



the platelet

JUN 2016

JOURNAL OF THE ITP SUPPORT ASSOCIATION

**COME & JOIN
NEIL DUDGEON
AT A FUNDRAISING
LUNCH . . .**



**. . . PLUS PLENTY OF ITP
INFORMATION & NEWS INSIDE**

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

In this issue . . .



There is plenty of medical news in this edition – on page 6 Dr Cindy Neunert examines the thorny subject of vaccinations and ITP, on pg 8 Dr Charlotte Bradbury (who will chair the QA session at the ITP Convention) reports on the research project she is heading at Bristol, and on pg 10 Dr Jecko Thachil explains the importance of platelet size.

We have several items from ITP patients outlining their experiences for the benefit of others, Shirley tries to steer us through the minefield of 'dodgy cures', and Rhonda tells us about the PLACE inspections which are going on in all hospitals. We touch base with our ITP contact in India, and Howard gives a persuasive argument on why you should not upgrade your computer!

Anthony is already looking ahead to the September Awareness Campaign (are we really half way through the year already?!) Also in September we will be holding our Patient Convention (a booking form should be enclosed with this Platelet) and on pg 5 we have details of the fundraising Charity Lunch featuring Neil Dudgeon and Dr Mike Smith.

On the topic of fundraising the trustees had some reluctance about running another fundraising campaign hot on the heels of Buy-a-Brick, but we really do need your help to fund a new Pregnancy in ITP Registry (pgs 15 & 26) to find the safest management for mother and baby.

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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 primarily run by volunteers, with just one part-time paid worker. It 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.

Shirley Writes...

Periodically we receive an email from an ITP patient or parent who has spotted someone selling a sure fire cure for ITP, usually on the internet, and they want to know whether it works and if it is safe. It is sad but true that scammers are out there purposely targeting people living with a difficult and frightening condition like ITP. Patients are especially vulnerable if they are newly diagnosed and have not had a previous health problem. I know from personal experience, I succumbed twenty years ago and spent hundreds of pounds on useless remedies when my son was first diagnosed with ITP. I bitterly regret that I have no idea what ingredients he was actually given.

In addition to those peddling expensive remedies there are others, possibly well-meaning individuals, giving free but useless advice about special diets that will increase platelet counts. One brought to my attention recently listed a number of foods that may (not will) to raise your platelet count. Included were sesame seeds, walnuts and milk, the very three that have each been written up by clinicians in major medical journals as the cause of ITP in an individual patients. Had the website author done a quick Google search for foods linked with ITP and misunderstood or is it just a bizarre coincidence?



Occasionally patients tell us they have asked their consultant about alternative remedies and find they get little response. This is not surprising as there is no evidence to prove or disprove these claims. We may worry about the prohibitive price of new licensed medicines, but part of the high cost is due to expenditure on rigorous double blind clinical trials to produce evidence of efficacy and safety. Without this process your doctor's guess is as good

as yours or mine, although he may give you an opinion based on his experience.

Many of us believe in self-help where possible (and thank goodness we do with the NHS under such pressure!) so it is not surprising that ITP patients scour the internet looking for some way they can improve their platelet count. The question is, how

do we sort the wheat from the chaff? Here are a few questions to ask yourself:

- Will the person/website gain financially from the advert?
- Do they have any expertise on ITP?
- Are they advertising an unknown product that could cause harm?
- Do you know if there are any poisonous ingredients in the product such as mercury?
- Are you reading a genuine news article or an advert? (Look for small text hidden

- on a newspaper or magazine page saying 'advertisement')
- Can you be sure that any reviews or statements are genuine?
 - Could medical quotes have been taken out of context?
 - Is the evidence anecdotal or factual?
 - Can they explain how the product works?
- And remember:
- 'Informed patients' should be able to recognise who understands ITP and who doesn't have a clue about it.
 - Genuine scientific discoveries make front-page news. If the first you hear about a new treatment is an advert on the internet, be suspicious.
 - Technical terms and jargon don't necessarily mean medical proof.
 - Be particularly wary of cures that claim success for a wide range of ailments.
 - The offer of hope is tempting, but dashed hopes can be devastating.
 - The presence of a doctor's name or face (real or assumed) in an advert is no guarantee the product works.
 - 'Natural' does not necessarily mean safe. Plants are natural but some are very poisonous!
 - 'Traditional' should not be confused with safe. Comfrey was used for centuries but is now known to cause cancer of the liver.
 - Use reason and logic – for example, if garlic is suggested to cure ITP would anyone in France or Italy have ITP?
 - If a food is genuinely likely to increase the platelet count, you should see a warning that people prone to blood clots should avoid it.
 - Beware of claims that a holistic remedy can cure a specific disease like ITP. (Liken it to your car – if the carburettor goes wrong it's no good having a general service. The car won't go until the carburettor is fixed)
 - Be wary of terms like 'may' and 'up to'. For example: This product may (but probably won't) increase your count by up to 50% (so could be 1%)
 - Differentiate between a suggested cure (unlikely) and something that claims to make you feel better in yourself (possible).
 - Don't let desperation cloud your judgment!

CHARITY LUNCH

in aid of **The ITP Support Association**

Come and join **NEIL DUDGEON**, star of TV's *Midsomer Murders*,
at the London Rowing Club, Putney,
on Thursday 15th September 2016, 12-4pm.

The event includes welcome drinks, 2 course lunch, draw,
Q&A session, photo and autograph opportunity.

Compère for the afternoon will be broadcaster and writer, **DR MIKE SMITH**.

Tickets £45 each or table of 10 £400

For more information or to purchase tickets call Debbie Lloyd on 07803 117180

or email debbie.a.lloyd@gmail.com



American Perspective

Dr Cindy Neunert MD

Columbia University Medical Center

Vaccinations and ITP: An ounce of prevention

Questions about ITP and vaccinations usually come about in one of two ways. First, is there is a link between vaccinations and the development of ITP? Second, can people on medications that weaken the immune system, such as corticosteroids or rituximab, safely receive vaccinations?

Vaccinations cause our bodies to react to a particular bacteria or virus and create a response from the immune system. This way the next time our body sees that bacteria or virus it is ready to fight and prevent us from getting the disease. Some vaccinations use bacteria or viruses that are killed, while others use live bacteria or viruses. Because vaccines are “stimulating” the immune system there is concern that this can lead to “confusion” of the immune system, causing the body to have an incorrect response and produce antibodies against one of its own cells. This is what happens in ITP, when the body produces antibodies against its own platelets.

As a pediatrician the question about the link between ITP and childhood vaccinations comes up frequently since children receive a number of vaccinations. The best information we have on this question is with childhood ITP and the Measles, Mumps, Rubella (MMR) vaccination. This is a common live vaccine given between 12-15 months of age and

then again between 4-6 years. The rate of ITP following MMR vaccination is about 1 to 4 cases for every

100,000 vaccines given. However the rate of thrombocytopenia following natural infection with rubella or measles is much higher, anywhere from 6 to 1200 cases for every 100,000 infected individuals. ITP that develops following the MMR vaccine typically occurs about 6 weeks after the vaccine. Much like non-MMR ITP, it is usually mild with significant bleeding being very rare and in 90% of children the disease is completely gone at 6 months. What about the child who has a history of ITP and needs their vaccination? Based on a review of cases, giving the first or second MMR vaccination to patients with a history of ITP does not lead to recurrence of the thrombocytopenia. In some cases, if the child has already received one vaccination, it is reasonable to have the child tested for a response to that vaccination and only provide further vaccination if no response is seen. When I talk to families of children with ITP, I try to offer reassurance and we discuss that it is better and safer for the child to receive vaccinations on time so they are protected from the natural disease.



Dr Cindy Neunert

If someone is on medications that weaken the immune system, there is worry that perhaps they could become sick from vaccines or the body will not respond appropriately. Vaccines may be less effective if the immune system is weakened. Any vaccines given during this time may need to be repeated after the effects of the medication on the immune system are gone. For example, patients who receive rituximab may not have a response to vaccinations for up to 6 months after the medication is given. It is also important to determine which vaccinations are safe to give. The Center of Disease Control (CDC) makes recommendations for vaccination during times when patients are on medications

that can weaken the immune system. Based on the CDC recommendations all vaccines using killed viruses or bacteria can be safely given even when the immune system is weakened, however vaccines using live viruses or bacteria may need to be delayed.

In the majority of patients with either a history of ITP or active ITP, vaccinations should be given on schedule. An exception should be made for patients who are receiving medications that may weaken the immune system. The most important thing is to discuss vaccinations with your doctor at the time they are regularly scheduled and before starting any new treatment.

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

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.

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.

ITP Research in Bristol

by **Dr Charlotte Bradbury MSc, BMBCh, FRCP, FRCPath, PhD**

Consultant Haematologist and ITP clinical lead, University Hospital Bristol

Senior Lecturer, University of Bristol

Direct feedback from adult patients with ITP regarding the difficulties they face in the first months following diagnosis has been the primary driving force for this research project in Bristol. Local (Bristol) patients have been fundamental to the formulation of patient relevant priorities for research and future treatments. Patients report that following diagnosis, avoidance of relapse, early achievement of a stable platelet count, reduced overall steroid dose and reduced hospital attendances are the most important goals for ITP management from their perspective.

At the moment, nearly all patients are given high dose steroids as initial treatment. In 20% of patients these don't work at all. For the others, the platelets improve whilst on steroids but most relapse when the dose is reduced or stopped leaving them back at square one. Only 20% of patients stay well long term. High dose steroids are associated with significant side effects with 98% of patients suffering one or more side effects (including mood swings, difficulty sleeping, weight gain, high blood pressure, diabetes, gastric irritation, skin thinning and osteoporosis). Patients who do not respond or who relapse will try other "second line" therapies which may or may not work. Many patients receiving multiple

courses of different types of treatments with associated side effects before finding one that works for them. In the meantime, patients often have several months before their illness is controlled and during this time they continue to be at risk of bleeding, bruising, accumulate drug side effects, suffer fatigue, and require frequent blood tests and hospital visits (sometimes admission). Physical factors combine with psychological stress through fear of bleeding, uncertainty of outcome, need for time off work and lifestyle restrictions due to bleeding risk to adversely impact on quality of life.

Although initial treatment for ITP is unsatisfactory, it has not been challenged for decades. The lack of new approaches has arisen from a chronic lack of research funding and clinical trials. The relative rarity (3/100,000 person-years), non-cancerous nature and rare impact on survival of ITP have prevented it being a priority for research funding in the past. However, this underestimates the profound adverse impact a diagnosis of ITP and it's treatment can have for individual patients, many of whom are young. There is also a costly financial impact for the NHS from the healthcare resources patients require when their illness is uncontrolled. In addition, the problems faced by patients with ITP mirror those

with other autoimmune conditions which as a group are common, affecting 3% of the population. There is an urgent clinical need to address this inequality, improving treatment for ITP through high quality research to allow patients with this condition access to improvements in care seen in other illnesses such as cancer or heart disease.

Our research aims to develop blood tests to improve prediction of responses to treatment and outcome so that for individuals, the most effective treatment can be chosen earlier at diagnosis and platelet count can be stabilised sooner to minimise the time period patients are ill and reducing side effects of drugs that won't work (i.e. they get better sooner).

Bristol is uniquely placed to carry out this research project:

1. We have strong collaboration with groups who already have an impressive research track record of research in other fields of autoimmunity that have strikingly similar clinical challenges and underlying pathology (but only differ in end organ target). In particular, we are working with Prof Andrew Dick and Dr Richard Lee who have incredible expertise in prediction of steroid responses in Uveitis (an autoimmune eye illness) which they are generously sharing with our scientific group.
2. The patients and relatives are amazing, very supportive and keen to improve things for future patients by contributing to research (I'm extremely lucky to look after them!)
3. We have strong collaboration with NHS BT department in Filton who have platelet immunology assays that are being adapted to define antibody specificity in ITP which may help predict outcome.

In short, this is a team effort approach for patient oriented research in autoimmunity. Adult patients with ITP under Dr Bradbury's care are given information about the study and invited to take part. Those that consent will have an extra blood sample taken for research. There is enormous potential to expand this research in Bristol and work with experts in other areas of autoimmunity and steroid responsiveness/biology.

The initial start-up funding for 2016 has come from successful applications to the Elizabeth Blackwell Institute (£25,000) and Above and Beyond Charity (£20,000) and the project was granted a favourable opinion by the Research Ethics Committee. We are delighted that 2 commercial companies have pledged to raise funds this year to enable the research to continue next year. "Dribuild" has pledged to raise £50,000 by various exciting activities and "Low Carbon Exchange" have also pledged to raise £20,000. ITP and this research has been publicised on local BBC radio, newspaper and BBC TV (all of which help to improve awareness and support for the illness). This research project is integrated into other measures to improve patient care at UH Bristol (including successful business case for an ITP clinical nurse specialist, local ITP guidelines, recent NIHR clinical trial application, recruiting to the national UK ITP registry, joining Bristol to the ITP forum etc).

Is being young, better?

“yes”, if it's platelets in ITP!!!!

by Dr Jecko Thachil,
Manchester Royal Infirmary

As the readers of The Platelet know very well, ITP is a condition where despite the increased production of platelets from the bone marrow, the immune system destroys them rapidly leading to thrombocytopenia. It is also well-known that individuals with ITP do not have the same bleeding tendency as those with the same degree of thrombocytopenia caused by a bone marrow problem. Also, the platelet count is a poor predictor of bleeding in individuals diagnosed to have ITP.

One of the reasons often provided for the reduced bleeding tendency in ITP is the predominance of very young platelets which are more active than older ones. Why may there be a larger number of young platelets in ITP? A reduced number of circulating platelets triggers signals to the bone marrow to increase the production of platelets. Since the platelets are required rapidly in the circulation, the bone marrow will allow the release of a large number of younger (immature) platelets to compensate for their reduced number in the blood. These younger platelets are more capable of

**The next issue of
THE PLATELET**
will be mailed out at the
end of September in
order to include a review
of the Convention

stopping bleeding than older ones and may explain the better bleeding profile in ITP.

In the process of platelet production, the size of platelets decreases with increasing maturation. In other words, less mature platelets are bigger in comparison with the fully mature ones. In the laboratory, an easily available test called mean platelet volume (MPV) gives the average size of platelets in the blood circulation. The MPV takes into consideration all the different sized-platelets.

So if the younger platelets are the most predominant, the MPV will be greater than but if the number of young platelets is small, the MPV will be normal.

In patients with ITP, the MPV is usually higher than normal and has been suggested to predict bleeding tendency to some extent. Although this measurement by itself should not be relied upon, it can be considered in combination with other factors like the extent and type of bruising and bleeding episodes to decide on treatment.

The MPV is also beneficial when investigating the cause of a

thrombocytopenia. Since the diagnosis of ITP is the exclusion of other conditions which can cause low platelet count, obtaining a through history in patients presenting with low platelet count is important. One of the key questions in this context is if thrombocytopenia runs in the family. It is unusual for ITP to be diagnosed in several members of the same family except in very rare circumstances. Thrombocytopenia noted in the family suggests a hereditary thrombocytopenia. Such patients may also have a very high MPV. Classification of thrombocytopenia disorders based on MPV has been suggested by Drs Noris and Balduini of Italian Gruppo di Studio delle Piastrine.

Since the crucial part of MPV is the younger platelets, it would be logical to look at the absolute number of these immature platelets. This can be obtained from the laboratory as the immature platelet fraction (IPF). Work

from brilliant researchers including the ITP world expert, Professor Bussel has shown that if the IPF is high, then such individuals are less likely to bleed from low platelet count compared to those who have a normal IPF and a similar count. This marker can this be helpful for two reasons— the first to understand whether, despite a very low platelet count the risk of bleeding is high or not and also as the next step, whether you need any treatments to elevate the platelet count.

In summary, it may be useful for patients with ITP to know their MPV or IPF, which can give a rough estimate of their potential bleeding risk. These measurements are easily available in most laboratories and may be considered part of the routine assessment during the clinic visits. It can form part of the decision process for starting new treatments, if at all or changing the present ones.



The Charity Shop

in aid of The ITP Support Association & The Fishermen's Hospital

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(We also collect spectacles for a third world charity)



Letterbox

I would like to share my experience with Platelet readers.

I had a horrendous tooth abscess and was due to have my tooth removed at the hospital. They had been reluctant to remove it at my dental surgery due to my ITP, so I had been seen at hospital as they were trying to drain it to relieve the pain. Whilst at the hospital yesterday I had bloods done to ensure my count was over 50 for the tooth extraction the next day.

The doctor phoned me the next morning to say my count was 172..... I was really shocked as I don't think, without medical intervention, I have had a count that high in about 20 years! I remember after I had viral meningitis my count improved, and as I think I heard there was some research looking at antibiotics and their impact on platelets I thought you would be interested. Over the last 2-3 weeks I had been prescribed 4 full courses of antibiotics, amoxicillin, co-amoxiclav, cefradine and then went back on co-amoxiclav.

I went to have my tooth removed and the senior consultant was concerned the count might be a false reading as it was so unusual. He decided to send me to have another blood test, (unfortunately this was after already having had the very painful injections!) and I was asked to go back in 4 hours. I received a phone call 2 hours

later to say my bloods were back and for me to return. My second count was 161, so still within normal limits! I think the consultant was as surprised as I was. On my records, the last highest count was in 2004 when it was 114 after a 5 day transfusion of Vigam before a surgical procedure.

Anyway, after a further painful set of injections and a bit of a struggle, my tooth was removed. I had very little bleeding!! I was a bit swollen and sore, as would be expected, but that is all.

I am now awaiting a procedure on my knee in the next couple of months in which they will go in with a camera and repair a tear. I am hoping my count will still be high and I won't need any treatment beforehand. I am still absolutely amazed at having a count within the 'normal' range and do wonder if it is the amount of antibiotics I was given.

Karen Welsh

Ed: This is yet another avenue of ITP research which needs exploring. You are not the first ITP patient to tell us of a raised count after antibiotics, which may indicate that in these cases ITP is caused by a bacterial infection. However we also occasionally hear that someone's platelet count has dropped after antibiotics!

Our ITP contact in India

Eight years ago Ajoy Roy from West Bengal, India contacted us for information as his niece had developed ITP, and we were interested to discover that Ajoy was Vice President (liaison) of the Hemophilia Society, Durgapur Chapter. Occasionally we receive emails from ITP patients or their family members living in India, and although we can give them general information we don't know anything about the Indian medical system or the availability and costs of drugs. With Ajoy's valuable knowledge working in a similar



Ajoy Roy, centre

field (although haemophilia and ITP are quite different diseases) we asked if he might be interested in being a contact for ITP in India. Ajoy was willing to do so, and we have since passed on his email address to anyone from India who gets in touch with us .



explaining that Hemophilia Society Durgapur Chapter organized free Hepatitis B & C screening tests, and free Hepatitis B vaccinations for 80 hemophiliacs. Dr. Surya Sen, Consultant Physician, Eastern Coalfield Limited, was the chief guest and handed over a cheque as an educational grant for the poor hemophiliacs, and this was followed by the patient check-up programme.

We were delighted to receive Ajoy's photos as we can



now put a face to his name!



Fantasic Fundraising!

We were delighted to receive £400 raised by teams of police officers from a charity golf day. Kev Shail captained the West Mercia team and Alan Gallimore the Staffordshire team in a Ryder cup format playing for the Mercian Cup, which was won by the West Mercia team. Various golf clubs had generously donated vouchers and gifts for the auction and raffle. Many of the officers had served on the Central Motorway Police Group with Mark Callandine, whose daughter Chloe has ITP. Our charity was chosen in recognition of the support we have offered to Mark, Nikki and Chloe, and to help fund more research into ITP. Mark tells us that Chloe has quite a reasonable platelet count at the moment, and although she gets easily fatigued her school are very supportive. We send our best wishes to her and a hearty thanks to the police officers who organised the event, especially team captains Kev and Alan, and to everyone who participated in the golf day.

Landi Wagner was one of the 7000 runners who participated in the Cambridge Half Marathon on 28th February from which she raised a super £370 for our charity. The thirteen mile course started in the centre of the lovely city of Cambridge and runners



Landi Wagner, triumphant!

passed by the Round Church, Kings College, The Fitzwilliam Museum and along The Backs before heading out of the City along the Trumpington Road to Grantchester, then back into the city via the Barton Road.

Valerie Hambelton has organised fundraising events for our cause on a number of occasions, and held a Craft Sale and Tea Party raising a very worthy £300 from her efforts.

We also received £300 from the Peter Clare Focus Group. Sebastien de La Hamayde who runs the networking group explained that it was set up as a non-profit organisation in memory of Peter who died of an ITP related illness in late 2012.

Nicola Hayes sent us £164 donation from the Market Bosworth Netball Club in Leicestershire. Nicola told us 'I suffer with ITP and my netball club have been so supportive of me, especially when my ITP is being a bit problematic! We're only a small club but recently, they very kindly raised the money to donate to the ITP Support Association.

Rhianne Jopson with her friends Megan and Alys organised a dance night and raised £114 for ITP as Rhianne's brother Lewis has ITP. We understand from Rhianne's mum Lisa that the girls rehearsed during break



Megan, Rhianne & Alys . .

times at school and performed to family and friends during the half term break. Well done to them for their excellent efforts!

Gt Wyrley Parish art group sent £75 as a donation to one of their nominated charities, Hope Baptist Church forwarded £50 that was raised in lieu of sending Christmas cards followed by a cheque from donations totalling £75, and we received £40 from Louvolite Window Blind Systems & Fabrics, employee based charity programme.



. . . practise their dance

We were thrilled to receive another cheque for £1500 from the wonderful Charity Shop of Great Yarmouth, run by Celina Baxter and Gloria Doyle aided by a small team of willing volunteers.

Our warmest thanks go to everyone mentioned on these pages, your efforts and support are very much appreciated.

Can you help us fund the new ITP in Pregnancy Registry?

As you will read on page 26, The ITP Support Association has been asked to fund the new ITP in Pregnancy Registry which is being set up to collect data on mothers who already have ITP, or who develop ITP in pregnancy. The balance between treatment and side effects can be difficult enough for symptomatic adults with ITP, but when the safety of a foetus has also to be taken into account the problems are compounded. Additionally, the mother's antibodies can cross the placenta and destroy the baby's platelets. By compiling data clinicians hope to identify the most safe and successful management strategies.

There is no state funding for ITP research or registries, so we are keen to fund this worthy project, but cannot do so without your help. Our income in the year ending 31st March 2016 was £80,000, and to fund the three registries (adult, childhood and pregnancy) will total £61,000 leaving very little for other projects in the pipeline, nor for our (albeit low) daily operating costs in providing information and support. We are therefore running a special appeal to raise money for the ITP in Pregnancy Registry and would be extremely grateful for any contributions either from fundraising events or as personal donations.

Prostate surgery and ITP

by Peter Mostyn

If you are male and aged over 50, your prostate might sooner or later become a problem which cannot be ignored. It's the cross we males have to bear! In which case, my own experience might be helpful to you.

I was 55 when my urine flow gradually reduced due to an enlarged prostate. I therefore started to have my Prostate Specific Antigen (PSA) blood test every six months. Not surprisingly my PSA climbed to around 7 but biopsies (not a test to relish) fortunately indicated cancer was not the cause. Benign Prostatic Hyperplasia (BPH) was diagnosed, and a transurethral resection of the prostate (TURP) was the solution. In this surgery, a device called a resectoscope, (a thin metal tube containing a light, camera and loop of wire) is passed along your urethra until it reaches your prostate, which means no cuts need to be made in your skin. (I hope you have envisaged which visible organ is being handled without me having to spell it out in layman's language!) The loop of wire is then heated with an electric current and is used to cut away the section of your prostate that is causing your symptoms.



So in August 2003 I girded my loins (a rather apt expression in the circumstances) and arrived at hospital for the TURP surgery. Although my pre-op had been carried out the week before, it was not until the surgeon and anaesthetist walked into my hospital bedroom for a chat prior to theatre later the same day, that they realised my platelet

count was only 113. As the prostate is a rather bloody organ (in addition to the bloody nuisance I had deemed it to be for the previous few years) I was packed off home without any surgery that day, presumably for fear the theatre would become awash with blood. A let-down seems another apt description for how I felt about this! Although my

platelets had been below the 150 threshold for the previous 15 years to my knowledge, this was the first time that I realised their scarcity might have pesky consequences.

After the hospital haematologist assessed me the following week and reassured the surgeon and anaesthetist that my ITP was not severe enough to worry them (or me), I returned for my TURP. I elected to have a spinal block rather than a general

anaesthetic, so I could watch the surgeon at work beyond the screen which I am glad to say prevented me from seeing exactly what he and his team were up to.

Suffice to say that the TURP was a great success. It turned the clock back several years and I felt that once more I was in charge of a fire hose! However, I was warned that after some 10 to 15 years, the hose would revert to being a sprinkler due to the prostate growing back again. Sure enough after 10 years the old symptoms increasingly returned: poor flow; woken up at night by a bladder that I could not empty; rushing to public urinals only to be first in and last out; urinary tract infections (UTIs) requiring antibiotics; and repeated prostatitis which felt like I was sitting on golf balls. Once again I was fortunate that the biopsy revealed BPH and not cancer to be the likely cause, though having 22 prostate samples taken via a needle piercing my perineum followed next day by a Land Rover test-drive experience over its specially designed off-road course, was not a piece of planning I would recommend to anyone else!

By this time, however, my platelet count had fallen to the range of between 83 and 97, and consequently the urologist correctly refused to carry out another TURP. Some form of laser surgery was now required. This time the resectoscope carries not a hot wire but a laser which unlike the TURP wire

seals the blood vessels as it removes the prostate tissue. Ideal for us middle-aged male members of the exclusive ITP club!

There are various types of laser surgery, though not every hospital offers them (if any of them at all) and they have their respective pros and cons. Green light laser surgery is perhaps the widest type of laser available, but having consulted Professor Google I selected Holmium Laser Enucleation of the Prostate – HoLEP. This is because, unlike the green light laser which vaporises the tissue, a HoLEP extracts the prostate tissue in pieces which can then be checked for cancer. A HoLEP also removes nearly all the prostate tissue (unlike a TURP which removes only around 33% of it) so I may have to live to be the world's oldest man before my prostate grows back to a troublesome size.

When you see a photo of the HoLEP machine, its compact size belies the skill with which it needs to be operated. There is no substitute for the experience of the surgeon, so I selected Mr Tev Aho who by last May had performed some 1000 HoLEPs, more I believe than anyone else in the UK. Being a New Zealander, he had actually worked in his homeland in the 1990s with his fellow countrymen who pioneered the procedure.

Mr Aho is based at Addenbrooke's where HoLEP is available on the NHS. But I was reluctant to join the end of the six months' waiting list as I feared my bladder might

be irrevocably damaged by my inability to void properly in the meantime. So with the benefit of insurance, I went to see him at a private hospital in Cambridge. The surgery was preceded by quite a debate about whether I should be treated like a normal patient as if I did not have ITP, or be given tranexamic acid after the HoLEP to reduce the risk of

bleeding. I am glad to say that the expert guidance from the ITP Support Association's medical adviser was endorsed by that of Mr Aho's haematology colleague, and I was successfully treated as a normal patient without any special ITP medication. Apparently a platelet count of around 50 or below would have been

the level at which I required anti-bleeding medication. (The risk of wrongly being given this medication is that further surgery might be required to remove the resulting blood clots from the bladder.)

If you read about HoLEP, you will see that a spinal block may be an option to a General Anaesthetic (GA). Mr Aho understandably prefers to work with patients under a GA so that there is no chance of the slightest

involuntary movement by the patient which could compromise the accuracy of his laser control. Remembering the look on 007's face as Goldfinger supervised the movement of the laser towards Mr Bond's groin, I readily agreed. On a more serious note, only in discussion with Mr Aho's anaesthetist last May did I realise that the spinal block I had so gleefully

selected in 2003 as being less risky than a GA, actually carries the possibility that unknowingly the anaesthetist can puncture a blood vessel near the spinal cord - which especially in an ITP patient might cause bleeding leading to paralysis. My expression when I learnt this, probably mirrored James Bond's whilst he was strapped to Goldfinger's bench!

Six months after my

HoLEP, I am delighted to report only beneficial outcomes. My fire hose has returned; I sleep through the night; no more UTIs; no more drugs; and no more sitting on golf balls. No incontinence and no impotence, as the carcass of the prostate and its surrounding nerves all remain intact. I just wish I had I had encountered Mr Aho's laser sooner! Amazingly I was only his second ITP HoLEP patient. I can but hope that any other ITP BPH sufferers are sitting comfortably and sleeping soundly!

ITP 'Friends'

a listening ear

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My ITP Story

by Linda Willis

When I was first diagnosed with ITP it was August 2010, and I was 62 years old. Whilst on holiday in Italy I noticed a lot of bruises which I put down to clumsiness, and bleeding gums which I thought was a dental problem.

When back home I went to my GP for a routine blood test for the blood pressure medication I was on. Having had the blood taken, we set off on the bus to do some shopping and had a pub lunch. When we got home there were numerous answerphone messages asking me to contact the surgery at once. A very concerned GP said my blood results needed to be repeated, and that I should go immediately to the Haematology department at the local hospital who were expecting me. It turned out that my platelet count had been 1, and was the same when repeated.

I was told not to move too much and admitted to hospital. I was started on Prednisolone, and after a bone marrow biopsy which confirmed diagnosis, I was discharged 5 days later with a count of 7.

I was monitored as an outpatient every few days and then weeks. My response was good at first, although I was awake most of the night, was permanently ravenous and started to gain weight.

In January 2011 I relapsed, so treatment changed to Azathioprine with a poor response. This was followed by Dexamethasone but I couldn't tolerate the side effects. I then had intravenous Rituximab.

By November 2013 my platelets were still low, with bleeding, and I had gained over four stone in weight. It was suggested that I take one of two options – splenectomy, which I declined, or Romiplostim. We had a couple of lessons from the Nurse Specialist on the injections and began doing them at home, my husband becoming very skilled at preparing and administering.

It took a lot of ups and downs and dosage adjustment but I now have 500mcg every 6 days. We had to buy an extra fridge to accommodate the supply of Romiplostim! It is not without side effects – headache, muscle and joint pain – but these are usually only for 24 hours and can be relieved with strong painkillers.

My count is now 10-20 at it's lowest point and 30-45 at best, although this may not be entirely accurate as manual examination of my blood film showed some large platelets, and these are unable to be counted by the analysis machine. However, I am symptom free and able to enjoy life.

PLACE inspections

by Rhonda Anderson

PLACE dementia criteria are for all areas of the hospitals throughout the country as they never know when a person with dementia will present. Many people using hospitals are elderly and may need a dementia friendly environment at any time.

As part of being a member of the Patients' Panel at my local hospital I get invitations to take part in PLACE inspections. PLACE stands for Patient-Led Assessments of the Care Environment. Theoretically volunteer patients in the team lead the inspection, and write the report with the support of paid hospital staff. A team leader is chosen from the patient representatives and we all make our comments and observations that are recorded for the report. There is a set format form that has many questions that have to be answered. Many are pass, qualified pass or fail. Some are yes or no answers or does not apply. Teams usually consist of at least 2 patients and 2 staff, but can be bigger. One new aspect of the inspection is to check that the environment is Dementia-Friendly.

Guidelines have been produced and I shall outline some of the criteria we are asked questions on in this article. Most people have some idea of what dementia is, through personal experience with a relative, friend or neighbour, and some unfortunately have the diagnosis themselves. According to Age UK (2014), there are over 100 types of dementia and they do not all have the same symptoms or combination of symptoms. There can be changes in cognitive function in information affecting memory, attention and language.

There can be changes in behaviour, memory loss, confusion, mood and personality changes, and problems with planning and doing tasks in sequence. There are 4 common types of dementia which include, Alzheimer's Disease, Vascular Dementia, Dementia with Lewy Bodies and Frontotemporal Dementia.

PLACE now includes questions on dementia and the environment as there are things in common such as difficulty learning and retaining new information, worsening spatial and visual abilities and confusion. Everyday things that were familiar, such as a toilet and remembering what it is for can be two unconnected processes. People with dementia may not be able to recognise themselves in a mirror, imagining they are seeing a stranger and this can be very distressing. Therefore the questions in the PLACE assessment are geared to see if the environment is as dementia-friendly as possible. The emphasis is on safety and independence, to keep the patient as safe as possible and as independent as possible for the longest amount of time. Consistency in the environment can help here, with for example, all toilet doors being red.

Improving the environment for one set of people usually has the effect of improving it for all people, but not in all instances. For example, 'no-touch' sensor taps are good for infection control, but not helpful as they are not familiar, and I have seen many people at washbasins in public toilets trying many hand waving strategies to get the taps to run! And these people do not have dementia.

Signage for visually impaired people may not concur with dementia patients. Sometimes decisions have to be made as to what will be the best outcome for the majority of patients.

Things to look out for are that flooring does not look like a step, it should not look like an obstacle or barrier, it should not look wet or shiny. It should not have a large or 'busy' pattern. There should be a delineation where the floor ends and the wall begins with contrasting colours and any obstacles should be clearly contrasted and able to be seen. The floor should be quiet to walk on and absorb noise. So a matt, non-reflective floor without noticeable pattern is a good floor for a person with dementia. Other floors can cause confusion and the patient may see things that were not intended, and be confused by the lack of contrast and the heavy pattern.

Signage must be consistent and very clear. Different symbols for the same thing can lead to confusion. This is particularly important for toilet signs as this can impact on privacy and dignity in the care environment. Using both pictures and words is important as people lose cognitive function in different ways at different times. To avoid frustration and agitation signs need to be placed so that people can find what they are looking for easily. A toilet sign on a wall may be confusing with the person pushing on the wall to gain access to the toilet. Signs that are too high or too low do not help as the dementia patient tends to look straight ahead. It takes them time to adjust to a new environment and so signs and clocks can help to alleviate confusion and anxiety.

Fixtures and fittings have changed over time and older people will not be so

familiar with mixer taps and all taps need to be clearly labelled hot and cold. They remember things from long ago rather than things that happened in the very recent past. This can also apply to the types of toilet flush where old style ones will be more familiar than push button and touch free.

Contrasting colours are helpful, so for example, a white toilet is familiar and it can be contrasted with a dark blue surrounding wall, the same for a white basin or white bath. An all white environment is not helpful as the units do not stand out and may not be easily found. The solution is often to make the toilet seat dark blue, however, very few people will have a dark blue toilet seat in their home or in public toilets, so my idea here is to have the surroundings coloured and keep the unit white. If the PLACE criteria are not met, it must be marked as failing.

Strong patterns send too much information to the brain and can cause 'sensory overload'. Wall coverings, bed lined and curtains can all be replaced with plainer patterns, as they wear out.

People with dementia do not often recognise themselves in the mirror and can feel a stranger is there with them, causing embarrassment, anxiety and confusion. Mirrors should be covered or removed, and consideration needs to be given to the way this can be done so it looks acceptable and is easy to do.

It has been very interesting to become aware of the needs of those with dementia and to see that hospitals have to give care to making their lives easier and more confident.

Have you heard

by Anthony Heard

ITP (IN THE PURPLE) for ITP

As I write these notes the bells are blue, the blossom is cherry and the magnolia is wearing it's Sunday best. So it is quite a stretch for the imagination to think as far ahead as the Autumn. But in this article we will, unashamedly be looking forward to the annual ITP September Awareness campaign. We will look at simple ways that everyone can get involved and help to spread the word about ITP.

ITP (IN THE PURPLE) for ITP
September Awareness

As most regular Platelet readers will know, we have been taking a fully active part in the annual September ITP Awareness campaign which has become a global event.

Spreading the word about our mysterious illness is so important. If we ITP sufferers don't make people aware of our condition, then frankly nobody else will. How many of us had never heard anything about ITP before we were diagnosed ? How many of us had been suffering symptoms of ITP long before we were diagnosed ? Certainly I was one of those people. So from my point of view if we can help just one other person from being in that position in the future then we will have achieved a great deal. We may even save a life.

The awareness campaign is of course important in so many other ways. It raises our profile, and gives us greater credibility

in the eyes of health professionals, potential donors, researchers and far beyond. Even more than any of that, by taking part in a wide variety of activities to raise awareness, believe it or not we can all learn something new and have a bit of fun too.

So the following 10 ideas are just a few relatively simple suggestions of things you can do to get involved.

1. ITP..... In The Purple for ITP. Just send us a picture of yourself wearing something purple for ITP. This is a global initiative which is being done on the last Friday of September BUT from our point of view just send us your pictures any time in September and we will post them on our Instagram and Facebook forums (with your permission of course)
2. Join our Instagram forum and share any of your ITP awareness or fundraising pictures with us. Of course you don't have to send us any of your pictures , you may just want to keep in touch with what other folk are doing. You can join for free via the following link.....<http://www.itpsupport.org.uk/socialnetworks.htm>
3. Join our Facebook Group. Over 3700 people have already LIKED our Facebook Group, so please do check us out via <https://www.facebook.com/ITP-Support-Association-195007237228999/>

4. Follow us on TWITTER and if you have done already, as over 1300 people have, then please ReTweet and LIKE any messages we post. It all helps to spread those messages further, especially during September. <http://www.itpsupport.org.uk/socialnetworks.htm>
5. Join our HealthUnlocked forum. We already have over 1500 people who have joined and you can do so for free via.... <http://www.itpsupport.org.uk/socialnetworks.htm>
6. Wear one of our wrist bands. They are available to order from <http://www.itpsupport.org.uk/fundraisingitems.htm>
7. Carry one of our Tote Bags, again available to order from <http://www.itpsupport.org.uk/fundraisingitems.htm>
8. Download our poster and display it at your hospital, clinic, GP surgery, workplace, community centre, library (always get permission first). You can download our poster from... <http://www.itpsupport.org.uk/docs/poster2016.pdf>
9. Hold an afternoon tea or coffee morning. These have been a very popular and successful awareness & fundraising event and great fun too.

10. Join our LinkedIn Group via <http://www.itpsupport.org.uk/socialnetworks.htm>

During September we will be posting out a Daily ITP fact on our Facebook Group, which hopefully can dispel some of the myths about ITP and educate people about the reality of living with ITP.

Don't forget we also have the ITP Support

Association Annual Convention on September 17th , full details at <http://www.itpsupport.org.uk/convention.htm>. And not forgetting the lunch being hosted by Midsomer Murders actor Neil Dudgeon and Dr Mike Smith on September 15th, full details at <http://www.itpsupport.org.uk/neildudgeon.htm>

TEXT GIVING

Don't forget that you can make a donation through **Justtextgiving** at your mobile operator's standard rate by texting the message ITPA22 and the amount (£1 – £5 or £10) to 70070.

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

So we have a lot to look

forward to in the Autumn and hopefully we have given you some simple ways to help raise awareness for ITP (and a bit of time to plan anything you might do).

Please do share any other awareness raising ideas by emailing them to me on anthony@itpsupport.org.uk.

However you spread the word take care and have fun,

Best wishes,

Anthony

Webwatch



by Howard Anderson

In the Association there has been some discussion about upgrading computers and software. In another life, I spent years of teaching, examining and writing about computing and software development so I had plenty of opportunity to look at these issues and share experiences with colleagues. The conclusion is quite sad really, Microsoft, Apple and now Google are masters of marketing, it is a great shame that their software products are not of the same calibre. By this I mean that sometimes things are not what they seem.

One magnificent achievement of their marketing is to convince customers they need the latest software, i.e. they must upgrade, but when looked at dispassionately, this upgradeitis* should be challenged, especially in a charity in which research and patient support should come first. Software and the machine it runs on are technical products that have specifications and performance criteria that are therefore easily matched to a user's needs. Where the software house have won is to get people to switch off this needs/performance analysis and convince them newer is better. That is often not true. Let us look at this in more detail.

Word-processing.

Most people produce documents that contain plain text, bold, italics and differing

fonts. Documents may also contain bulleted lists, tables and images. Very few people use any other facility, indeed in my years of teaching IT and computing I found that most do not even know these other facilities exist. Now, does the current version of your software provide these facilities? Microsoft Office Software as old as 1998 does, so how does the 2016 versions improve on this? Ease of use? Hardly, all versions are about the same in that respect for this set of features. When Microsoft brought out their XML based DOCX file format it was worth upgrading to an Office version that could read and write that new format as other people were sending those in emails. Apart from that, there is nothing to gain at all over Office 2003 (the 1st DOCX version) apart from the warm glow you may get from knowing you have made Microsoft that little but richer. The same applies to Apple software, the vast majority of users neither know about nor care about the newer features of "upgraded" software. When asked, they are usually quite unable to say what benefit is accrued from the upgrade, only the feeling they must have it, it is "better", "faster", terms that are not quantified nor understood.

Spreadsheets.

Excel has provided all that 99.99% of users need since before Office 97. Most have no idea of the powerful macro language and software development environment that

exists behind the familiar screens or the advanced formulas. Most don't use formulas any more complex than the very old SUM() or AVERAGE() so why get a version that will do multiple regression analysis or allows an ODB database link to an SQL server? What I mean is, if you don't know what these terms are, you don't need to upgrade to get them!

Operating systems.

Windows XP is no longer supported by Microsoft. So what. It stills works on millions of machines around the world and will continue to do so despite veiled worries about "security" etc. If it worked in 2014 it will work now, work in the sense of meeting the user's needs as against the desires of Microsoft or the street cred of geeks. Where an operating system needs upgrading is when some required software will not run on the older systems. This is the master-stroke of marketing, they create the desire for upgraded application software (apps), people then need an upgraded version of Windows/OS, this also often means new hardware. Once done, users go back to using less than 1% of the facilities, just as before. Software companies also resort to lying. I use Paint Shop Pro version 7, now 16 years old; Microsoft says it will not run on the latest version of Windows. That is a lie, I use it on Windows 10. I use it because it matches my needs despite also having the latest version of Adobe Photoshop which is powerful yet very cumbersome. The old Paint Shop Pro is quick and simple and I use it for

everyday tasks; do I need to "upgrade" it? No, a performance/needs analysis says so.

It is good business for Microsoft, Apple and Google to convince people they "need" the latest offer, cunningly masquerading as an upgrade, but these changes have other consequences, older working and satisfactory software no longer works, the hardware on which it runs is no longer adequate and time spent learning the older systems is now wasted as new and "better" software needs to have time allocated to training. All this costs time and money and when the job is done, people go back to what they were doing very well on the old set-up.

If we all worked for some cash rich company it would not matter (much), but most do not, it is better to spend the money saved on ITP research rather than falling for a slickly presented set of lies and half-truths. One must look dispassionately at needs and plot them against system performance, anything else is throwing away money. So the question is, does your machine do what you need it to do? If so then leave it alone!

Happy surfing!



News and Views

Pregnancy in ITP Registry

The ITP Support Association is sole funder of the ITP Childhood Registry and part funder of the ITP Adult Registry. The data collected by these registries has increased the understanding of ITP resulting in improved management practices.

Dr Sue Robinson of Guys and St Thomas's Hospital in London recently asked if our charity could fund a new ITP in Pregnancy Registry which it is hoped will identify the women who need lots of additional care and those that just need a gentle eye. But we need your help to provide the funds!

Dr Robinson explained "Pregnancy in women with ITP accounts for almost 1 in a 1000 pregnancies in the UK. Pregnancy is a precious time, health care professionals endeavour to provide patient focused care and where possible we must avoid over medicalising pregnancy in women with ITP. How doctors and midwives look after women with ITP in pregnancy has changed over time. To define best practice and determine exactly when additional treatment is really required data collection regarding expectant mothers with ITP women and their newborns is

essential. The planned addition of an ITP in pregnancy registry to the Adult ITP registry is an opportunity not to be missed!"

ITP research completed

A pharmaceutical company sponsored a project aiming to understand ITP symptoms and impact from the patient's perspective, and to use this information in the development of new treatments. Last autumn, members were invited to participate in a project conducted by Modus Outcomes, a patient-centered research company, and facilitated by the ITP Support Association.

A total of 110 members expressed interest in participating in this research and a total of 60 telephone interviews were completed in two rounds, the first one completed in late 2015 and the second round in Spring 2016. Telephone interviews were recorded and transcribed verbatim and are currently being analysed by Modus Outcomes. More information on the findings of this research will be shared once available in upcoming newsletters. The ITP Support Association has received a donation from the pharmaceutical company for facilitating this project. Thank you to everyone who participated.

CONDOLENCES

We are extremely grateful for these donations in memory of loved ones who have passed away

£310 received from Robert Smith in memory of his wife Doreen

£1000 received from Linda Paisley in memory of her husband.

We send our very deepest sympathy to Robert and Linda, and we thank them, and their family and friends, for their kindness in remembering our charity.

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.

Medals and Badges - any, and not limited to military items, other medals and badges accepted.

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.

Take a look in the loft. You would be amazed how much that old junk could raise for a good cause!

Help raise funds by saving your stamps and send them to the ITP office. Send other items direct to Stamps N All quoting The ITP Support Association

To arrange collections (over 10kg), please telephone 0845 257 0813, Monday to Friday, 9am to 5pm.

Small lots / donations can be mailed, direct (please ensure correct postage is paid) to:

***Stamps N All, Dept ITP, PO Box 245, Plymouth, PL5 2WX**

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

Stamps N All is a recycling specialist - assisting charities, groups and clubs with their fund raising.

If you feel that your organisation might benefit from the Stamps N All zero cost** fund raising solution, please call David on 0845 257 0813 to discuss how Stamps N All can help you. **Terms & Conditions apply. Stamps n All (Sole Trader), which means that all goods donated to Charities are paid for, but the sole trader profits from goods purchased

New! ITP logo shopping bags £2.50

Save yourself the 5p charge that you have to pay on each plastic bag that you use in supermarkets and large stores by purchasing our new foldaway sturdy but lightweight, re-usable shopping bags.

Made from polypropylene and weighing just 80gsm you can carry several of these in your pocket or handbag so you don't find yourself without them when you reach the checkout. Measuring 46 x 38 cm these are available in lime green, bright red or navy blue with our ITP logo printed in white.



USE THIS FORM TO

- **MAKE A DONATION**
- **CHANGE YOUR ADDRESS**
- **JOIN THE ITP SUPPORT ASSOCIATION**
- **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)

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)



**The ITP Support
Association App.**

*SAE is greatly appreciated

Please complete:

Name _____

Address _____

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 _____

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