



# the platelet

JUN 2017

JOURNAL OF THE ITP SUPPORT ASSOCIATION



**ITP NEWS, INFORMATION & ADVICE,  
CONVENTION REVIEW, PATIENT  
STORIES, AND LOTS MORE ...**

# THE ITP SUPPORT ASSOCIATION TEAM

Charity Registration No:1064480

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

# In this issue . . .



Phone apps are becoming very popular as a digital aid for people with chronic diseases to track and manage their condition, and on page 12 we have exciting news of a new ITP app. It is being developed by Novartis who are in consultation with us to ensure it meets patient needs, and we would welcome your comments and ideas.

The topic of bone marrow biopsy is tackled in the American Perspective column (pg 6), and opposite (pg 7) you will find advice on whether to pull loose milk teeth in children with ITP.

One of our cover girls tells of a full and outgoing life (pg 8) despite growing up with ITP, and in News & Views (pg 25) a mother makes a plea to find other children with ITP who could meet up with her 8 year old son.

We have photos, comments and a review of the 20th Convention (pg 16), Anthony Heard reports on Rare Disease Day at the House of Commons (pg 19) and Derek Elston briefs us on the Plasma Therapeutics meeting in Prague.

Our treasurer, Michael Levy, summarises The ITP Support Association's end of year accounts (pg 4) and we invite supporters to become Associate Members in our membership update (pg 5).

Finally, we are pleased to pass on news of Dr Drew Provan's replacement at the The Royal London following his retirement (pg 23). We are delighted that he has affirmed his willingness to remain as a medical advisor to The ITP Support Association in the foreseeable future.

*Front cover: Kirstina Reitan , St Neots Sweeps & Milkmaids, Rebecca Wood, Jaclyn McCann & Martin Mclver*

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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.

# Money Matters

## The ITP treasurer's summary of our end of year accounts

At the time of writing I have just completed the draft accounts for the period 1st April 16 to 31st March 17 ready to send to the external auditor. These will be published on the Charity Commission website in due course and can be viewed on line at [www.charitycommission.gov.uk](http://www.charitycommission.gov.uk) (search for The ITP Support Association by our charity number 1064480.)

The accounts show a deficit for the year of £61,360 resulting from our total expenditure for the year of £154,650 exceeding our income of £93,290. Included in the expenditure [£154,650] is the sum of £112,988 for research projects of which £92,240 represents monies awarded to fund some of these projects but not yet paid. Although these awards were agreed in January, payment has been delayed (to the frustration of the researchers who are raring to go) because of hospital/



university paperwork at the centres where the research is due to be carried out, and thus this amount is due to be paid in the current year. In addition we anticipate paying a further £45,000 to the adult and childhood ITP registries in this financial year. Bank balances at year end stand at £204,612 which is sufficient for the Association to pay the promised research grants, carry out its

primary function of patient support, pay its bills and keep a safety reserve in the bank. However, interest in ITP research is definitely increasing and we can only continue funding new and exciting projects with your generous donations and plentiful contributions from fundraising events. You've made it possible in the past, and we hope we can count on your continued support!

**Michael Levy FCA**

## The Charity Shop

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

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# ITP Membership update

As most Platelet readers will know, membership of the ITP Support Association costs just £10 and is open to anyone with an interest in ITP. Patients, people in remission, family members, supporters and health professionals – are all very welcome to join us. For ease of administration subscriptions paid by cheque become due each calendar year on January 1st, whereas those paid by Direct Debit renew automatically from the date they are set it up.

## **Full membership benefits include:**

The Platelet (our quarterly journal); access to our 'ITP Friends' counselling volunteers; further information on ITP and related topics in our numerous free booklets and factsheets; a free ICH alert card to inform medics about ITP in an emergency; your questions answered by key volunteers with assistance from our medical advisors; concession ticket price for the annual ITP Support Association Conventions where you will meet others and hear presentations from top ITP specialists; the opportunity to voice your opinion in occasional (optional) surveys gathering data on ITP (some from pharma agencies offer payment to participants).

## **In remission? Not the person with ITP? Support us as an Associate Member!**

For people with an interest in ITP who don't wish to access our ITP membership benefits listed above we invite you to become a supporter of our charity, by becoming an Associate Member. Your annual subscription of £10 will help provide the core funding which enables our charity to function. You can register for access to the Members' Area of the website if you wish. Anyone with an interest in supporting our work can become an Associate Member, so do please encourage family members and friends to join and assist our cause.

## **Have you registered for access to the website members' area?**

Full members and associate members can register for access to the Members' Area on our ITP website [www.itpsupport.org.uk](http://www.itpsupport.org.uk). There you will be able to access The Platelet and various other publications, and view presentation slides from the latest ITP Convention.

## **Our promise to you**

We will NOT bombard full or associate members with emails, telephone calls or postal appeals for further funds, and (with the sole exception of Parkes Printers who mail out the Platelet) we do NOT share our mailing list with any other organisation.



# American Perspective

**Professor Spero Cataland MD**  
Columbia University Medical Center

## **Bone Marrow Biopsy and ITP: “Wasn’t I Supposed to Get One?”**

I recently met a patient in the clinic who was referred for a possible diagnosis of ITP. She seemed a bit more nervous than most patients when I first met her, and I soon learned her anxiety stemmed from her fear of having a bone marrow biopsy performed. Her close friend told her the story of her grandfather’s diagnosis of ITP and the bone marrow biopsy that he had to undergo. She was relieved when I told her that she would not likely need a bone marrow biopsy after my evaluation of her case (and she didn’t need one). So when a diagnosis of ITP is suspected, which patients need to undergo a bone marrow biopsy?

Understandably, the mention of a bone marrow biopsy procedure brings on significant anxiety for patients. A bone marrow biopsy procedure is intended to sample the fluid in the bone marrow cavity of the pelvis (to evaluate where the blood cells are produced), but also to obtain a “biopsy” of the bone marrow itself for physicians to understand how the bone marrow is functioning in its production of blood cells. It is typically performed when there is concern for abnormal bone marrow function based

upon the presence of low levels of blood cells (white cells, red cells, and platelets) or concern for a cancer involving the bone marrow (leukemia or lymphoma) when abnormal cells are found circulating in the peripheral blood.

Historically bone marrow biopsies were performed in all suspected ITP patients who were over the age of 60 to exclude a diagnosis of myelodysplasia (MDS). MDS is best described as a pre-leukemic condition that is more common in older adults. MDS can initially present with low blood white blood cells, red cells, and platelets and could initially look like ITP. Since there are no tests that can specifically diagnose ITP, and therefore the diagnosis of ITP is based upon excluding other explanations for the low platelet count, then you can understand why many patients with suspected ITP underwent bone marrow biopsy procedures in the past.

In recent years physicians no longer routinely perform bone marrow biopsy procedures in patients with suspected ITP. Bone marrow biopsies are only done in a few patients with other clinical or laboratory



features present that raise suspicion for another blood disease other than ITP (abnormal cells in the blood, a low white blood cell count or anemia, enlarged spleen or lymph nodes, or concerning symptoms such as pain, fever, and drenching night sweats for example) will undergo the procedure to exclude other bone marrow diseases as the cause of the low platelet count. This approach is now common in both in pediatric and adult patients. Bone marrow biopsies may also be considered in patients with suspected ITP who have failed to respond to standard treatments including steroids and IVIG. It is expected that roughly 2/3 of patients will respond to steroids or IVIG treatments, but when they do

not physicians may consider a bone marrow biopsy to evaluate the possibility of an alternative diagnosis. This may be especially true if a physician is referring a patient for a splenectomy. In these cases the doctor is trying to exclude other diagnoses (that might not improve with splenectomy) before the patient undergoes the surgical procedure.

The end result of this change is that fewer patients with suspected ITP will undergo a bone marrow biopsy. This routine use of the bone marrow biopsy in ITP patients over the age of 60 has largely been replaced by a careful history, and review of the available blood tests to exclude other bone marrow disorders.

## Loose milk teeth – to pull or not?

We received a phone call from a mother expressing concern that her child with ITP had a very loose milk tooth that was bleeding. She didn't know whether to give it a tug and deal with the bleeding or whether it is better to let the process be as gradual as possible. The child's count was around 50 but he was not symptom free. As this was a weekend she was unable to get advice from her dentist or doctor.

Dr John Grainger, one of our paediatric medical advisors, kindly sent a very prompt reply. He advised leaving the tooth to come out naturally, especially if some blood had been oozing already, as pulling it too early usually causes more blood vessel damage. If there was an obvious bleeding point he suggested trying to press some gauze over bleeding point for 10-15 minutes. Tranexamic acid could be used if they had any at home for previous bleeding problems.

Dr Grainger added that he wouldn't usually expect much dental bleeding in this situation with a child's platelet count above 30. He suggested getting the platelet count checked on Monday followed by a visit to the dentist.

# Growing up with ITP

by Rebecca Wood

I was diagnosed with chronic ITP at the age of two. I am now nineteen and although I still have ITP, I live a full and outgoing life.

As I was so young at the point of diagnosis I do not fully remember my history as an ITP patient. However, I do remember the numerous hospital trips and emergency hemorrhages from my childhood. Like many ITP patients, doctors were unsure of my condition initially and so I got tested for many conditions, including leukemia. After being diagnosed with ITP the doctors suggested that the autoimmune response might have been triggered by a severe case of chicken pox, which I had aged one year. I find this interesting as a large majority of females on my father's side of the family all have autoimmune conditions such as rheumatoid arthritis and lupus tendencies. Surely there must be a genetic link to all these autoimmune cases in my family- but as you will know we still do not understand fully why ITP occurs.

My experience with ITP included extensive bruising, severe nosebleeds, mouth ulcers and purpura. Consequently, I spent a lot of time in hospital getting infusions to try and replace my platelets. I was such a regular patient at one point I had my own bed and teddy bears on the children's ward and attended the hospital 'school'. I

had to have blood tests every day, as my count would always be below 10, but my mum was always by my side to comfort me and make sure everything was okay.

After trying different treatment options, including steroids my parents made the decision for me to have a splenectomy at the age of five. Removing the spleen does not always work and involves risks, like any surgery, but they hoped this would give me the opportunity for a better quality of life. I went to St George's hospital in London, and stayed for 2 weeks for the surgery. I still remember clearly coming out of the surgery, seeing my parents and getting a lip sponge put in my mouth, which I did not like. I felt very ill after the surgery but really wanted to get back to school and see all my friends.

I think my family expected an instant change in my condition, but initially the splenectomy did not appear to have made any difference in my condition. Then, gradually my count started to increase up to around 40, which for me was absolutely amazing. I began to visit the hospital less and learnt to manage my condition at home. Due to the splenectomy I began to take a low dose antibiotic everyday, and still do to this day as well as getting more vaccinations. To date my count is generally around 50, but will drop when I become ill.

Since then my mum has raised me to live a normal life, and participate in the majority of activities. I occasionally had a bad nosebleed and bruised easily but nothing we could not manage. When I joined secondary school I seemed completely fine, if you asked any of my friends they would have not even known I had a blood disorder. I think even I began to forget the severity of bleeds that can occur with ITP, and also the susceptibility to some types of illness due to the splenectomy.

I completed secondary school with amazing GCSEs and started sixth-form where I studied biology, chemistry and psychology. I think being a teenager with ITP can be tough at times, you want to be independent but your parents are so used to protecting you and worrying about your illness. You have to start learning to completely manage your ITP, and splenectomy independently, which I never really grasped as a young teenager. You start puberty, periods can be a problem and you start socializing more including drinking alcohol. Alcohol thins the blood for a start, so is not great for ITP patients but is such apart of our society now, it would be wrong to get left out.

Lots of ITP patients suffer from fatigue; luckily I have never seemed to have this symptom. However, during A-levels I decided I wanted to become a doctor and started studying extremely hard to get into medical school. I think I thought I was 'superwoman': I volunteered, studied all the time, became head of charity committee, had a bar job, a busy social life, I danced, went to the gym,

even had time for a boyfriend! Then I got very tired, I just kept falling asleep for no reason. I started to feel quite low in myself and my platelet count must have dropped. One night I got a fever and couldn't stop being sick. If you have had a splenectomy and develop a fever you must go to hospital as it could develop into something severe such as sepsis. In A&E they diagnosed me with glandular fever, probably due to all the stress of A-levels. It was a horrible experience, but it really reminded me that I do have a chronic disorder and that I needed to have a better work-life balance.

After being reminded of my illness, I think I learned to take care of myself better. I learnt about chronic ITP again and what I need to do to manage my condition whilst having a normal life. My mother started to notice a difference too I think, and was glad I was taking more responsibility of my health.

A year on and I have just returned from travelling Australia and New Zealand, and am so excited to start at Exeter medical school in September.

I really wanted to write a brief outline of my ITP history, as I do not think this illness should limit anyone from reaching his or her dreams (as cliché as that sounds). If you asked my mother when I was first diagnosed what she thought I would be doing age nineteen, I do not think she would have guessed the actual outcome.

*(See front cover, Rebecca in the snow 'on top of the world')*



# Letterbox

I want to reassure ITP sufferers who have been prescribed prednisolone and consequently experience taste disturbance problems, where food does not taste as it should.

In January 2013 I had acute ITP which initially was quite serious - I was admitted to Kings' College Hospital for three or four days because of the bleeding. By April I had been weaned off prednisolone completely. My platelets returned to normal, and so far I have had no further problem with ITP. But the taste disturbance continued for quite a while, for 10 weeks or more. I could not enjoy coffee or tea, or, more serious for me, beer! And no food tasted as it should.

Sometime ago I read online of a woman who was very worried that her food and drink should taste so awful after taking prednisolone - she was worried it would remain like that for the rest of her life. Well, I just wanted to reassure anyone who's having this horrible taste disturbance following prednisolone, that it will gradually fade right away. And thank heaven for that!

**Patrick Noakes**

*Thank you for sharing this and offering reassurance, Patrick. As a show of hands indicated at the Convention the topic of*

*drug side effects is often not discussed at appointments, and consequently patients don't know which are common, which are rare, and how long they may last. Interestingly a Google search didn't find a single medical site listing taste disturbance as a side effect, but it was certainly referred to on numerous social networking sites.*

*Shirley Watson*



Being diagnosed with ITP in October 2015, was quite a shock! I had no idea about these things called platelet running around in my body (in my case a lack of them)! With the ease of internet access in the 20th century, and search engines my wife and I started to investigate further to try and find out more information.

Being of an age of over 40, I am slightly sceptical of everything I read on the Internet and therefore knowing was this information accurate? What sources to believe? Where had this information been collated from? I felt I had slightly more information, but I was still with an appetite to find out reliable facts.

While sitting waiting for one of my now many blood counts, at the Macmillan

unit at Milton Keynes general hospital, I was lucky enough to find a copy of "The Platelet" to read. This was "GOLD DUST" I had struck it rich. Wow there are other people like me out there!

This allowed me to subscribe to the ITP support association. So I have learnt more about this disease and has lead me to attending the ITP conference yesterday in London.

The event was extremely informative. With every session being helpful and useful. They were all set out in a fun and relaxed atmosphere. While the clinicians kept their presentations short and sweet, they where full of facts to kept me enthralled. Each lecturer had their own style, and brought with this: audience participation, experiences from sufferers that they had managed, and helpful, useful information to take away and discuss with my consultant. ( I brought with me a 20 sheet A5 notepad that is now full of information that I can refer to and use going forward with my treatment).

I would like to thank you, the team and the wide range of speakers/specialists that helped to put on this conference. I cannot thank enough the doctors/participants that will have taken up their own time to come along to help, give advice and elevate some of the worry that

me as an ITP sufferer has. Well done on everyone involved for a fantastic event! I am very much looking forward to the next conference.

**Russell Jones**



I would just like to thank you for the wonderful conference on Saturday last. It was so encouraging to meet lots of other people in the same boat and to be able to swap stories and experiences. It was the first time in 15 years that I have been able to do this.

For that opportunity alone I must thank you all but also the wonderful speakers through whom I learnt several very interesting and new facts! I wish I had known some of these before! A small operation I recently had could have been cleared up far more quickly if I had known better what to ask about!

I particularly look forward to the launching of the App which I will fill to the brim with information.

The venue was magnificent and the catering superb so all in all a fabulous day. Once again very many thanks to you all. You really are a lifeline for me on many occasions.

**Sylvie Tye**

**If you would like to write to The Platelet please email your letter to [info@itpsupport.org.uk](mailto:info@itpsupport.org.uk) or post it to The Platelet Mission, Kimbolton Rd, Bolnhurst, Beds MK44 2EL**

# ITP pocket log

by Mervyn Morgan

Many of you will use smart phones or tablet devices as part of everyday life so this item will be of interest.

At the recent ITP Convention at the Royal Society of Medicine in London there was a short presentation on a potentially exciting piece of technology called 'ITP Pocket Log'. This application (App), which will be available on both IOS and Android will allow users to keep track of their ITP symptoms, test results, medications plus much more.

Each menu item will provide the following options:

- 1 - My Symptoms - Inputs free text symptoms, scores from one to ten, plots graph of symptoms.
- 2 - My test results - Records platelet count.
- 3 - My medications - Details drugs name, prescribed by, formulation, date started, diet considerations, frequency, repeat prescription date and dose.
- 4 - My notes - Captures to do list, activities, question to doctor and side effects.
- 5 - My calendar - Pulls through symptoms, appointment, medications and notes on a calendar.
- 6 - My reports - Displays notes and test results in report format.
- 7 - My contacts - Lists details of doctors, nurses, pharmacy, insurance and the ITP Support Association.

8 - My profile - Details patient's name, gender, date of birth, weight, height, diagnosis date, blood type, allergies, hospitalisations and other diseases.

9 - More on ITP - Contains further information about ITP: diagnosis, known causes of ITP, management, ITP in children, ITP in adults, ITP in pregnancy; ITP Support Association contact details, how to stop a nosebleed, holiday arrangements, dental treatment, alert ICH info, ITP blood tests, treatment table, Centres of Excellence Map; ITP research - make a donation (website), benefits of membership ( website).

The plan is to launch the 'ITP Pocket Log' app in the autumn, however we would like to hear from you with regards to what other features could, potentially, be added to the App in the future.

Please email us at [info@itpsupport.org](mailto:info@itpsupport.org).uk with your first impressions, tell us what additional features you would like to see and how would you like to be informed once the app becomes available.

Please note: all personal data inputted into the 'ITP Pocket Log' will reside within the app, on the device being used. No information will be transmitted from the app, unless the user chooses to actively initiate an email transmission or print instruction from the app.

Mock-up of the 'ITP Pocket Log' main Screen



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# Fantastic Fundraisers!

We kick off with a huge and hearty thank you to **Jaclyn McCann and Martin McIver** who raised a staggering £1669 from the Glasgow Kiltwalk because Jaclyn's cousin has just had a relapse of ITP. The Royal Bank of Scotland Kiltwalks take place in Scotland at 4 venues during the year, Glasgow, Edinburgh, Aberdeen and Dundee. Jaclyn and Martin were among over 7000 people who did the beautiful 23 mile walk on April 30th from Glasgow Green to Balloch.

**Kirstine Reitan** participated in the Two Peaks Challenge. raising an amazing £1,208 for ITP. Kirstine told us "It

certainly was a challenge! We had an awful lot of weather; snow, hail, gales, rain, fog . . . But I really enjoyed the weekend. I am sending a photo taken after the Ben Nevis climb. It was so wet and windy up high that it was difficult to take photos hence the shot from the bottom of the mountain!" An amazing achievement Kirstine, both in completing the Challenge and raising such a fantastic sum for our cause.



**Kirstine Reitan at Ben Nevis**



**Jaclyn McCann & Martin McIver**

**Lynn and Kevin McVittie** in Co. Durham sent an impressive £800 from three activities: £200 was raised by their friend Hazel Watson at the Plain and Purl Wool Shop in Washington, Tyne & Wear, £250 was collected by Lynn's Friday Keep Fit Class, and Kevin and Lynn raised £350 with a band concert. We are most grateful to Lynn and Kevin, and everyone who helped them raised this worthy total.

Congratulations to **George Watson** who became a nonagenarian on the 1st April. His wife Joan (Shirley's sister) arranged a 90th birthday party and a collection from Joan and George's family and friends raised £210 for ITP.

Our thanks goes to **Paulene Cattle** for sending £142 from the collection box at her 'Chalk' shop in Southfields, London. **Atlas Trading Group Ltd** raised £117 from their collection box thanks to Simon Gledhill, the Managing Director of this family run company. Simon kindly supports our charity as his 10 year old son has ITP.



**Joan & George Watson**

An annual event each January 1st in Dumfries and Galloway is the Crossmichael Marina Dip when over 50 swimmers brave the freezing cold waters to celebrate the start of the New Year. Amongst the bathers were **Tricia and Sally Thomson** who raised £111 for our charity from their courageous deed as Tricia's husband Neil (Sally's Dad) has ITP.

**Shirley, Natalie and Mervyn** held a coffee morning on Friday 3rd March at ITP HQ. Unfortunately this was the very day of Storm Doris which deterred some, but nevertheless £100 was raised from the stout-hearted visitors who braved wind and rain to join us.

**The Rotary Club of Billericay Mayflower** very kindly sent us £75 from the annual Billericay Christmas Market, and thanks to Andy of Crystal Print for nominating our charity.

And finally, yet again, we send a heartfelt thanks to the wonderful Celina and Gloria at **The Charity Shop in Gt Yarmouth** who sent another £1,000 at the end of March.

### **Heartsease names us their Charity of the Year!**

We were delighted to hear from Patti Pitt that her ladies folk dancing group, Heartsease, has chosen The ITP Support Association as their Charity of the Year. Patti and her husband Roger have been supporters of our charity events in Bolnhurst over many years, and Roger was the architect who drew and submitted the plans to build our HQ. Heartsease ladies dance all around the UK and travel to some events in Europe, so watch out for them performing at a Folk Festival near you! A mixed dancing group attached to Heartsease is known as St Neots Sweeps and Milkmaids (*photo front cover*), and as both groups have been running for 40 years they always looking for younger members to join them.



### **CONDOLENCES**

We are extremely grateful for these donations in memory of loved ones who have passed away and send our very deepest sympathy to their family and friends.

£350 was received in memory of **Maureen Carpenter**

£415 was received in memory of **Margaret Marshall**

# 20th Convention Review



**Dr Jecko Thachil**

*"All the speakers were great communicators and hugely knowledgeable in their respective fields. The whole day struck the right note with so much information injected with a little light-heartedness"*



**Dr Nichola Cooper**

*"I shall go to my next hospital appointment with much more confidence"*



*"I went to this ITP convention in some trepidation, but came away feeling stronger and hopeful"*



**Prof. George, Prof. Newland & Dr Scully**

*"My thanks to Shirley & her team – a superb programme once again, and a well-chosen venue"*



**Prof. Hunter, Prof George & Dr Cooper**

*"Everyone, including the expert doctors, were so friendly"*



**Dr Marie Scully & Prof. Victor Blanchette**

Our 20th Convention was a sell out event, held at the Max Raine Lecture Theatre at the Royal Society of Medicine on Saturday 13th May. The venue was exceptional, and a perfect setting for the superb line up of internationally recognised speakers from the UK, USA and Canada. We were pleased to renew acquaintanceships with regular visitors to our conventions but there were also many new faces which included some newly diagnosed patients.

After registration accompanied by tea and coffee with Danish pastries and croissants the joint CEOs opened the event. Mervyn Morgan extended a welcome to all and Shirley Watson gave a brief outline of how things had changed since our first Convention in 1998. She handed back to Mervyn for a short description of a new APP currently being developed for patients to record their individual ITP history. Afterwards a show of hands indicated that the vast majority of the audience would use the app, and Mervyn invited their feedback.

Professor Jim George from Oklahoma, a visitor to at least half of our 20 conventions, gave a very interesting presentation on the Treatment of ITP 1931- 2017. This took us from splenectomy to TPO drugs, and showed how little was known about ITP 80 years ago compared to today. Professor George left us in no doubt that we are most fortunate to have a lot more treatment options now than in 1981, let alone 1931!

Dr Maria Scully from UCLH (University College Hospital, London) involved the audience in her session on ITP – Questions we forget to ask; Information we forget to give. It became apparent that many patients didn't know what their ITP management plan was, or how long they were taking

their particular treatment, and issues such as sport and holidays was not commonly discussed with their consultant.

Dr. Nichola Cooper from the Hammersmith Hospital in London ran the first of 2 keypad response sessions in which she tested the audience's knowledge of matters relating to platelets and blood. Each question had multichoice answers and the screen showed the percentage of votes for each option. Dr Cooper backed up the answers with explanatory slides and took follow up questions from the audience.

After the coffee break with delicious home-made biscuits, Dr Jecko Thachil from Manchester Royal Infirmary presented the Practical Aspects of the TPO drug use. He emphasized that the choice of TPO drug is a matter for discussion between the patient and the consultant, with due account being taken of how they are administered and the adverse effects of the various drugs. Dr Thachil suggested how patients can help reduce the risk of blood clots which can be a risk with these drugs, and he outlined two cases where he had listened and learnt from his patients.

For the last session before lunch Dr Scully introduced a head to head discussion between Prof. Jim George and Prof. Adrian Newland (Royal London Hospital) on the topic Is splenectomy an outdated treatment for ITP? Statistics show that splenectomy is performed less often in the UK than the USA, with some UK specialists removing the spleen very rarely indeed. However, both of our eminent professors from either side of the Atlantic agreed that splenectomy has a place in the treatment of ITP, but Professor Newland emphasized that it should not take place unless an indium labelled platelet

spleen scan showed that platelets were destroyed predominantly in the spleen, rather than elsewhere in the immune system.

After a superb 'hot fork' lunch and delicious desserts the afternoon programme commenced with a welcome return of Professor Victor Blanchette from the Hospital for Sick Kids in Toronto, Canada. His presentation looked at Shared Decision Making in the Management of Children with ITP - the Toronto experience. Professor Blanchette looked back to when children in Canada and the USA had been much more aggressively treated than in the UK, and how in Toronto, depending on the symptom severity of the child, they had worked to emulate the UK with observation as opposed to intervention increased from 34% of children in 2007 to 71% in 2012 with these cases safely managed. He advocated that where treatment is needed, a short course of prednisolone (without a taper) has no more side effects than IVIg and is more cost effective especially in countries with limited options.

This was followed by a further keypad session by Dr Nichola Cooper who asked if the audience had changed their mind about splenectomy following the pre-lunch discussion. The audience answered questions surprisingly quickly and showed they had a good grasp of matters relating to ITP. Dr Cooper included a few bogus options in the answers which caused much amusement.

Professor John Hunter, a Gastroenterologist Research Fellow from Cambridge, had been commissioned by the ITP Support Association four years ago to investigate a possible link between food intolerance and ITP, and the first phase of research raised questions about the role of gut

bacteria in ITP. Prof. Hunter reported on his investigations looking at changes in the colonic microbiome in ITP. His presentation covered unfamiliar ground for those conversant with ITP and blood, but attempted to tackle the question so often asked by ITP patients as to whether their ITP could be caused by diet or gut-related problems.

After tea (more delicious homemade biscuits!) and raffle which made a wonderful £260, Derek Elston, a trustee and volunteer of the ITP Support Association gave a short presentation about the work of a clinical study group concerned with bleeding disorders he was co-opted on to two years ago. From this group, a Priority Setting Partnership was established to ask patients of all bleeding disorders what they would like to see researched. The two prime patient groups are the Haemophilia Society and The ITP Support Association. Other stakeholders include analysis economists; clinical representatives from London, Cardiff and Oxford and blood transfusion service, and physiotherapists. The group are asking patients to complete a questionnaire at [www.stopthebleeding.org.uk](http://www.stopthebleeding.org.uk)

The day ended with a lively Question Forum ably chaired by Professor Adrian Newland where the audience put their questions to the panel of speakers. There had been more than usual audience interaction during the day, but there were still plenty of questions to be fired at the expert panel. As ever, it was a lively and informative session to end the day.

Shirley Watson closed the meeting with a hearty vote of thanks to the clinicians for their very valued participation, to the ITP team for all their efforts to make the day successful, and to the audience who had supported the event.

# Have you heard?

by Anthony Heard

## GETTING RARE in the HOUSE

It was a great pleasure to attend the Rare Disease Day House of Commons Reception on Tuesday February 28th. The theme for this year's Rare Disease Day was Research and we were treated to some really interesting presentations by our guest speakers on a packed agenda.

I have attended the House of Commons Rare Disease Day Reception on 5 occasions now since 2011. I only missed the 2016 event because I couldn't find any platelets to take with me. My count had fallen below 20 on February 8th 2016 and back on the steroids all the unwanted side effects made me feel very unwell. The main issues were nausea, headaches, tiredness, insomnia and aching joints. Thankfully I was gradually taken off the steroid in April 2016 and have been on Mycophenolate Mofetil (MMF) successfully since then. Latest count (today May 15th) ..... 191 ! Hooray !!!

So this year with plenty of platelets on board and no side effects from the MMF, I was fighting fit to attend the House of Commons Reception. What a very interesting afternoon it proved to be. There are so many positives to be gained from attending the Reception, not least hearing from the guest speakers who have a broad range of experience and knowledge across a wide variety of rare disease matters. But more important is meeting

other rare disease sufferers, listening to their experiences, good, bad and ugly.

Being something of an old timer now with my eleven purple years behind me, it is not unusual to meet some familiar faces at the House of Commons Reception. It is always good to hear how other people have been getting on with their rare journeys.

The event reminds us all that it is not just ITP that is rare. Our purple problem is just one of so many rare conditions, with literally thousands of people going through their own day to day struggles. We are all supported by families, friends and carers who go about their work, often unnoticed and largely unsung. Rare Disease Day acknowledges all of us and goes some way to draw attention to our individual battles and the heroes who support us.

One of the key issues in recent years has been the campaign to agree a rare disease strategy for the UK and then more importantly, getting a plan to implement it. The difficult part has been getting progress on the implementation, especially in England. Sigh !!!!

The UK Strategy for Rare Diseases was finally agreed in 2013 and included 51 key commitments. It was agreed that the strategy must be implemented in full across all 4 parts of the UK by 2020. Now

that may seem to be ample time but there is a huge amount to do and apparently it involves many complex issues. My own personal view is that 7 years is far too long and the deadline should have been much shorter. It all sounds like the familiar tale of kicking a difficult ball into the long grass.

Let's face it, if you really want to get something done then you will and the stiffer the target or deadline the more urgency you SHOULD put into achieving it. I mean 7 years, let's put that into perspective... WW1 lasted just over 4 years, WW2 just short of 6 years and The Beatles entire career as a band lasted only 10 years ! This 7 year implementation really is a hard day's night by comparison me thinks.

England has been much slower than our Welsh, Scottish and Northern Irish counterparts in implementing the Rare Disease strategy. At the Rare Disease Day House of Commons Reception, the Minister responsible for rare diseases Nicola Blackwood MP, expressed her determination to make sure that the Rare Disease strategy was implemented by the Department of Health. Without wishing to sound too grumpy, she would say that wouldn't she ? Clearly the implementation of the strategy in England needs sharper focus and more urgency. The old adage of failing to plan means planning to fail seems to apply.

A recent report by the All Party Parliamentary Group on Rare, Genetic and Undiagnosed Conditions, entitled Leaving No One Behind - Why England Needs An Implementation Plan for the UK Strategy For Rare Diseases was actually published on Rare Disease Day ( A link to the report is provided at the end of this piece ). The report took 3 months to compile, received evidence from patients, carers, health

professionals and experts. It unsurprisingly concluded that the UK Strategy for Rare Diseases has not been implemented in England, and there are a number of commitments where NO ACTION has been taken at all. It does not seem to advise WHY NOT and of course it fails to attach any responsibility.

The report concluded we have a strategy without a plan (if it sounds a bit BREXITY then you probably

get the picture). My worry is on a number of levels but the first thing I wonder is ... WHY is it ALWAYS England that seems to lag behind or be different to the rest of the UK ? Another thing that strikes me as worrying is ... if we had allowed things to drift without pushing for this report, presumably NOTHING would have happened ? I know that we British have run our entire approach to World affairs on doing NOTHING and waiting for events to unfold BUT really when it comes to our

#### 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.

lives, my life then well. AAAAGH ! I'm almost purple with rage as well as purple with ITP !

So what happens now ? We have a nice, shiny report, expensively put together no doubt. It tells us what we already knew, it confirms that nothing much has been done in England to implement a strategy agreed in 2013 so where do we go from here ? Well as usual the politicians seem to restate that they are committed to delivering the Rare Disease Strategy across all of the UK. But they don't seem to say when, how or who by. Actions not words are needed NOW not in some far off realm in another galaxy.

The only thing we rare disease sufferers can do is keep badgering our MP's (especially in England), keep rare disease awareness in the faces of those who matter and hold them to account. I know for sure that I will be attending next years House of Commons Reception on Rare Disease Day and I will be asking WHAT PROGRESS have we made in implementing the Rare Disease Strategy. I will also write to my MP too and join with Rare Disease UK in pushing our case. I really don't like prevarication, if we commit to doing something then let's do it. If we don't want to do it or can't, then say so and come up with an alternative.

But as an ITP sufferer why does it actually matter whether or not we have a UK Strategy for Rare Diseases ? Well, there are many reasons why it is so important for us ITP folk and based on my own experiences, here are just 2 of them. ....

- Better diagnosis of rare diseases.
- Better coordination of care, treatment and follow up.

The UK Rare Disease Strategy has 51 key commitments and two of them tackle issues that I soon realised were apparent in my own case. In terms of my own ITP diagnosis it took 7 hours of tests and observation in my local Accident and Emergency (A&E) Unit before a definite diagnosis was issued. The hospital had no ITP specialist on duty on the evening I was at A&E, and had to telephone one to get confirmation of the suspicions of the A&E team that I had ITP.

Please don't think that I am complaining about my diagnosis or the process that was undertaken to get my ITP confirmed. On the contrary, the hospital did everything they could, within their power, to get me diagnosed as soon as they could. But it doesn't mean to say we can't improve things for folk in the future does it ? My story is hardly unique and I am sure other people have even more tales of woe to recount regarding their ITP diagnosis. My story is certainly not likely to be as harrowing as some, I am sure.

Another aspect of my ITP experience which has no doubt been one that other purple people have encountered is the lack of coordination between the various parts of the National Health Service/ hospital in my treatment. I have had 2 check up appointments booked in for me with my ITP specialist, in both cases I even had letters to confirm the date and time of the appointments. In both instances I checked in at the hospital in good time for the appointments only to be advised that they had unfortunately made a mistake, they had double booked my specialist

and had to cancel my appointment. Now again, I am sure that other people have had this or worse but it is just so annoying, taking time off work, the costs involved and the stress of it all too. And don't get me started on hospital parking fees !!

So whilst a UK Rare Disease Strategy will not put everything right at an instant at least it does contain commitments to try improve things. If we don't push for the strategy to be implemented then NOTHING will ever change. There are no guarantees that even with a strategy, our rare disease lot will radically alter but doing NOTHING is simply not an option in my view. If you do NOTHING, I can guarantee that you will get NOTHING.

What we can all do is JOIN Rare Disease UK for FREE, because adding to their considerable numbers means the weight of their argument on our behalf grows ever stronger. We owe it to ourselves to press our case. If we don't do it, nobody will. It will get kicked into a field with very long grass.

I am certainly not suggesting that everything is negative because clearly huge strides have been made with the Rare Disease Strategy in the rest of the UK, outside of England. We should indeed be very positive to think that we actually do have a Rare Disease Strategy at all because so many nations do not. But that said, we must get the strategy implemented or it will all have been a waste of time. Of course it is difficult but nothing worthwhile was ever easy !

On March 29th it was finally agreed by Phillip Dunne MP Minister Of State for Health, that a full implementation plan will be developed by NHS England by the end of the year in accordance with the Strategy for Rare Diseases. This is really positive news, albeit I am tempted to say NOT BEFORE TIME. But it's better late than never I suppose. The following link gives a useful update from Rare Disease U.K. <https://www.raredisease.org.uk/news-events/news/government-announces-plans-to-implement-the-uk-strategy-for-rare-diseases-with-nhs-england/>

Until next time when we will be looking forward to ITP September Awareness .....

Platelets Up

Best Wishes



### Useful links for further information...

UK Strategy for Rare Diseases ....  
<https://www.raredisease.org.uk/uk-strategy-for-rare-diseases>

Rare Disease Day 2017 events  
<https://www.raredisease.org.uk/our-work/rare-disease-day-2017-1/>

Leaving No One Behind is the full report on implementing the Rare Diseases Strategy in England  
<https://www.raredisease.org.uk/media/2757/final-for-website.pdf>

To join Rare Disease UK for FREE  
<https://www.raredisease.org.uk/join/>

# News from ITP Centres

We are sure Platelet readers will join with us in sending Dr Drew Provan our very best wishes for his retirement from the Royal London Hospital, although he will still have interests in ITP and remain as our medical advisor.

Dr Tom Butler, Haematology Clinical Lead at the London issued the following statement:

*As you all know, Drew Provan retired at the end of August and we have been working hard to recruit a new consultant to take on the medical leadership of our internationally renowned immunohaematology research and clinical centre.*

*I am really pleased to be able to announce that we have now appointed Dr Vickie McDonald to this role, she will formally start with us late July/early August but is already collaborating with us on various projects. She brings a wealth of clinical and research experience in immune platelet disorders. She has been a consultant at Guys & St Thomas' NHS Trust for a number of years, looking after patients with ITP, TTP and thrombosis. Her original PhD was in the immunobiology of platelet disorders and she has experience in setting up national registries and multiprofessional clinical teams. She has the experience and enthusiasm to hit the ground running and we are all looking forward to her joining us. As well as leading on ITP, she will be joining the haemophilia and thrombosis teams and this aligns nicely with the*

*existing clinical and research activities of the department in a way that should synergise well.*

*I would like to thank Drew for his ongoing support as he has very generously come back regularly to run ITP clinics and provide expert advice, despite his retirement. I would also like to specifically thank Louise Taylor for providing ITP clinical expertise throughout this time, Dan Hart for helping with the clinical trials and ITP registry side of things and several other people who have enabled us to look after our patients in this transition period.*

*We already have several active research programmes and the largest NIHR research portfolio for non-malignant haematology research in the UK. This means we are providing our patients with the most pioneering treatments available as well as engaging in research to develop new treatments.*

*With new leadership and new plans for the future we are looking forward to doing even more.*

We welcome Dr McDonald to this important post at a leading ITP Clinical Centre, and look forward to working with her.

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Our congratulations go to Birmingham Children's Hospital which has received the designation of Overall Outstanding from the Care Quality Commission, and is the first children's hospital to do so. See the CQC report at <http://www.cqc.org.uk/location/RQ301>.

# The PPTA in Prague

by Derek Elston

The Plasma Protein Therapeutics Association Annual Meeting, which took place in Prague on 14<sup>th</sup> & 15<sup>th</sup> March, covered the latest information relative to the extraction and purification of blood extracts for safe use by patients. It was attended by many physicians concerned with the treatment of rare diseases for which plasma products are so vital.

In his annual report the chairman emphasised the problems of supplies encountered in various parts of the world and how they were tackling the problems. He also reported on the strategic goal to ensure the availability of safe, high quality plasma for fractionation. A further goal is the elimination of trade barriers and other discriminatory practices to achieve open access to plasma protein therapeutics globally.

The chairman reported the standards adopted are to be updated to meet 2017 requirements for the prohibition of financial gain about human parts from living and deceased donors.

In 12 years the UK has seen a 93% increase in the use of plasma protein due to prophylaxis in immune intolerance coupled with an increase in life expectancy and available funding.

Immunoglobulin (IVIg) use in the UK has increased to 88gms per 1000 population in 2014 from 28gms per 1000 population in 2002. This has been credited to new patients and longer life expectancy.

Plasma has been declared safe in the USA and Europe despite a recent media

production in Europe which was based on old data and mis-information. This report was centred around blood donors being compensated for donating their blood, thus making blood a commodity on the open market. The presenters stated that blood plasma was more valuable than oil! The report stated that few checks if any were made on the donors or their personal lifestyles especially in the USA. They also stated the USA provides half of the plasma required by Europe to meet the demand.

It is comforting to know, the EU has far reaching legislation covering the collection of plasma and its use. We trust these regulations will continue in the UK after Brexit to safeguard our patients who rely on this product. There are currently meetings being held to discuss the maintenance of the current relationship for research and treatment. Whilst some countries recognise donors by recompense by the state, this is not necessarily considered derogatory, but equally not encouraged.

The plasma collected is screened and treated extensively to eliminate viral infections like hepatitis B and C and type 1 HIV. Every effort is made to ensure the products we are given, are safe and not contaminated.

The patients advocacy body for plasma reported they now have over 60 patient organisations within the group and are concentrating on capacity building within the groups.

*(Derek's visit was kindly funded by the PPTA)*

# News & Views

## ITP in Pregnancy results published

In 2013 the ITP Support Association funded a project lasting over 2 years in which Dr Angharad Care and the team at Liverpool University and Women's Hospital collected data on the current management of severe ITP in pregnancy. Dr Care presented the results at our Convention last September in Bradford-on-Avon, and we were delighted to learn that their article Severe Primary Autoimmune Thrombocytopenia in Pregnancy has just been selected for publication in the British Journal of Obstetrics and Gynaecology.

## Beware driving if on Revolade

One of our members flagged up a warning for Revolade which she hadn't heard mentioned before. The patient leaflet advises: *Don't drive or use machines*

*unless you are sure you're not affected. We thank her for bringing this to our attention so others on this medication are aware.*

## Would children with ITP like to meet?

We heard from the mother of an 8 year old boy with ITP that he feels very isolated with the disease and would greatly benefit by meeting or being in touch with some others of his age with ITP. Because most children with ITP get better quite quickly chronic ITP is more rare than in adults, and as such we have never arranged a meeting for children. We would like to hear from parents of children with ITP to establish whether there is enough interest for us to arrange a get-together. Meanwhile are there any youngsters with ITP willing to communicate with this young lad on Skype?

## 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.

# Patient Safety News

## New organisation to improve patient safety in England

The Healthcare Safety Investigation Branch was launched on 1st April 2017. Although it is funded by the Department of Health this new organisation will function independently with the sole purpose of improving patient safety in England. The HSIB currently has a team of 30 people who have the necessary skills to identify risks, investigate the causes of health safety incidents, and to make recommendations to stop them being repeated, but they will not be focusing on establishing blame or liability. They also have access to independent advisers who have expertise as patients, clinicians, representatives from pharmaceutical companies, manufacturers, and regulators.

Any organisation, group or individual may report a single event or multiple incidents that they believe require investigation using the safety awareness form found on the HSIB website at <http://www.hsib.org.uk>. The HSIB have a criteria to help them assess which reported incidents

should be investigated, and they will be expecting to carry out approximately 30 systematic investigations a year.

The Patients' Association likens the HSIB to organisations such as the Air Accident Investigation Branch which allows professionals involved to give evidence in order to discover what happened without fear of prosecution. The HSIB

## ITP 'Friends'

a listening ear . . . . .

Rhonda Anderson

0208 504 2688

[rhonda.anderson@virgin.net](mailto:rhonda.anderson@virgin.net)

Derek Elston

0151 625 8213

[derek.elston@btconnect.com](mailto:derek.elston@btconnect.com)

Dave Farrow

01664 852218

[davidfarrow40@yahoo.co.uk](mailto:davidfarrow40@yahoo.co.uk)

is being seen as an addition to the current complaints service, not a replacement. Their website asks that any complaints should first be taken up with the place where the problem occurred, and if you are not satisfied then you can escalate your complaint to NHS England, The Charity Commissioning Group (CCG), the Care Quality Commission (CQC) and various

other bodies. It doesn't make it entirely clear where the HSIB fit in, other than the incident must have happened in England after 1st April 2017 and have the potential to lead to significantly better healthcare through improved practices. Every incident will be permanently logged on their database to assist early recognition of problem areas in healthcare.

## We can accept any of the following.

**Any Stamps, old Envelopes\*\*, First Day Covers, Postcards\*\* (including Pre-1940s Birthday Card 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.

PLEASE

NOTE!

Stamps n' All are closing in December so if you have been collecting stamps etc. please send them to us soon.

We will be looking for another collection agency

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

## Organisations covering patient safety incidents in Wales, Scotland and N. Ireland

The independent inspectorate and regulator of healthcare in Wales is the Healthcare Inspectorate Wales <http://hiw.org.uk>. They are responsible for reviewing healthcare organisations or services in Wales in response to concerns raised about a particular incident or events, dependent upon seriousness and/or frequency of occurrence.

The Scottish Patient Safety Programme (SPSP) is part of Healthcare

Improvements Scotland [http://www.healthcareimprovementscotland.org/our\\_work/patient\\_safety/spsp.aspx](http://www.healthcareimprovementscotland.org/our_work/patient_safety/spsp.aspx). The SPSP is a unique national initiative that aims to improve the safety and reliability of healthcare in Scotland and to reduce avoidable harm, whenever care is delivered.

The Northern Ireland Adverse Incident Centre (NIAIC) investigates adverse incidents and provides relevant safety guidance as part of the Department of Health <https://www.health-ni.gov.uk/articles/reporting-adverse-incident>.



## 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 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 R on the back of your cheque if you wish to contribute to the ITP Research Fund)*

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 \_\_\_\_\_ *\*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