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the platelet

JOURNAL OF THE ITP SUPPORT ASSOCIATION

itp
Immune Thrombocytopenia

FLYING HIGH WITH ITP

ITP CONVENTION REVIEW, & LOTS MORE INSIDE

THE ITP SUPPORT ASSOCIATION TEAM

Charity Registration No:1064480

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In this issue . . .

As you may have noticed this edition of The Platelet is rather late so we accommodate news of the Charity Lunch, Global ITP Meeting and our Patient Convention which all happened in the third week of September. In fact we had so much to cram in this issue that two items have been carried over for the December edition.

Included within these pages, Shirley welcomes a new member to the team, Mervyn Morgan, and looks back at the first year in the new headquarters. The American Perspective essay considers spinal anesthesia for childbirth at a time when there is increasing interest in ITP during pregnancy. Howard's Webwatch discusses the perception of health care between the UK and the USA, while Anthony describes his frustration on finding he has had another relapse of ITP, and considers his treatment options. Sheila Catchpole outlines her own ITP journey and Meg Abernathy-Hope urges people with ITP to follow her example and become ITP Warriors! Derek reports on the annual European Haematology Association which is growing in size year by year, and we welcome our ITP veterinary advisor.

Cover Photos

Meg Abernathy-Hope 'wing walking'

Dr Drew Provan at the ITP Convention

Dr Peter Keissling (UCB) presenting an ITP donation to Shirley Watson

Contents

Shirley writes...

Update on The Platelet Mission

It is hard to believe that on the 19th September a year will have passed since the ITP Support Association had the grand opening of its new headquarters, The Platelet Mission! Working in the new office suite instead of the old coal house in our garden has been an absolute joy, and although we had sometimes gritted our teeth at the extra cost and work demanded to meet building regulations, it has been well worth it. The very well insulated wooden shell with its heat exchanger air conditioning units is easy to warm up in the winter and keeps cool in the summer. Nearly all the interior work of the Platelet Mission was done by my husband Frank with help from his friend Tim King, and without their amazing efforts the building cost would have been at least doubled.

Mervyn Morgan

Our meeting room, known as the Steven Sims room, has been very useful for meetings of the charity's trustees, to welcome health professionals, pharmaceutical company representatives and various other visitors. We have also held a couple of coffee mornings and intend to continue with these fundraisers at regular intervals.

The charity's Buy a Brick fund raised an absolutely fantastic £50,483 between its launch in January 2014 and the Opening Day in September 2015, exceeding our target by over £20,000! Although this didn't cover the total cost of the building and site, it certainly paid for more than half. It is comforting to know that The ITP Support Association has no rent or mortgage to find each month, just the running costs which are mostly electricity and the telephone line.

It hasn't all been smooth sailing. We have an ongoing saga with BT cutting our phone line 3 times, and in July I was sent a summons from Bedford Magistrates Court relating to The ITP Support Association's non-payment of business rates – which Bedford Council had instructed me not to pay while they made a decision! They had been deciding on the charity relief amount since September 2015. When I rang to express my anger at the summons the council were very apologetic and gave us full charity relief.

As our charity has expanded it has become ever more difficult for me to keep up with the increasing workload. Having the necessary office space at our HQ for someone to join the team, in August we advertised for a Senior Administrator. I'm delighted to announce that in early September we appointed Mervyn Morgan, whom some of you met at the ITP Convention. Mervyn has considerable administrative and management experience in both the charity and public sector, and has already come up with ideas to improve services and streamline our operation. I'm sure that his input will benefit the office team, the key volunteers, and most importantly, the membership.

Your questions answered

Q I live in Australia and have had ITP since 2014. I was first on Prednisol, then in the last two years I have been taking Eltrombopag. My platelets have been going well with eltrombopag but when I stopped taking it my platelets dropped down again and the haematologist put me back on it again.

As I now want to get pregnant the haematologist told me to stop eltrombopag as it may not be safe for the baby. I am worried about whether it is possible for me to get pregnant and have a healthy child, and if so, which medication I can use to get me through pregnancy without issues for me and for the baby?

The haematologist said that Prednisol might be a better treatment for me if I want to become pregnant but when I was on this before it was horrible on my mental health as my mood was terrible and it was a bad experience for both me and for my partner. I would rather not to take Prednisol again.

A *We are pleased to hear that you ITP is currently under control with Eltrombopag. We do currently avoid using Eltrombopag in pregnancy. This is because Eltrombopag can cross the placenta and we don't have enough experience to say whether it's safe for the baby or not. The same goes for breastfeeding. In future, we may get more information on whether Eltrombopag is safe for the mother and baby in pregnancy but for the present time, we would advise that women use alternative medications that are tried and tested in pregnancy – prednisol being one example. There are other options as well.*

Whether to stop Eltrombopag while trying for pregnancy or waiting till there is a positive pregnancy test requires discussion with your doctor. The risk of coming off before pregnancy is that you don't know how long it will take (and long term prednisol is not ideal for example) however the risk of not stopping is that you might not realise you're pregnant at a suitably early stage to stop the medication in a timely fashion and there could be a risk that the platelet count will drop during any swap over. ITP itself is usually straightforward to manage in pregnancy and the risk to the mother and baby are very low. Even in complicated cases, there is usually an option that works. Some women find pre-pregnancy counselling helpful and it may be worth asking if that option is available to you through your local maternity services.

Dr Will Lester

University Hospitals, Birmingham

American Perspective

Prof Spero Cataland MD
The Ohio State University


Prof. Spero Cataland

Thrombocytopenia, Spinal Anesthesia, and Childbirth: Truly a Moving Target

As a hematologist that specializes in non-malignant hematology, I get the opportunity to meet and interact with many different physicians across many different specialties. The questions surrounding patients on an aspirin or with a decreased platelet count can become more complex in differing clinical contexts. One such example is the pregnant patient that is found to have a decreased platelet count, or has a prior diagnosis of ITP. In these cases the risk of bleeding both during the pregnancy, as well as at the time of delivery, needs to be considered when determining if treatment will be necessary for her low platelet count. Additionally, if the expectant mother with a low platelet count desires spinal anesthesia for her delivery, the risk of bleeding related to this can be specifically concerning.

In general, a platelet count of 50 or higher is adequate for most surgeries, with the exception of neurologic surgery, or open-heart surgery where a platelet count of over 100 may be desired. However, the answer to the question: "What is a safe platelet count for spinal anesthesia" is not an easy one to answer. The combination of the limited clinical research data in pregnant ITP patients, as well as the justified concerns for bleeding complications that could lead to a devastating neurologic injury, can lead to widely differing answers to this question. While a "safe platelet count" is desired this has to be weighed against the side effects of treatments that may be needed to achieve this. The best available research suggests that a platelet count of 80 or higher is safe for a mother to have spinal anesthesia, but there are also studies that have suggested that a platelet count as low as 50 may be equally safe. This uncertainty can lead to patients getting many different answers to the question of "what is a safe platelet count for spinal anesthesia". I recently bumped into a colleague who happens to be both an expert high-risk obstetrician and an expert in obstetric-related hematologic issues. He proceeded to ask me about a case of a patient with ITP that was in the hospital with an impending delivery and a platelet count that was 60. I asked him what the anesthesiologist on call today thought about the platelet count, and he said: "fortunately the 50 anesthesiologist is on today, and not the 80 one". This highlights the variability in platelet count that is used by different physicians and that while 50 would be okay for one it might be too low for another.

So what is an expectant mother with a history of ITP to do in these situations? In general, if physicians are aware of a situation in advance, and have the opportunity to both evaluate the patient in advance, and familiarize themselves with the diagnosis of ITP, they will be more at ease with the delivery. We will routinely have our patients meet with the anesthesiology group as an outpatient well in advance of her delivery for this reason. Communication in advance between the obstetrician, the hematologist, and anesthesiologist will usually make for a smoother delivery, and the ability of patients to receive spinal anesthesia if that is their preference. It also allows time to make plans for any treatment that might be required in advance of delivery to get the platelet count to a "safe" level so that spinal anesthesia is an option for the patient.

Ultimately each patient must be analyzed individually, weighing the risks and benefits of spinal anesthesia in the context of their platelet count and how easily it can be achieved. With advance planning the process should be a smooth one, allowing for a "comfortable delivery" for both mother and anesthesiologist.

A Singular Journey (part of it by rail)

by Sheila Catchpole

or,
1. Patient, 2. Problems, 3. NHS Consultants

Act 1 Scene 1

A crowded commuter train pulling out of Waterloo station, almost five years ago.

A phone rings and, checking that I'm not in the quiet carriage, I answer. At the other end my husband says our GP needs to speak to me, within the next hour. I look around, but decide against treating my fellow passengers to matters medical.

That's how the sequence of events, in which I found myself to be of greater interest to the medical profession than I'd have chosen, was set in motion! I'll try to relate it in a way I hope could encourage or help others diagnosed with ITP, their friends or families. If I fail, I can vouch for the wonderful Support Association we have!

The Background

For some time the GP had felt I might be anaemic, and we'd reached an accord whereby I reported for quarterly blood tests and accepted treatment with iron tablets when my haemoglobin level fell. I never felt any better when taking them, but my doctor did! On the train I'd thought "bother, something's up", but it turned out something was down. This time my platelets were of concern, dropping from a consistently normal level to a dangerous one. The tests were repeated the following day and, when the results were the same, I was given a Haematology appointment for the day after. Tests, scans and a bone marrow biopsy followed, to provide the fullest picture before a diagnosis could be given. I felt fine, just wanting to know what might be wrong and what could be done about it. So far as I knew nothing sinister was suspected.

A Single Whammy

A locum consultant gave us the results of the various tests a few weeks later, leaving to the end the news that I had Non Hodgkin Lymphoma. (Don't worry – I'm not writing this for the wrong support organisation!) The consultant left us in shock while he went to find a Macmillan Booklet to hand over, then said I'd be monitored regularly under a Watch and Wait programme. I wanted to know the worst and was told the likely number of years I might expect to live. Over the next couple of months it seemed hard to extract answers to the questions I thought of between appointments. Almost in desperation we sought more information by visiting a haematologist privately, taking a list of questions. She was certainly knowledgeable, and had received all my test results. Her estimate of my remaining life span was shorter than the consultant's. We arrived home better informed, but downhearted. I really wanted some good to emerge from my situation and decided I'd like to donate a kidney, but my husband was opposed to the idea. In fact he felt so strongly I thought he'd murder me first. This would of course have been a solution, but perhaps not the neatest! Disappointingly, enquiries revealed that with a diagnosis of cancer my 'bits' couldn't

be used, so domestic harmony was quickly restored. However I was still concerned by the attitude of the first consultant and considered asking to be referred to another.

A Double Whammy

(but a very thorough consultant)

At my next appointment I was seen by a different locum consultant. Her first comment was that she didn't think I was suffering from Non-Hodgkin Lymphoma! Yes, she continued, I had the diagnosis which couldn't be overlooked, but she'd examined my results very closely and felt the small clone of B cells, revealed on immunophenotyping, was too small to account for my condition. She told my GP she thought the "thrombocytopenia is most likely autoimmune in nature and there is a possibility that she may have a very early stage low grade lymphoma". Her immediate concern was why my haemoglobin levels were so low. She arranged for tests to be carried out, but I needed to be given steroids first to raise the platelets to a safe level. After several weeks they'd soared to 88, I undertook the tests and was relieved to discover the results were normal. My positive response to the steroids convinced the new locum that I did indeed have an autoimmune disease, ITP, which would now form the focus of our attention. Delighted that my new consultant had comprehensively undermined the credibility of the two life sentences delivered on me earlier, nothing could have persuaded me to request a move from her care. We continued with a Watch and Wait regime for both diagnoses and kept an eye on the haemoglobin.

The Symptoms

Throughout this time my platelet levels usually hovered in the twenties. Once off steroids they'd quickly dropped. Scans showed my spleen was enlarged and I found I ran out of stamina ahead of the things I wanted to do. NHL and ITP can share many symptoms. The first purpuric rash on my legs was alarming, and I had no idea what it was. I showed it to the GP, who arranged for me to go immediately to hospital in case I needed a platelet transfusion. On most days I could have had my husband arrested for domestic violence by showing bruises all over my body, and at different times I had some spectacular spontaneous haematoma, two of which were serious enough for me to be seen at Haematology the day after their appearance, for full blood counts to be taken. Despite this I felt well and continued with life normally, pacing myself when necessary.

The Dilemma

Watching and waiting was interrupted eighteen months ago. A drop in platelet levels to 12 and a further haematoma led my third (and permanent) consultant to decide that the time for treatment had arrived. The dilemma was which should be tackled, the ITP or the NHL? Further scans and a bone marrow biopsy showed the lymphoma had grown since diagnosis, but only slightly. She decided to target the ITP and I embarked on a course of Mycophenolate tablets, the dose of which was increased when I tolerated them well. Eagerly we returned after a few weeks to discover the impact they'd had, but nothing had changed so the treatment was curtailed. It was now the turn of NHL, and a course of Rituximab was organised, administered over four weeks. Once again we returned optimistically to discover the outcome, but again there was no change. I felt an expensive NHS failure! However, the consultant knew that Rituximab could

show a late response, so she arranged for a scan of my spleen a few months later. My platelet levels remained stubbornly low, but the spleen had returned to a normal size, leading the consultant to conclude that I was in remission from the NHL. As an unexpected bonus my haemoglobin level had returned to normal, including the ferritin component. I reverted to the Watch and Wait programme as Rituximab's greatest fan and a partial NHS success! The consultant did discuss thrombopoietin agonist therapies with us, but I was disinclined to pursue the possibility of trying them so long as I felt well.

The Latest Scene

That situation prevailed until my most recent appointment, in June. A few days before, as I gathered my thoughts in preparation, I realised I hadn't noticed any unexplained bruising recently. I mentioned this to the consultant as we waited for my blood test results to come through, adding flippantly that I'd therefore expect the platelets to be in three figures. At that moment a nurse arrived with the results, which showed a platelet level of 143 and normal haemoglobin! The consultant had no explanation, but didn't think Rituximab was likely to have had such a late surge. As a precaution the tests were repeated, but without a change in the readings.

And Now

I don't feel euphoric or triumphant. I am quietly grateful, but as puzzled over what happened to trigger the first scene of this article as I am about what happened to cause the latest. I know ITP is unpredictable, and I still have the NHL diagnosis. Under Watch and Wait I'll continue to give each any attention they require, but no more than they deserve.

Lessons and Observations

On this journey I've learnt to be optimistic, but realistic. Just after my first diagnosis we were due to embark on a three week narrow boat circuit, on which I'd be in charge of operating over 200 locks on various canals. Suddenly this seemed like an accident waiting to happen, but the worst thing I suffered was indignation at the increased cost of insurance when I honestly reported my situation. Particularly in the early days it sometimes felt like a struggle to discover information I needed to understand the position I was in, often when I didn't know enough to be aware of what questions to ask. Along the way I've encountered wonderful medical staff, highly qualified and combining proficiency with a welcome sense of humour. But my first prize would be awarded to the humble BICC biro, which seems to be the most essential and effective piece of kit in an oncology nurse's armoury, instantly dislodging and dispersing, through the merest flick of a finger applied to its outer casing in the right direction, any bubbles that dare to develop inside intravenous tubing!

A Final Thought

Now the only way Shirley knows about me is because we were recently in touch on quite another matter. My husband and I decided we'd like to provide her and her team with something they might not otherwise have at The Platelet Mission. After several weeks, which involved Shirley and a tape measure, we achieved our collective goal. Now I'm really not attempting to establish a causal link between a good deed and welcome news, nor draw any conclusion, but it might just be worth a try?!

[We are most grateful to Sheila & Derek for the beautiful vertical blinds! – Shirley]

TPO drugs

Should anticoagulants be prescribed for platelet counts over 50?

One of our members asked if we were aware that on some social media message boards there seemed to be reports of doctors prescribing anticoagulants to patients on thrombopoietins (drugs that encourage platelet production) whose platelet counts rose above 50.

We raised this question first with Dr Drew Provan who replied 'I have never prescribed anticoagulants for patients like this and I am not sure who has. Maybe there was a reason such as a strong history of recurrent thrombosis. But most of us would not be keen to use the new drugs in this setting'

We then queried it with two other medical advisors to ascertain whether it might reflect individual practice.

Professor James George from the USA responded 'Social media has its advantages, but medical advice is not one of them. There is no reason, no basis, to give anticoagulants for high platelet counts caused by eltrombopag or romiplostim. Not for counts above 50, not for counts above 500, not at all. Even when platelet counts surge in an extremely sensitive response to a TPO agent, up to 1,000,000 in our experience, it's only for a brief time, several days, and is not a risk for thrombosis.'

Dr Jecko Thachil explained 'ITP is a condition where the risk of blood clots or thrombosis (in the veins as with DVT or PE and in the arteries as with stroke and heart attacks) is slightly increased

This risk is further enhanced by TPO-R agents. The clots can occur at lower than 100 counts as well, and not just with very high counts

It is not yet widely accepted practice to prescribe anticoagulants like warfarin or eliquis/ Xarelto along with TPO-RA in ITP despite the increased clotting risk.

This may be because

1. to avoid the bleeding risk with the blood thinners, the platelet count has to remain above 50 at all times

2. Blood clots can occur at lower counts

3. Not everyone on TPO-RA will get the clots (we don't know yet whether there are identifiable risk factors specific to TPO-RA)

However, the best thing to do is to treat and control other risk factors for arterial clots like hypertension, diabetes, cholesterol, being overweight and smoking and with venous clots, being active and avoiding prolonged immobility etc.

ITP 'Friends'

a listening ear . . . . . .

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An ITP Warrior!

by Meg Abernathy-Hope

My name is Meg Abernethy-Hope, I am nineteen years old, I live in Bristol and I have ITP.

I was diagnosed on August 15th 2014, I had gone to the doctor about a physio appointment for my knee. I had been at Boardmasters the weekend before, dancing in mosh pits and sleeping on the ground, so wasn't too worried about the few bruises I saw. But I noticed two on my wrist the size of a 10p and asked to have a blood test as this wasn't anywhere that I knew I had bashed.

After the doctor's appointment I went to work – I'm a Nanny so had a family of four children that needed looking after. I got a phone call from an unknown number saying that I needed to go into hospital, at first I thought it was bogus. I didn't know who this person was, I couldn't check if they were official or not, and they sounded really panicked. My parents were down in Cornwall and I didn't want to worry them so I didn't tell them what was going on. My best friend dropped me to A&E and there I sat for the best part of 8 hours, seeing a few doctors and having a few blood tests until they came to the conclusion that I either had leukaemia, hepatitis or ITP. My Nan told my parents where I was and they raced back from Cornwall to check I was OK. I was told I would have to stay the night. Honestly I was in shock and disbelief, but two hours later it was confirmed I had ITP and a count of just the 1 platelet.

My life has been a huge rollercoaster of ups and downs and as those who have ITP know, it's the treatment that drags you down more than anything, the tedious step ladder in which we must follow to see what will work and what won't. I had huge water retention from the steroids, the IVIg left me drowsy and dazed, and injecting myself weekly was agony.

By February I had had enough, my boyfriend had left me, I was doing my final year of A-levels and nothing seemed possible. I was diagnosed with depression and can honestly say I had hit rock bottom with a thud. I was modelling before my face got fat and I didn't have the energy to go to the gym. I missed being in front of the camera and on stage and being happy with myself. I decided it was time to take matters into my own hands, get back out there and have a giggle so I entered Miss Bristol 2015. I took my best friend with me to do my makeup, but she wasn't allowed upstairs for insurance reasons, so we made our own fun! Sat in the toilets with a bottle of champagne I had been given for my birthday in the October, I was finally able to drink again! After lots of walking on stage and being asked questions it came to the moment of the crowning. I was gobsmacked to find out I had won Miss Eco 2015! How amazing, I was presented with a sash and a tiara and in utter disbelief! Next

up was the winner! As I stood watching the other girls time slowed down as contestant number 9 was called, I looked around to see who the winning girl was, only to have someone pulling a tiara off my head, and that's when it hit me. I was number 9! Little old me, the girl with the bruises and lack of self esteem had won a beauty pageant, and I honestly was not feeling very beautiful at all! I competed in Miss England 2015 but wasn't placed and I am happy to say that just being there was enough for me and it was a great and very overwhelming experience.

In May 2016 I finally had my spleen removed after various tests in London and lots of waiting, as it was decided that this would make me stable. I now do everything I want to do, including wing walking *(see front cover photo)*, going in a hot air balloon and riding my horses again. Body image for teenage girls is a real struggle and that's without having ITP or anything else. I have learned that we are all better for the experiences we have and it truly does make us who we are. I am now working alongside

my consultant Dr Charlotte Bradbury to help change the treatment for ITP, we have raised nearly £100K with £34K being raised in a day with the help from DriBuild. Lots of local companies had been helping out including

White Dove Photography and Low Carbon Exchange. After two years of craziness I am starting university in September and will be going to Bristol Old Vic Theatre School.

Please, what ever your age, how ever low your platelets are, don't give up on what you love, I have the most supportive family, a boyfriend who has never left my side and friends that understand naps are a priority. I still get tired and I still have my down days, my ITP could spiral out of control at any minute, but I'm taking things day by day and being grateful that I am still here and have all the love and support a girl could need!

Please find me on Facebook or any other social media under my full name or megaberhope, I would love to have a chat with people like me, I am in the process of creating a coffee table book with people's stories and experiences in! We are the ITP warriors and we've got this under control!

ITP Global Meeting

by Mervyn Morgan

The ITP Support Association recently had the honour of hosting another international meeting of ITP groups at a venue close to the lovely town of Bradford on Avon. After the recent heavy rain and storms we were blessed with some welcomed sunshine, helping to change the perception of our overseas guests about British weather.

The meeting, organised and chaired by the ITP Support Association's CEO Shirley Watson MBE, brought together

ITP group representatives from around the world including Denmark, Finland, Italy, Netherlands, and Sweden and from further afield USA and India.

Shirley opened the meeting by thanking Derek Elston for organising the travel arrangements for the participants, and Novartis for fully sponsoring the event, as without their support this meeting would not have been possible.

During the introductions it was interesting to note the differences in size and scale of the various associations and more importantly how ITP is perceived and handled within some of the countries represented. During the updates from each of the groups it was clear that many of those countries represented at the meeting use Facebook as one of their main communication tools enabling patients and relatives to contact their respective association to seek help and advice.

Shirley shared the progress made in the United Kingdom, with the setting up of 33 ITP Clinical Centres; 16 Adult Centres, 11 Childhood Centres and 6 Centres catering for both adults and children.

Davy Charlottenfeld, the representative from Denmark, who also carries the ITP message to a number of adjacent countries (Norway, Poland and Romania), shared his experiences of trying to get people together in some of these locations, in particular Norway which does not have an ITP Association but has an excellent doctor who is willing to get things moving.

The representatives from Sweden and Finland (Monika Westerberg and Marjo Holmala) both had similar experiences. In

Finland there are no ITP specialist services available but patients are referred to their nearest hospital. In Sweden the ITP Society has around 60 members; it also has a good following on Facebook with around 200 people taking part. In addition Sweden now has 4 or 5 ITP specialists available.

Caroline Kruse and Nancy Potthast from the Platelet Disorder Support Association in the USA gave some background to the founding of their organization and outlined their progress with a new ITP Global Alliance Awareness website which in time will include individual pages for each recognised ITP group from around the world.

Dr John Fleming from Novartis gave an update on the use of Eltrombopag and the reduction in the calcium avoidance time before taking the pills.

Ajoy Roy, the representative from India gave a fascinating presentation focusing on the challenges (both medically and socially) being faced by patients with haemophilia and ITP on the Indian Sub-Continent.

One of the key points coming out of the meeting was that of drug and specialist availability. In some countries the medical knowledge surrounding ITP does not cover the latest advances, and there are patients who need to see an ITP specialist but few if any are available, whereas Theo de Wispelaere and Mark Wezenberg of Netherlands and Barbara Lovrencic of Italy reported that they have good access to treatments and specialist care.

The overall aim of the Global Meeting was to share best practice and to see how all the groups can pull together with a common aim, to provide support for ITP sufferers no matter where they are located.

Fantastic Fundraising!

After running her first half marathon in April 2015 and raising over £1111 for the ITP Support Association **Lisa Lunnun** decided to do it all over again by taking part in the 2016 Yorkshire Half Marathon. Lisa said "As an ITP sufferer myself I know only too well how hard it can be to fight the fatigue and train for something like a half marathon. However, after completing the half marathon last year, raising money and awareness for the ITP Support Association it spurred me on to do it all again". "With friends, family and my fiancé cheering me on I successfully completed the Plusnet Yorkshire Half Marathon 2016 - (a very hilly and demanding course!) in 2 hours and 27 minutes and raised £400 for the ITP Support Association. I'm already planning to sign up again in 2017!" What a fantastic achievement. Well done Lisa!

Lisa Lunnan - another success

We were over the moon to receive yet another cheque for £1,500 from our superb **Charity Shop** in Great Yarmouth. Thank you to Celina Baxter and Gloria Doyle and their small band of willing volunteers.

The Year 3 Pupils (aged 6/7) from **Dulwich Hamlet Junior School** were each given £1. They were each asked to use their £1 wisely and think of a way of making money. For example some purchased ingredients to make cakes, others bought card and made book marks and some made badges.... you get the idea! From the initial outlay of £90 the children made £356 which was then shared between two charities chosen by the children, ITP being one.

A big thank you to the Minister, Elders and Members of the **Trinity Presbyterian Church** in Wrexham, we were thrilled to receive a cheque for £142 being the sum recently collected for The ITP Support Association.

Thanks to **Sallie Richardson** we received a cheque for £38.50 through the Giveacar scheme after she donated her car.

Mrs Hackman and the School Children from **Haydonleigh Primary School** held a collection and raised £30 for the ITP Support Association.

James Mcglynn took part in the Great Manchester Run and raised £215 which will go towards the ITP Pregnancy Registry Fund.

We are extremely grateful to **The Burford Trust** who sent a donation of £500, and thank the unknown person who nominated our charity as a worthy recipient for this very welcome contribution.

In December 2015 Year 6 children from **Whitehouse Primary School** made decorations to fundraise for the ITP Support Association as part of their Erasmus + European School project. Year 6 ran a Christmas market selling goods made by pupils from Germany, Spain, Italy, Kildare, St James's Primary and Whitehouse. In addition to £50 raised for the local Children's Hospice from selling the fudge at the key stage 1 Christmas Show they also made a further £140 which the children decided to donate to the ITP Support Association. Thank you to Year 6 and Mr Steven Head for making this possible.

Whitehouse Primary School children

Lastly, we send a huge 'thank you' to everyone who sent donations to the Pregnancy in ITP Registry or to our general funds.

CONDOLENCES

We are extremely grateful to have received £500 received in memory of

Sandra Oliver

Our very deepest sympathy goes to Sandra's family and friends, and we thank them for their kindness in remembering our charity.

Not another Midsomer Murder!!

by Derek Elston

Detective Chief Inspector John Barnaby's log :-

Date 15th September 2016 ,

Time : 12.30

Location : London Rowing Club, The Embankment, Putney, London SW15

Weather : Bright sunshine with an external temperature approaching 30º

CRIME : CHARITY LUNCH

Neil Dudgeon & Dr Mike Smith

I was called to investigate a large number of revellers attending at the above premises for the sole purpose of joining together, to commit a felony on their own funds. By the time I reached this idyllic location, the felony was well under way with many sporting glasses filled with an alcoholic beverage.

It transpired that during the lunchtime period, the company present enjoyed a sumptuous lunch, and were in generally very good spirits all led and encouraged by the infamous gangster, that well know broadcasting personality from the Jimmy Young radio show, Dr Mike Smith.

It was then left to me to start to investigate this dastardly act and to answer questions from the offenders regarding the felony and ITP, in particular. As with all investigations, I enjoyed persuading offenders to admit to the act of felony and further coax extraction of further evidence from their pockets.

Overall, the investigation was able to produce sufficient evidence that convicted the offenders. They were found guilty of committing a felony on their own pockets for the sole benefit of the ITP Support Association. The legal representatives of the guilty however are appealing the decision and are asking for the crime scene to be revisited and the felony to be reconstructed next year for further evidence to be discovered. Even the offending cousins from America agreed to this action being taken and extradition will ensue.

We would like to express our sincere gratitude and appreciation to Neil Dudgeon, Dr Mike Smith, The London Rowing Club, the caterers and everyone who attended and contributed so generously. A very special thank you to the event organiser Debbie Lloyd for all her hard work, and to 'all3media' who sponsored the event. We'll report on the final total in the next Platelet.

Letterbox

What a lot there was of interest in June's Platelet - and so much of it resonated with my experience!

The American Perspective reminded me that I am almost sure that my ITP was kick-started by a Typhoid inoculation in 1989. After the jab, I had a very high temperature, the rigours, the lot. Within a few weeks I started seeing the bruises that were not explained until I had a routine blood test when first pregnant in 1993. I count myself as supremely lucky (cf the Bristol research) that I was pregnant when first diagnosed so never treated with steroids - just immunoglobulin when my platelets fell below 30 for my first baby. I was then watched conservatively until pregnant again in 1998/9 when, again, I was only treated with immunoglobulin to raise my platelets for a safe birth in 1999. For about ten years my platelets hovered between 25 and 45, never needing treatment, but, in the past ten years, they have drifted slowly higher and higher and now stand at about 100. My experience in pregnancy makes me very glad there is now a Pregnancy Registry.

Also, like Karen Welsh, my experience used to be that my platelets used to rise when I was ill. My haematologist would phone – 'Great news - you are at 60. How are you feeling?' Usually, I was feeling dreadful as my observation was that the more ill I was, the higher my platelet count rose. Sometimes I had taken antibiotics, but not always. So I began to imagine that, when I was ill, the immune system slowly turned its attention to the virus that was attacking me, thus allowing the platelets to rise. I have no idea whether this is scientifically plausible.

The web watch also rang lots of bells as I am resisting attempts to make me update my PC and associated software as it rejects all the updates it is sent.

Finally, I attach a 'purple' photo of me taken with a friend on the occasion of my silver wedding anniversary.

Rosemary Hayes-Milligan

Convention Review

by Derek Elston

A Hole in One?

Not literally, but certainly our annual convention, held this year at the Cumberwell Park Golf Club, was an achievement and in one word, excellent.

Cumberwell Park Golf Club is located on the outskirts of Bradford on Avon in the lovely county of Wiltshire. With close proximity to Bath and Bristol, it proved a popular destination at what turned out to be, a stunning venue.

Cumberwell lecture theatre

Drs Bertrand Godeau & Charlotte Bradbury

Dr Angharad Care

The agenda was balanced with many topics not previously considered and some new national and international faces undertaking presentations.

As ever the day started with an introduction by Shirley Watson who brought us all up to date with the events of the last twelve months. This included the development of the Platelet Mission which has been an absolute wonder for all working behind the scenes, the very recent appointment of a Senior Administrator, Mervyn Morgan, to ease the burden in the office, and an overview of our involvement internationally. She welcomed the audience which represented 3 continents, with visitors from India, USA, Netherlands, Finland, Sweden, Denmark, Italy, Ireland, Belgium and France.

Dr Drew Provan chairs a discussion group

Our first speaker was Professor Bertrand Godeau from the Henri Mondor Hospital in Paris who considered in some detail, *Management of the Refractory ITP Patient.*

Discussion group chaired by Dr Will Lester

Dr Bertrand Godeau

A refractory patient is one who has failed to respond to splenectomy and several therapeutic lines; has a low platelet count and is affected by bleeding. This is a very difficult situation for the patient and a problem for the consultant. Prof Godeau took us through the various steps that should be followed; considered the pathogenesis and finally arrived at the conclusion and recommendation for steps to be taken.

Dr Will Lester, Queen Elizabeth Hospital, Birmingham, was then introduced. As you will all be aware, he is one of our medical advisers who contributes relentlessly behind the scenes, so it was good to see him in person making a presentation, *Primary vs Secondary ITP. What does this mean and does it matter?*

Primary ITP occurs in 80 – 90% of cases, but secondary makes up the balance and is due to some other underlying cause. In diagnosing ITP, haematologists would always consider underlying causes and not just assume it is primary. Underlying causes could be an infection; other auto-immune conditions; blood cancers or due to medications being taken.

This presentation was followed by Dr Angharad Care, clinical research fellow from the Liverpool Women's Hospital. Those who attended last year will have heard her presentation on her research. This year she kindly made a presentation on the results of this research in a national cohort study which was undertaken by 202 consultant led units between 2013 and 2015. She was ably assisted by three reporting clinicians from UKOSS.

The summary of the research showed this to be the largest reported cohort of severe ITP in pregnant women. There was a high rate of PPH and an extremely low maternal and neonatal morbidity level of approx. 1 in 10,000 pregnancies. There was no difference in outcomes between patients treated antenatally or during labour, but it was noted that treatment carried some risks.

The first discussion group sessions started with delegates being split into three groups. Feedback from these popular sessions shows that patients derive satisfaction from being able to question and discuss individual problems with consultants and others.

The Golf Club then provided a varied and excellent lunch which not only provided a respite from presentations, but afforded raffle tickets to be sold.

The afternoon started with a presentation by Dr Drew Provan from the Royal London. A well-known and respected medical adviser to the ITP Support Association, his presentation was entitled ITP in the 21st Century. He reported he had some good news and some bad news. The good news is we understand ITP a lot better and have new TPO drugs. The bad news, they still cannot diagnose ITP, as one single disease, haematologists do not always agree on how to treat ITP and there is no clear treatment pathway.

What a start and eye opener! There

followed a detailed and explicit explanation of what is known with regard to genetic approaches. What could be known may be considered as looking for a needle in a haystack in respect of SNPs – single nucleotide polymorphisms. These alter DNA sequences which causes variations and not mutations! There are around 10 million SNPs in humans hence the haystack. He concluded that research had meant we have not learnt much, there were weak associations and was of little use so perhaps time to abandon this line of research.

He went on to consider Exome sequencing which is a far more manageable research and here the ITP Registry was playing an important part of the research.

He considered advances in clinical management with less focus on platelet counts with individual treatment and an increase in the use of drugs specifically designed for ITP. Since 1996 there had been 4 separate guidelines published for the treatment of ITP but in reality, it was still in a muddle. He did not think we should abandon the old drugs yet as some still had very good responses, He also reported that splenectomy rates had fallen from 13% pre 2010 to just 2% post 2010.

He then considered the new TPO Receptor agonist drugs, Romiplostim and Eltrombopag. Both these new treatments have produced some excellent results and following use and studies of patients in receipt of these drugs, some 30% had sustained responses.

He completed his presentation with a summary of his talk and findings and informed us all that other new drugs are in the pipeline which in time it is hoped they will be added to the list of available treatments.

After this detailed presentation, tea and coffee was very welcome during which time the raffle was held followed by an auction of one particular prize, 10 bottles of a superior wine with a wine tasting in the winner's own home for 4 people.

The convention was ended with our usual question forum, this year chaired by Dr Charlotte Bradbury from Bristol University Hospital with our guest speakers in the firing line. As ever, they acquitted themselves with distinction.

The convention was closed by Shirley Watson having thanked our speakers for their time and input, the golf club for their excellent facilities, co-operation and organisation and finally the volunteers.

Finally, should anyone wish to view the slides from the speakers, they can be found on our website.

Do you have a case history you would like to share with our readers? If you do, please email me at nev@itpsupport.org.uk

EHA Report

by Derek Elston

WHAT DO 5 DAYS IN COPENHAGEN; 10,000 PEOPLE and 252 PRESENTATIONS HAVE IN COMMON?

Answer:– The 21st Congress of the European Haematology Association, held 9th – 12th June 2016

I was again extremely pleased to be able to represent the ITP Support Association at this annual event, accompanied by my wife Rosemary. In addition, we also had representatives from the Denmark and Netherlands ITP Groups in support. We were also pleased to welcome Caroline Kruse and her husband Ken from the PDSA, our counterparts in the States. EHA is open for all haematologists from all over the world, not just Europe, and provides a marvellous opportunity for clinicians, pharmaceutical companies and patients organisations to meet, learn, contribute and network. We all missed the company of Marion Haas from Germany who unfortunately passed away on holiday earlier this year. She was a devoted advocate for ITP not only in Germany, but also in other European countries. A great loss and our thoughts are with her family..

The congress was preceded by an invitation from Novartis Oncology for Caroline Kruse and myself to attend an ITP Global Patient Advisory Board meeting on the 8th June also in Copenhagen. Apart from we two, we were accompanied by representation from patient groups from Brazil; Slovakia; Italy, Denmark (haemophilia) and Romania.

The goals of the meeting were :-

- To obtain insights on potential barriers to ITP diagnosis and optimal care.
- Gain advice on how best to manage ITP for adult and paediatric patients
- Better understanding of patients' needs and expectations in medication adherence.
- Elicit guidance on Novartis proposed patient resources and materials.
- Obtain feedback on Novartis patient support program and materials.

The meeting started around 12 noon and we finally ended around 9.30 that evening. This proved a most interesting and brain storming day and allowed the patient groups to put forward many of the concerns of patients. Not surprisingly, these concerns were largely common to all groups especially cost and availability.

Novartis also provided copies of their new presentation literature, in draft format, on the medication they provide, namely Revolade (eltrombopag) for the treatment of ITP. They looked to the patient groups to pass comment and be critical. We all agreed that the literature was extremely informative, both for clinicians and more importantly for us, the patients. Some minor alterations were proposed but we all felt, the design, presentation and content were excellent.

EHA started on the Thursday morning, bright and early. Unfortunately we did not arrive at the congress centre in time

for the opening. We had to move hotels and then navigate the rail network from the centre of Copenhagen to the conference centre, a journey time of 40 minutes with one change en route.

We eventually arrived at the Bella Centre, registered and obtained our passes and found our way to the exhibition hall where we shared a booth with other patient organisations. When we arrived, a ten minute walk from the entrance no less, we could not have been more pleased. Prime position in the booth looking down the aisle between the pharmaceutical booths and close to a coffee bar!

We soon set up our stall and hung the international ITP poster in a predominant position. All our fellow groups had brought literature in their own languages, and this was placed on display for passers-by to help themselves. By the end of the congress, there was very little left. Most of the pamphlets on ITP, in all languages, had been taken by doctors, nurses and many others concerned with the care of patients. Those of us manning the booth were pleased to talk and answer questions on ITP.

Two of our eminent advisers, Drs Nichola Cooper and John Grainger were speakers in a satellite symposium on Thursday the 9th based on Immune Thrombocytopenia (ITP) and Aplastic Anaemia (AA). This session chaired by P. Schienberg from Sao Paulo, Brazil considered the current understanding and looked what the future may hold for these two conditions.

Friday morning started at EHA with a scientific working group meeting at 08.30 on Thrombocytopenias and Platelet function disorders, which was not being specifically concerned with ITP.

Saturday session late afternoon considered platelet disorders. This session was chaired by Dr P. Gresele from Perugia, Italy, and was a very detailed medical study. Dr J.Bussel (USA) provided the results on a safety and efficacy extended study on treatment with eltrombopag in adults with chronic ITP. Dr D Chines presented a similar study on Romiplostim in splenectomised and non splenectomised patients with ITP. These results were featured in the poster displays.

Platelet disorders were very well represented with poster displays which were available to all delegates to inspect and discuss with others attending, including the presenters of the various sessions. We enjoyed a very interesting discussion with Dr Bussel on ITP and the results of the two studies.

Since the start of this year, I have been very closely involved with the EHA Patients advocacy board and the question of European Reference Networks, something which many have never heard of let alone know anything about.

What are European Reference Networks?

European Reference Networks (ERNs) are platforms for clinicians and researchers to share expertise, knowledge and resources across the EU. This initiative of the European Commission, supported by all Member States,

aims to address common challenges faced by professionals when diagnosing and providing highly specialized healthcare in complex, rare or low prevalence diseases. This relates to ITP. It does not interfere with already existing networks. ERNs will improve clinical outcomes and quality of life of people living with these type of conditions across the EU. ERNs are part of the legal framework of the EU Patients' Rights in Cross Border Healthcare Directive. Funding will be provided by Member States and the European Commission to run these networks. EURORDIS has worked hard to ensure that patient involvement will be a key element of ERNs and their governance, and this has been adopted by the European Commission Expert Group for Rare Diseases. Hematology and Rare Cancers are two of the 22 disease groupings where the Commission and Member States have encouraged applications for ERNs.

More information on the EC website: http://ec.europa.eu/health/ern/implementation/call/index_en.htm

List of ERN applications: http://www.rd-action.eu/european-reference-networks-erns/coordination-of-rare-disease

The EHA advocates have been extremely active in promoting this initiative. Apart from many international teleconferences, hours of reading and preparation of material, the advocates have ultimately prepared a proposal for submission to the EU assisted by various eminent haematologists from around Europe and particularly France, Holland and Austria. Within this proposal I am pleased to say, we have four of our ITP Forum members included as being centres of excellence for visitors to the UK with ITP. UK residents will benefit from a similar facility in EU countries when travelling abroad I think regardless of Brexit. There is still a long way to go before final approval and publication, but we are on the right track.

This subject of ERN was featured in a business session on the Saturday and included a presentation by Joan-Lluis Vives Corrons coordinator for the previous rare haematology ERN (EuroBloodNet ERN), Ananda Plate (Myeloma Patients Europe) on the patients perspective and involvement of patient advocates and Till Voigtlander from the Board of Member States. This session was attended by over 80 delegates and completely filled the conference room we had been allocated. We thought this was a most positive result and augured well for the future of both the ERNs and also the advocates involvement and contribution within EHA.

Topics for each business session are submitted to EHA, considered by a committee and decisions made as to inclusion. The EHA advocates are allocated normally two sessions at congress to make any presentations approved by the EHA committee. The subjects matter is open for any advocate to propose and is then voted on by all the advocates. This year, the ITP Support Association submitted a subject for a presentation in conjunction with Thea Breuer, a phycologist from the Netherlands. This subject was to look at, and consider, the psychosocial effects of rare conditions and their treatment, a topic which is increasingly being raised and questions asked relating to many conditions. We were outvoted by 1. Maybe next year, in Madrid – who knows.

[Ed: As it is not our charity's policy to finance overseas trips, The ITP Support Association is extremely grateful to Novartis Pharmaceuticals for assisting Derek with his travel and accommodation costs to attend this meeting.]

Have you heard

by Anthony Heard

The Moment You Know, You Know, You Know !

For us ITP folk there are certain moments in our individual purple journey's that become etched in our memories. I'm sure most of us remember the date when we were first diagnosed or perhaps the date we gained remission if we have been lucky enough to achieve it. Well for me an equally memorable date is Saturday February 6th 2016. I can even remember an exact time .... 8pm .... It is the moment that I knew, that I knew, that I knew, my ITP had returned. The following is an account of my 2016 so far.

I had been in remission since June 2013 following a second round of Rituximab treatment. I also had some success with the same drug with a similar period of remission from June 2010 to April 2013. Like many of us ITP sufferers I had long realised that my rare yet persistent condition could return at any time. A bit like the proverbial bad penny it could turn up whenever it took the urge. Having been diagnosed in July 2006 and having numerous encounters with Prednisolone and a brief flirtation with Azathioprine I had certainly been through the ITP mill so to speak.

Anyway, my appointment with my latest relapse eventually came on February 6th this year. It was at 8pm and just over an hour since I had been watching England win 15 points to 9 against Scotland, in what was to be the first leg of a 6 Nations Grand Slam. Well completely out of the blue (or should I say purple ?) , and totally unprovoked my right hand developed the tell tale purple bruise. The all too familiar ITP tattoo.

Undoubtedly this was the moment that I knew, that I knew, that I knew, it was back. My Mr Hyde had returned to disturb the relative serenity of my Dr Jekyll. The ITP jack had well and truly sprung from its' box AGAIN. Despite trying to explain the huge bruise away as a possible accident from earlier in the day, my wife and I both knew that it could be nothing else but the return of our unwelcome foe.

So off we trundled to the Royal Berkshire Hospital first thing the next Monday morning February 8th at 8am. We had contemplated reporting to A and E on the Saturday evening but as I had not had any other symptoms apart from the bruise we decided to just take things easy on the Saturday evening and Sunday, then report to hospital on the Monday first thing. We both knew what the outcome was going to be. We had trodden this same path many times over the last ten years and I suppose that we arrived at the hospital with weary resignation.

A blood test revealed that my platelet count was only 20 and that it had fallen from 100 since my last test only 2 weeks ago. So it was no wonder that I had started to bruise. The next step was yet another round of Prednisolone treatment to get my platelet count back to safe levels. I had always responded very quickly to steroid treatment

in the past, so we were reasonably confident that I would do so again. This would be my 5th steroid encounter in my ITP decade.

So it was back on the familiar Prednisolone horse at 85mg per day accompanied by 20mg of Omeprazole. We ITP sufferers know that the problem with the old steroid nag is that it is never a favourite because of the truly awful side effects. It might eventually get you round the course but it certainly hits most of the fences around the track. Anyway, my Platelet count responded really well and increased to 141 after the first week. However it wasn't the only thing to increase. My waist, my body mass index, my blood pressure, my chins, my weight, the speed with which I ate, the amount of food I consumed, my temper, my mood swings, my headaches, my waking up in the early hours of the morning all made unwanted gains as they are prone to do when on the steroid.

At the outset of this round of steroid treatment I made it quite clear to my specialist that I would only go back on the Prednisolone short term, just to get my platelet levels safe and then we would look at other treatment options. He agreed with my view and suggested the following options for our consideration.... 1) Another round of Rituximab, 2) Mycophenolate (MMF), 3)Eltrombopag, 4)N-Plate. These options were just an initial list and obviously much depended on how quickly or even if my count responded to the steroid.

Fortunately my platelet count responded well, albeit with a few blips along the way. My count rose to 144 after the first week of going back on the steroid. Having been in remission since June 2013 I'd almost forgotten what a joy it was to visit the hospital weekly to get a blood test. How had I managed to cope without it and what did I do with my time ? It really is such a nuisance having to spend so long traipsing up and down to the hospital as we all know. And don't get me started on parking charges.

Anyway by April 21st my platelet levels had stabilised at consistently around the 150 mark and my steroid dosage had gradually been tapering down. Now was the time to strike while the iron was hot and sneak in my new anti ITP weapon. My specialist and my wife and I had a good discussion about what to do and when to do it. Now was the time for Mycophenolate to be introduced. In addition to full discussions with my specialist I also took the opportunity to get my case referred to the ITP Support Association medical panel. I am so grateful to Shirley for doing this for me and to all the advice offered by the panel. Ultimately however, we all have to make up our own minds about how to proceed but it sure helps to have

TEXT GIVING

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The Association will receive 100% of your donation which can be increased by adding Gift Aid.

excellent information to help you make the decision.

For those not familiar with it, Mycophenolate is another immune suppressing drug which looks to raise 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 much less nasty side effects. But as usual we have to emphasise that we all respond differently to all these treatments and all encounter different side effects to varying degrees. Mycophenolate is most often used in cases of organ transplant to help prevent the transplanted organ being rejected. https://www.medicines.org.uk/emc/medicine/23880

The Mycophenolate, like Rituximab can take 2 to 3 months to impact on the platelet count so it is important to dove tail it with any existing treatment which is holding the platelet count safe. So the idea for me was to start the Mycophenolate whilst still on the steroid albeit at a reducing dosage. In this way we hoped that whilst the Mycophenolate was taking hold the steroid would prop up the platelet count. This strategy commenced on April 23rd and I have been taking 500mg of Mycophenolate twice a day since then. This is the bare minimum dosage apparently, probably slightly less than the suggested lowest dosage of 600mg twice per day. The steroid dosage was slowly reduced by sensible increments each fortnight until June 25th when I stopped all Prednisolone. The Omeprazole stopped 2 weeks later.

So where are we now, where are we now ? My platelet count was 169 at my last blood test on July 26th. I have had no bruising or any other symptoms since the initial bruise I got back on February 6th. I am still on 500mg of Mycophenolate twice a day and no other medication. The only side effects I seems to have had were more to do with withdrawing from the steroid than the Mycophenolate, although I suppose with the overlap of medication it is difficult to say for sure which drug was the culprit. I know that I suffered terrible head aches, cramp in my legs and feet, hot sweats and achy knees and legs once I stopped taking the steroid. These have subsequently stopped.

I can say that I am delighted to see the back of the steroid. Unless absolutely desperate I do not want to ride that horse ever again. This time on the steroid I seemed to be less tolerant of it and I'm not going to put myself through it again. Hopefully the Mycophenolate will continue to prop up my platelets, without any side effects. Only time will tell I guess. But meanwhile I am now checked only monthly at the hospital. My next challenge is get my weight, waist, BMI and diet back under control, and lose a couple of my chins.

As ever, until next time ... Platelets Up !

Best wishes ... Anthony

You can check out my weekly ITP blog at

http://anthonyheard.simplesite.com

Webwatch

by Howard Anderson

On a number of occasions over the years, we have seen a sharp difference in the perception of health care between the UK and the USA. The questions we get asked from the USA relate to why should treatment x, y or z be used "because it is so expensive". We are most fortunate to have the NHS, health care free on the point of delivery. This system leads those managing the NHS budgets to work towards lower costs, a drive that is further backed up by NICE, the National Institute for Health and Care Excellence who decide on which treatments are available. The difference we see between the UK and the USA is that over there, people feel over treated, that some doctors use medicines and investigative procedures with less concern over their costs or even necessity. It is hard to be sure if these are merely perceptions or are real.

The King's Fund shows that in the USA, the spend on private health care only as a percentage of GDP is almost as high as the total NHS & private health spend in the UK, the total of private and public in the USA being about double that of the UK. Are people sicker in the USA or does the overtreatment story have some validity? http://www.kingsfund.org.uk/projects/nhs-in-a-nutshell/health-care-spending-compared.

The NHS is at the top of the political agenda with some politicians eying the huge health profits made in the USA with envy, these people will say the NHS is not affordable and a move to a private system is required, some will even say that is urgent, but the difference of perception we see as an Association leads one to the opposite conclusion, something in the US system needs looking at if the treatment of choice is almost automatically very expensive.

Our members ask us which treatments are the best, that is why we encourage eminent medical practitioners to advise us, but some members are surprised when watchful waiting is prescribed! Clearly this is a cheap option but would the prescription of an expensive treatment be better?

The American Institute of Medical Sciences & Education have a page at https://www.aimseducation.edu/blog/us-vs-uk-allied-healthcare/ which outlines some of the differences between the systems, the concerns are much the same, over costs and especially waiting times. But apart from the costs and waiting times, the site states something that some in the USA may find surprising, that in the UK healthcare is taken to be right not a privilege. Perhaps this is the key difference in perception, when we are sick here, we are treated without question and apart from a few headline expensive treatments, the choice of treatment x, y or z is based far less on cost and far more on the benefit to the patient. So when we are asked about treatment options in the USA, we

must first outline the above to show that our perception of what is best may be different.

In view of the very high costs of healthcare in the USA it is no wonder that so many take the "alternative" route, trusting unqualified alternative therapists instead of the qualified practitioners available on both sides of the Atlantic. When flying across that ocean, if one was half way and was told that the pilot was self-taught, had not had a rigorous test nor a recent medical, most people would be quite frightened, especially if heading into worsening weather. But this is exactly the case with most proponents of alternative therapies, they are like that pilot, keen, they believe in what they sell but have no evidence that what they sell is any good or even if it is safe. The pilot may point to several successful landings he has made in the past month, but would you get on that aeroplane? If not, why would you chose an alternative therapy, especially one that deliberately contains mercury to affect the "cure" as some do?

Happy surfing!

You can raise money for ITP with the following schemes...

Give a Car

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.

easyfundraising.org.uk

Shop on-line and raise money for ITP! You shop directly with the retailer but by signing up to 'http://www.easyfundraising.org.uk/causes/itpsupportassociation' for free and using the links on the easyfundraising site to take you to the retailer, a percentage of whatever you spend comes directly to ITP at no extra cost to yourself. You'll get access to hundreds of exclusive discounts and voucher codes.

Spend £100 with M&S online or Amazon and you raise £2.50 for us. £100 with WH Smith puts £2.00 in our pocket and so on. There are over 2,000 retailers on their site, and some of the donations to ITP can be as much as 15% of your purchase.

We can accept any of the following...

Any Stamps, old Envelopes, First Day Covers, Postcards** (including Pre-1940s Birthday Cards and World War 1 silk cards**) -** used or unused.
Please leave a 5 to 8mm border around stamps.
**If foreign stamps (of any date) or UK stamps postmarked BEFORE 1970 are on envelopes or postcards - DO NOT REMOVE THEM! They may be worth more as a collectible item complete.

Coins and Bank Notes - any and all, old and new, from ANYWHERE in the world, obsolete or otherwise.

Precious Metals - including broken jewellery, old trophies, gold, silver etc.

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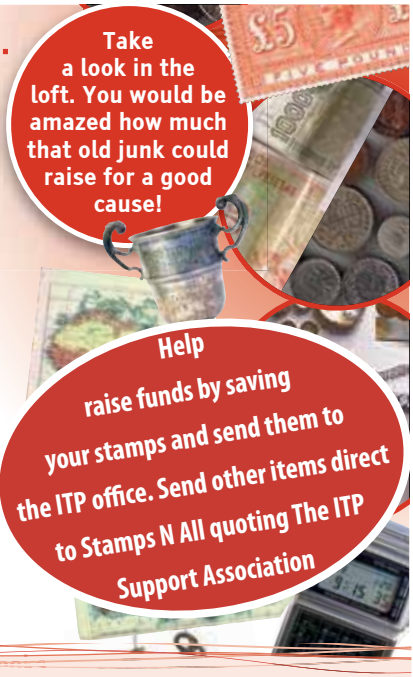
Costume Jewellery - is accepted.

Keys and Locks - any age or types.

Metal Cutlery - any Metal Toys, Ornaments & Cutlery - any age, type or condition.

Watches - Quartz or wind-up, working or not.



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*NOTE: Please include sender's name & address (details for internal use only & will NOT be passed to third parties).

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News & Views

The ITP Support Association has received a number of questions about ITP in dogs from both the UK and the USA, and from the correspondence it is apparent that the condition is no easier to manage in dogs than it is in humans, and sometimes their symptoms are more unusual and dramatic. We are extremely grateful to veterinary specialist Dr Andrew Kent for his help with these difficult cases and are pleased to list him on our website as our Veterinary Advisor.

USE THIS FORM TO

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- **DISCONTINUE RECEIVING THE PLATELET**

Please tick the appropriate box(es). All donations are very gratefully received and acknowledged unless you write 'no receipt' on the back of your cheque.
(Please make cheques payable to The ITP Support Association)

The ITP Support Association App.

☐ I would like to join the ITP Support Association to receive an information pack* and The Platelet quarterly, and enclose £10 for membership subscription.

☐ I have changed my address from (postcode) _____
Please send The Platelet to the new address below.

☐ I wish to discontinue receiving The Platelet. Please remove my name from the mailing list.

☐ I enclose a donation of £_____ *(Please write PR on the back of your cheque if you wish your donation to support the ITP in Pregnancy Registry*

Please complete:

Name _____

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_____

Please indicate your interest by circling one of the following:–

I am an: • ITP patient • parent of ITP child • family member • friend/other • health professional

We do not badger donors or members for further donations nor pass their names to other charities

Signed _____ **An SAE for info packs,or for donation receipts, is much appreciated!*

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