.

Steve Syddell

Your Questions

Q *Question from Mara Cosovic*

I recently had a hamstring injury I would previously have taken ibuprofen to ease the inflammation.

I read that this was not good for a person who has issues with platelets.

Any advice regarding alternatives?

A *Dr. Drew Provin replied*

Dear Mara, I'm sorry to hear about your hamstring injury and I can understand the need for some decent pain relief for this. Drugs like ibuprofen, which is a non-steroidal anti-inflammatory drug, can interfere with the way platelets work. For this reason, we are slightly anxious if patients with low platelet counts (who have a higher incidence of bleeding) start taking a drug like ibuprofen which can further increase the risk of bleeding. However, it really depends on your platelet count and if your platelets are above 50 then I think you should be able to take ibuprofen for the injury. If your platelets are less than 50 it would be wiser to stick to paracetamol, I think, because paracetamol does not interfere with platelet function. Hopefully this will heal fairly quickly and you will not need to take the anti-inflammatory drug for long.

Q *Question from Mrs M Mckenzie*

I was on Revolade for 6 months which got my levels up to 56 and have been stable at that for 12 weeks now, but I have had really sore legs since then especially my joints is this a common side effect?

A *Dr. Drew Provin replied*

It is good to hear that Revolade has had some impact on your ITP and you have a safe platelet count of 56 which is great. It is also reassuring to see that your platelet count has been stable over the 12 week period. There are numerous side effects reported with all drugs and muscle pain has been described with Revolade, so I would not be surprised if the leg/joint pain is related to it as well. The options you have are: to continue, if the pain is not too severe, or you could switch to another similar

drug for example Romiplostim which works in a similar way to Revolade and hopefully would not have the joint pain problem which Revolade seems to be causing. Many of these side-effects ease off after a while, even if you continue the drug but it really depends on the severity of the joint aches. If they are very troublesome then I would suggest switching to Romiplostim.

Q *Question from Claire Bailey*

My name is Claire Bailey and I was diagnosed with ITP in 1992 at the age of 12. My platelets at first stayed constant at a level of 45. Since 2010 they have slowly dropped to 12, and now back up to their highest 65 after finding success with Romiplostim. I still have my spleen, after having an indium scan it was discovered that my platelets are mostly destroyed in my liver, my platelets are not very responsive to prednisolone.

My question is: how damaging to my platelet production is being exposed to toluene? I work with the chemical through solvent glues that I work with in my job. The internet tells me that toluene can decrease my platelet production, but I love my job!

Should I be avoiding toluene like superman avoids kryptonite?! Is there more of a sensitivity between me breathing it in compared to it being absorbed through skin contact? Should I ask other people to leave the room if they are using it and it means I am inhaling the vapours.

A *Prof. Adrian Newland replied*

An interesting question. It is good that your platelets have responded to Romiplostim and are stable and this is good indication that your bone marrow can produce platelets properly. When the liver is responsible for platelet destruction steroids may be less effective. Toluene is used very widely as a solvent and is present in many products in daily use such as petrol, paints, adhesives and fingernail polish (to name a few) so we are all exposed to small amounts on a daily basis and will be familiar with the smell. In the majority of people the degree of exposure is however unlikely to be high enough to cause problems unless exposed to significant quantities on a regular basis. If you were exposed to sufficient concentrations to affect the bone marrow then there would also be other more general effects as well such as tiredness, headaches,

Your Questions cont...

sleepiness and dizziness amongst other things.

Occasional, casual exposure of the type you describe is unlikely to be sufficient to do this. The body does remove the small amounts that are inhaled fairly effectively and this type of exposure is unlikely to lead to any build up that will cause you long term problems. There is probably little difference between either inhaling or it being on the skin. I think it is a question of being sensible. Occasional exposure to someone using glue is probably not a problem but daily regular exposure to large amounts may be an issue. But as I have pointed out we cannot avoid regular exposure to small amount as it is all around us in many guises. The important thing is that your bone marrow has responded by producing platelets in response to the Romiplostim and that is the positive and should allay your worries.

Q *Question from a Gentleman*

Thank you for any response in advance.

I am a sixty plus man being treated for ITP with Romiplostim. It has indeed been a positive benefit for my health as I recently had an S-ICD implant. My platelets have stayed above 50 to 100 for approximately two years. My concern is what are the chances that my body might start to reject the drug in the future? and also if it were to might I be offered Eltrombopag? I am acutely aware of the expense of these drugs to the NHS and I would pose one further question and that is what would happen if the guidelines for prescribing these drugs changed because of the expense? Would it be likely it could be stopped in my case.

For a man of my stature you are talking of 6 packs per week to give me an effective response.

A *Prof. Adrian Newland replied*

It is gratifying to hear that you have had such a good and stable response to Romiplostim and that this has been sustained. Many patients in the early studies remained on treatment and have continued responses for 7-8 years, and some probably longer. While there is a possibility of losing the response we believe this to unusual and certainly after such a long period.

There have been studies where patients have failed to respond to one of the thrombopoietin stimulating drugs being transferred to the other and the response rate is high. It is better for those who changed because of side effects or problems with administration but still around 50%. There would certainly be no problem in you receiving permission to switch agents but hopefully that will not be necessary. The guidelines are very unlikely to change because of cost and the likelihood is that as drugs come off patent and competitors enter the market the price will actually fall. We hope so!

Over the last year or two we have been looking at stopping treatment in patients who have had a long term response and around 30% maintain the response off all treatment, even when the count is not in the normal range. We count a stable response of at least 6 months. The treatment can be restarted if necessary but many patients have remained off treatment. This may be worth discussing with your haematologist as it is a big step to take if you have previously had problems with earlier forms of treatment.

Q *Question from Paula Freeman*

I would be very interested to learn whether there are any other ITP patients who are currently on Warfarin. I have been diagnosed as having Atrial Fibrillation, and because my Platelets count is in the 60's I have been put on this drug. The cut off point is 50, so if I dip below 50 I have to come off the drug until the platelets increase. I never thought I would need blood thinning medication and I have to have Platelet blood tests as well as INR blood tests constantly, which is very tiresome.

A *Dr. Jecko Thachil replied*

Atrial fibrillation is a very common problem in individuals when they get older. An incidence of 0.5% at age 50-59 years to almost 9% at age 80-89 years has been reported. Because of the high incidence of this condition, it is not uncommon for a patient with ITP to be also having AF.

Persons with AF are at an increased risk of stroke (blood clots in the brain circulation) depending on the number of risk factors they may have in addition

Your Questions cont...

to AF. This risk is assessed by a scoring system called CHADS2 VASC score. If a person scores two or more, it is advisable to have blood thinning medication to prevent the complication of stroke.

As you rightly pointed out, the general recommendation is to keep a platelet count above 50 to allow blood thinning medications. One of the 'requirements' of treating ITP in the absence of bleeding is this scenario.

In relation to blood tests for the blood thinning medication (which I would assume is warfarin), you can discuss the possibility of switching to more recent anticoagulants which are popularly called as direct oral anticoagulants. They have the benefit of needing NO monitoring which reduces the number of blood tests. Once again, the platelet count does still have to be above 50 for the DOACs to be prescribed.

Q *Question from Corinne Gorman*

I would be grateful for advice please about what is the available information / research concerning ITP and using HRT? I am a registered member.

I was first diagnosed with ITP in 2002 and last received treatment with Steroids and Rituximib in 2011. I am 52 years old and keen to start on HRT to manage my perimenopausal symptoms, but don't want to do this without checking firstly about what current medical advice is available.

Do you have any specific leaflet on this issue or is it possible to ask one of the support group's medical advisors?

Many thanks as always for your support.

A *Dr. Jecko Thachil replied*

HRT may be useful for symptoms of menopause but detailed assessment and lifestyle measures first are advised by the National Institute of Health and Care Excellence <https://www.nice.org.uk/ng23>. If your general practitioner considers HRT is helpful for you, then it may be reasonable for you to have it for a period of time to alleviate specific symptoms not made better by lifestyle changes. Please do check whether it may cause unscheduled vaginal bleeding,

which may be rarely noted as a side effect of HRT within the first 3 months of treatment. This may be an issue especially if your platelet count is less than 30-50. On the other hand, it is also useful to ensure that you don't have any risk factors for blood clots. This is because HRT is associated with a very slightly increased risk of blood clots and increasingly, we think ITP may also be associated with slightly increased thrombotic risk.

Q *Question from Angela Smith*

I first had ITP in 1997 which may have been caused by taking quinine based anti-malarial.

I continued to intermittently have very low platelets and none of the treatments were effective.

In 2009 I had a splenectomy; it was completely successful, and my platelets have since been normal.

A few weeks ago, much to my surprise I was diagnosed as having a DVT with a D Dimer of 29,000. and there is no obvious explanation for this. Can this have any connection to my ITP history or my lack of spleen? I am 76 and otherwise in good health.

A *Dr. Will Lester replied*

Although ITP is primarily considered as a risk factor for bleeding, there is increasing evidence that patients with a diagnosis of ITP also have a slightly increased risk of thrombosis (eg DVT) – a sort of 'double whammy'. Thrombosis can sometimes even occur when the platelet count is low, which can make treatment with anticoagulants quite tricky. It is unclear how much of the thrombosis risk relates to the ITP itself. We know that many 'autoimmune' conditions are associated with an increased risk of thrombosis and there are many theories about why this happens. It is also likely that the treatments we use for ITP can increase the risk of thrombosis; in your case, this is splenectomy. There are some scientific publications suggesting that having a splenectomy increases the risk of thrombosis compared to those who don't have one. So, in summary, both your ITP history and the lack of spleen are potential risk factors for the DVT.

24th Congress European Haematology Association – June 13th 2019, Amsterdam

This year the congress was attended by a record number of over 12,600 delegates from 6 different continents. The venue was the Rai Center in the southern suburbs of Amsterdam well served by the local and national railways, the metro, trams and Schiphol airport only a short train journey away.

As always, the program for presentations was vast with a total of over 200 sessions covering all aspects of haematology, both malignant and non-malignant conditions. In addition to the sessions, the usual poster area displayed presentations and included posters compiled by various haematologists and scientists. The photograph shows Alex Kruse with Dr James Bussell who together with our own CEO and a selection of our medical advisers, were responsible for the poster on the Novartis I-Wish program. Alex, who is a medical student in New Orleans, was on hand to discuss this poster together with Dr Bussell, Dr Nichola Cooper and Dr Drew Provan. These areas always provide an unrivalled opportunity for the professionals, patient group delegates and the pharmaceutical companies to meet and talk over the congress content as well as the poster content on display.



Alex Kruse, PDSA Dr James Bussell, Weill Medical College, New York City (USA)

The sessions devoted to ITP were extremely varied and covered the new proposed guidelines both in the USA; the UK and in Europe with presentations by Dr D.Kuter; Dr Drew Provan and Dr. F.Zaja.

The management of refractory ITP during pregnancy was presented by Dr N.Cooper. Her presentation was extremely important and was very well received.

In addition, there were three very short scientific sessions entitled Alleric Polymorphism of platelet glycoprotein genes GPIA and GPIB as a possible predictive marker of response to therapy in patients with primary immune thrombocytopenia. This session was presented by Irina Zotova from the Russian Research Institute of Haematology and transfusiology, Saint Petersburg.

The second session was entitled TNFG – A blockade corrects the monocyte/macrophage imbalance in primary immune thrombocytopenia. This was presented by Yajing Zhao, Qilu Hospital, Jinan, China.

The third presentation related to the safety and efficacy of an anti-frn antibody, Rozanolixizumab, in patients with primary immune thrombocytopenia; Interim results of a phase II multi-dose study. This presentation was by Tadeusz Robak from the Dept. of haematology, Medical University of Lodz, Copernicus Memorial Hospital, Lodz, Poland.

All these presentations were exceptional even if being extremely medically technical. They all received a very good response from those attending.

This year, the patient organisations represented within EHA were even more involved than in the past. At the commencement of the congress, all patient delegates who had been granted fellowship status were requested to attend a capacity building program. During this program, delegates were instructed on

24th Congress European Haematology Association – June 13th 2019, Amsterdam cont...

how to obtain the best information and benefit from the congress.

On the Saturday, EHA had allocated three sessions commencing at 08:00 for presentations to be given by the patient representatives to the congress. Whilst not directly relating to ITP, they were of importance to patient groups generally and haematologist delegates. Much was to be learnt by all.

Session 1 was entitled Access to treatment: How to ensure patient access to innovation and affordability.

Session 2 – Role of patient-reported outcomes (PRO) in haematology: Is it time to see its value.

A most enlightening session with speakers covering topics on how to build PROMS into study design: the role of technology to improve patient experience: What the future may look like: presenting PROBE (PRO, Burdens and Experiences): PRO to assess Patients needs in haematology: Nurses perspective.

This presentation was attended by over 150 delegates and an overflow area was provided outside the main conference area for that session.

Session 3 – Managing the hype on CAR T cell therapy: Perspective on CART cells and other cellular therapies in haematology.

Whilst this has no relation to ITP, it was a fascinating session with a presentation by Dr B.Koffman from the USA who himself had undergone CAR T cell therapy against his cancer. For him, the therapy had worked but like all treatments and medication, it does not work for everybody. It is a very toxic therapy. His presentation was supported by Ananda Plate who discussed the future of patient partnership model of integrating patient preferences on CAR T therapy. Finally, the nurses role was presented by Ni Chonghaile in delivery

of a successful outcome to CART cell therapy.

The patient organisations within EHA over the last two years have changed considerably. Over the preceding eight years, the patient involvement within EHA has developed and grown and as evidenced above, are now playing a very important role within the haematology world. This has undoubtedly been encouraged by the management of EHA who recognise the important role patients play in everyday medicine. The patient involvement has been overhauled and we now have a patient board of 17 members representing 17 different haematological conditions. Undoubtedly the majority and largest are the malignant conditions but we, the non-malignant conditions, are playing as large a role as the malignant representatives. We have a new very experienced co-ordinator who in herself is the European Coordinator for the Lymphoma Coalition. This year in Amsterdam, ITP were undoubtedly the most pro-active group of patients at the patient's hub. Representatives, apart from ourselves, were from Denmark; Italy; the Netherlands and our friends from the PDSA in the USA.

The hub or patient's booth was located for the first time in a predominant location at the cross roads within the exhibition area. This fabulous location kept us all very busy and information pamphlets were being taken off the desk as quickly as they were being displayed. As far as I can recount, the ITP groups were the only condition with pamphlets in multiple languages which was a great plus for ITP even though English is the accepted language at the congress.

The involvement of the patients within EHA is increasing and we as a group, are represented on several EHA investigating committees, the most recent considering patient safety and the effect bureaucracy has on research. Most of these meeting are either via teleconference or at EHA offices in the Hague.



The congress is an interesting way to spend four days of concentrated effort and to learn. From a record of steps taken, we recorded that over the time of the congress, we walked in the order of fifteen miles. The busy congress did not allow very much time for any social activity, but the all the patient representatives present did manage Tapas together on the Thursday evening. The ITP representatives were kindly entertained to dinner on the Friday evening by our counterparts from the Netherlands and subsequently on the Saturday by our friends from over the pond. It is always a pleasure to be away from the congress with the other groups which allows us time to talk and discuss matters affecting ITP in a relaxed atmosphere with friends.



Next year the congress is in Frankfurt and I suspect the attendance will be greater again. We are already looking at what contribution the ITP European groups can make.

Derek Elston

**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

Dublin ITP Patient Day

Official Report

FIRST IRISH PATIENT DAY IN MORE THAN A DECADE FOR RARE BLOOD CONDITION



On 13 April 2019, immune thrombocytopenia (ITP) patients from around Ireland, were welcomed to the ITP Support Association Patient Day in Dublin supported by Novartis. Chaired by Mr. Mervyn Morgan (Chief Executive of ITP Support Association), the meeting provided patients with an opportunity to discuss their experience of ITP with other patients and to learn about their disease from experts in the field.

Last held in Dublin in 2004, this year's meeting featured talks from Ms. Nicola Harten (Clinical Nurse Specialist, Connolly Hospital, Dublin), Dr. Gerard Crotty (Consultant Haematologist, Midland Regional Hospitals, Tullamore, Portlaoise and Mullingar), Prof. Adrian Newland (Professor of Haematology, Barts and The London School of Medicine and Dentistry, Queen Mary University of London, UK) and Mr. Derek Elston (ITP Patient Mentor).

Additional highlights from the meeting included a Q+A session, an overview of the ITP pocket log and patient breakout groups. The meeting was

attended by 55 ITP patients from across the country.

Managing Symptoms

In her talk entitled 'Managing symptoms', Ms Nicola Harten spoke about how to manage disease symptoms and implement a supportive self-care strategy. Providing practical tips for everyday life, she provided clarity, comfort and support.

The main symptoms of the disease include bleeding, bruising, blisters, petechiae rash, abdominal discomfort, heavy menstrual bleeding, fatigue and worry. Empowering patients to help themselves, each symptom was discussed compassionately, with simple management tips offered.

Some practical tips to manage bleeding:

- Avoid excessive consumption of alcohol as it can diminish platelet counts.

- Some contact sports may need to be avoided; take advice from your doctor in this regard.
- Oral hygiene is very important in ITP, but if gum bleeding is a problem, avoid dental floss and use a soft toothbrush.
- Know the medications that can cause bleeding. Talk to your pharmacist or doctor when getting a new medication to make sure it is safe for you. Be sure to tell them that you have ITP.
- For women with heavy menstrual bleeding, there are medications/contraception you can take to alleviate this.
- For men, if bleeding while shaving is a problem, consider changing to an electric razor.
- If you are going for surgery, let your Health Care Professional (HCP) know at least two weeks in advance.
- Avoid deep muscle injections.

Treatment Options

In his talk on 'ITP Management-Treatment options', Prof. Adrian Newland stressed how important it is for patients to own their illness and educate themselves on its various facets. He explained the individualised treatment approach and gave an overview of the classical and novel treatment options.

ITP is rare, he explained; the average GP may only see one or two ITP cases throughout the course of their whole career. Therefore, it is important that patients educate themselves on the illness and play a strong role in its management. The average haematologist in the UK, sees approximately one new ITP patient a year. It is important that patients find a HCP who understands their illness, and can support them on their journey.

His advice for patients:

- Own your illness- be your own best advocate.
- Educate yourself about your illness.
- Doctors are not always aware of what is worrying you. You must develop a good relationship with your HCP so you can discuss your real concerns.

Platelet Count

ITP, previously called 'idiopathic thrombocytopenia

purpura', is now known to be a disorder of the immune system, characterized by a reduction in platelet count, explained Dr. Gerard Crotty in his talk entitled; 'Treatment of ITP; Practical Aspects'.

ITP affects all ages and in adults is mostly chronic with a variable course. Most ITP is primary, he told the audience, meaning that there is no other underlying cause of the reduced platelet levels. Secondary ITP, (caused by an underlying disease), is less common, but may also require treatment. Dr. Crotty reviewed the diagnosis, treatments and challenges of treating both primary and secondary ITP.

ITP is a diagnosis of exclusion, meaning that there no definitive tests for the disease. When a patient presents with low platelet levels, the haematologist investigates, to rule out other causes for the low levels.

Some practical advice from Dr. Crotty:

- Tell your HCP of other medications you are on, including homeopathic medicines.
- Give adequate notice to your HCP if you require an operation. We may need time to get your platelets up to a level that is safe for surgery.
- Pregnancy can affect ITP in an unpredictable way; it can improve or worsen. Plan pregnancy where possible and discuss with your HCP.

ITP Pocket Log App

Mervyn Morgan presented the ITP pocket log to the audience. Initially launched in the UK in 2017, the ITP pocket log was developed by Novartis, in conjunction with the ITP Support Association.

This app helps patients to manage their disease and optimise discussions with their HCP. There are several functions to help patients keep track of their symptoms, test results, medications etc. Data entered by the patient will be held within their device and will not be transferred to a third party. It could however, if desired by the patient, be downloaded to be shared with their HCP.

The ITP pocket log will be available in Ireland from August 2019.

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.

Southport ITP Local Support Group

Next Meeting: Saturday 21st September, 2pm start

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

Nottinghamshire ITP Local Support Group

Next Meeting: Tuesday 24th September 7pm start

Venue: Grange Hotel, 73 London Road, Newark, NG24 1RZ

Cheshire ITP Local Group Meeting

Next Meeting: Friday 27th September 11:00am to 1:30pm

Venue: De Trafford Arms, Alderley Edge, SK9 7AA

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.

South Wales ITP Local Support Meeting

Next Meeting: Monday 7th October 2:00pm to 4:00pm

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

Sussex ITP Local Group Meeting

Next Meeting: 26th October 10:30am to 12:30pm

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

Devon ITP Local Group Meeting

Next Meeting: Friday 1st November 11:45am to 1:45pm.

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

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

East of England ITP Local Group Meeting

Next Meeting: Thursday 14th November 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.

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

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

UK ITP Support Association Convention 2020 Sponsorship Options

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



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



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- Company logo on convention program cover
- Acknowledgment in Special Thanks section of convention program
- Recognition during convention opening presentation
- Two full convention registrations and two exhibitor registrations

EXHIBITS

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

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

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 organizations 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 organizations 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!**

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.

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

We also have lots of ITP branded items available on our on-line shop at 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

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

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

