SEP 2017

the platelet

JOURNAL OF THE ITP SUPPORT ASSOCIATION

itp
Immune
Thrombocytopenia

ITP NEWS, EVENTS, INFORMATION, PATIENT STORIES, & LOTS MORE INSIDE

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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.

Call for Volunteers!

The Association was run for many years by volunteers alone, but as the charity expanded it became necessary to take on paid staff working regular hours, albeit part-time. We have lost two long-term volunteers this year, and to safeguard the future of The Association we need some younger blood (with or without platelets!) Please email Shirley on shirley@itpsupport.org.uk if you are interested in any of the volunteer opportunities outlined below.

First and foremost we urgently need a Social Media Assistant who can network, tweet, share ITP information and ideas, and monitor discussion content. You don't need to live near HQ but ideally we are seeking someone with a reasonable knowledge about ITP and its treatments who has attended at least one ITP Convention.

Secondly Michael would like an Assistant Treasurer to work with him, with a view to taking over this role in the not too distant future. The ITP accounts use Paxton charity software (which only runs on PC, not Mac). This post would suit an experienced treasurer or accountant. Although much work can be done from home an occasional visit to HQ would be desirable.

Finally, if you have any skills that you think would be useful to us, if you live near HQ and would like to help our with admin, gardening or coffee mornings, or are interested in becoming a trustee when a vacancy arises, do please let us know.

Shirley Watson

(Chair of the Trustees)

Front cover: EHA meeting , Alan Thomas, Phil Platt, Theodore and Sebastian Greenwood

Contents

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 Associaton to enable its operation and to fund vital research into ITP. All donations are gratefully received and acknowledged.

News from the ITP office

by Mervyn Morgan, CEO

As I sit down to write this month's article for the Platelet many of you will be taking a well earned holiday somewhere in Europe, and if the TV News is to be believed you will also be enjoying temperatures reaching around 40°C. However please spare a thought for those of us who remained in the UK, on occasions (more than I care to mention) it has been cold, wet and at times very windy. We even had part of a tree come down at the side of the Platelet Mission but thankfully Frank Watson was at hand to cut away the offending limb before it could do any damage to the side of the building.

It is hard to believe that 12 months have raced by since I joined the team at The Platelet Mission but I must say it is a pleasure to work with everyone involved with the ITP Support Association, a team dedicated to helping its members and those affected by the condition.

Over the summer it has been business as usual at the Platelet Mission, answering enquiries from both members and non-members alike as well as fulfilling the many orders that we are receiving from the online shop. Proving to be very popular at the moment are the wristbands (with September being ITP Awareness Month) and the ITP Recipe Book which contains favourite recipes contributed by ITP patients and supporters.

Membership of the Association continues to grow, with new members signing up every week. Please remember being a member of the ITP Support Association is not limited just to those with the condition, it is also open to partners, family members and friends, in fact anyone who has an interest in raising the awareness of this condition.

The more we can grow the membership the more we can help the Association continue its work supporting those whose life has been affected by Immune Thrombocytopenia. We are also examining other membership options for possible introduction later in the year, these include life and family membership options, updates will be published on the Associations website.

Before I close, as this edition arrives in the post (September) we will be in the middle of ITP Awareness Month, please remember to paint social media purple this September, don't forget to use #ITPaware! You can also purchase Purple ITP Awareness Wrist Bands from our online shop at www.itpsupport.org.uk.

ITP Research Study

Research Study open for adults with ITP

A number of UK ITP Centres are conducting a clinical research study of an investigational drug (PRTX-100) in the treatment of chronic or persistent Immune Thrombocytopenia (ITP). This study is being done to see if PRTX-100 will interfere with the immune response related to ITP and prevent your body from destroying your platelets and to evaluate its safety in individuals with ITP. If you received treatment for ITP and still have platelet counts below 50, or are on no treatment and have a platelet count less than 30, you may be eligible for the trial.

To be eligible for the study you must also:

- Be 18 years of age or older
- Have previously received treatment with one other standard ITP treatment

The following ITP Centres are open for the study:
Hammersmith Hospital (Dr Nichola Cooper – National Co-ordinator for the study)
Royal London Hospital (Prof. Adrian Newland)
Derriford Hospital (Dr Tim Nokes)
University College London Hospital (Dr Marie Scully)
St George's Hospital (Dr Steve Austin)
University Hospital, Southampton (Dr Rashid Kazmi)
Guy's and St Thomas's Hospital (Dr Susan Robinson)

How to register on the study

If you believe you meet the eligibility criteria stated above and are at a participating hospital you should speak to the doctor you usually see. If you are not at a participating hospital you will need to ask your GP or consultant to refer you to the Centre of your choice. In the first instance you may wish to find out what the trial entails by contacting Camilia Vladescu (Clinical Trials Co-ordinator at Hammersmith Hospital) by phone or email and she will talk you through the trial. If you then decide that you would like to take part, you can asked to be referred.

For further information, please contact Camilia Vladescu by telephone on 020 3313 4306 or by emailing Camelia.Vladescu@nhs.net

American Perspective

Professor James George MD
University of Oklahoma Health Sciences Center


Prof. James N. George

Don't Forget Splenectomy: Chapter 2"

In 2010 I wrote an American Perspective titled "Don't Forget Splenectomy". As new treatments are used more often, I think it's time to say again, "Don't forget splenectomy". This American Perspective is focused on adults with ITP.

Splenectomy

In the beginning, there was only splenectomy. Splenectomy was the first and the only effective treatment for ITP until steroids began to be used in the 1950s. During this era, every patient who was diagnosed with ITP and who had severe thrombocytopenia with bleeding symptoms had a splenectomy. Almost 90% of patients responded with an increased platelet count; two-thirds of patients achieved a normal platelet count. In almost all patients who responded, the response was durable for many years. Even in this ancient era before antibiotics and modern transfusions, complications were rare. These observations provide the basis for confidence in splenectomy as an effective treatment for ITP.

Steroids

Steroids suppress the immune system, and therefore can suppress the autoantibodies that cause platelet destruction in ITP. When steroid use began, platelet counts of most patients promptly increased, but also in most patients, platelet counts fell again when steroids were stopped. The side effects of steroids soon became apparent: facial change, mood disorders, bone weakness, risk for infection, and many other issues. In 2017, the most effective steroid treatment is a high dose of dexamethasone daily for just 4 days. This may be repeated at three weeks if the platelet count does not increase. Most patients increase their platelet count and about one-third of patients maintain a safe platelet count (over 30,000) one year later. With use of steroids, splenectomy became the "second-line" treatment for adults.

Rituximab

Rituximab is a stronger immune suppressive drug and it doesn't have the side effects of steroids. Beginning 20 years ago, rituximab appeared to replace splenectomy as the "second-line" treatment. But with more experience we have learned that the response to

rituximab is significantly less than with splenectomy. Approximately half of patients have an initial response, but after 5 years only 20% of patients have maintained their response. Therefore, splenectomy remained the most effective treatment for achieving a durable and complete response.

TPO drugs *(drugs that mimic the natural hormone, thrombopoietin, which stimulates platelet production)*

Beginning 10 years ago, two TPO drugs were approved for treatment of ITP: romiplostim and eltrombopag. Both are impressively effective, increasing platelet counts in about 80% of patients. These drugs must be given continuously (romiplostim is a subcutaneous injection given once per week; eltrombopag is a pill taken daily). When they are stopped, their effect stops in almost all patients. In a few patients, a spontaneous recovery from ITP occurs and the platelet count remains normal when the TPO drug is stopped. The long-term, maybe lifetime, use of these drugs can provide effective treatment, but they are expensive and the long-term risks are unknown, although they appear to be few.

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.

Splenectomy

So what is the role for splenectomy now? After all these years, splenectomy remains the most effective treatment for ITP. Splenectomy provides the highest frequency of durable responses. The other treatments certainly have important roles in the treatment of patients with ITP, and it is appropriate to try other treatments before considering splenectomy. But when other treatments fail, or use of the TPO drugs forever isn't appropriate, splenectomy is always there. It's a treatment that can provide permanent safe platelet counts without need for other treatments.

There are tests in the UK, done by Professor Newland and his colleagues, using radioisotope-labeled platelets to determine whether the spleen or the liver is the principal organ causing platelet destruction. But even when the test identifies the liver, not the spleen, as the principal organ, 50% of patients respond to splenectomy.

Of course splenectomy has risks, as any surgical procedure has. And since the spleen is a principal organ to make antibodies and provide immunity for infection, there is an increased risk for infection. But current immunizations for pneumococcus and other bacteria are very effective, and risk for serious infections following splenectomy is much less than it was a generation ago.

The Bottom Line

Splenectomy remains the most effective treatment for patients with ITP. When ITP is a serious problem, remember splenectomy.

Splenectomy – a dying art?

Last year (2016) was the centenary of the first splenectomy for ITP and until the early 1950s it was the only treatment available. It was often the first, and only, line of treatment and was undertaken liberally. Results were excellent reflecting the fact that many of the patients were treated who did not actually require such definitive treatment. With the advent of newer options, in particular steroids, treatment could be given that supported patients until they achieved a spontaneous remission or responded to the less drastic therapy pushing surgery further down the line.

Steroids became the mainstay of treatment from the mid-1950s and were used extensively despite their well-known side-effects and long term complications. There is no doubt that steroids currently remain the first line treatment of choice but with our current understanding the aim is to give as little as possible for as short a time as possible. We know that for the patient who is refractory, or rapidly relapses, there is no value in continuing on a high dose. Lower doses may have some value in combination with other treatments but this needs to be determined on an individual basis. There can be no hard and fast rules. The type of steroids used varies throughout the world and there is no good evidence that one type, or dose level, is better than another. This remains an issue of local experience and patient preference.

Splenectomy has remained established as the 2nd line treatment of choice, in view of the historical understanding of its high level of response, and until recently has remained so. The surgery itself is relatively straightforward and trouble free, and is particularly so if laparoscopic surgery is available. However, it is an operation and does remove a substantial part of the patient's immune system and does require life-long protection against infection. For the patient who responds and requires no further treatment the outcome is excellent but for those 40% who either do not respond, or later relapse, there are significant risks of infection despite the use of immunisations and penicillin. This is particularly the case for patients receiving subsequent immune suppressive treatments and there is an associated mortality. Whatever our views as clinicians, patients are aware of these issues (and the alternate treatments now available) and the rate of splenectomy in the western world has dropped dramatically. Patients are less keen to undertake surgery where the ultimate successful outcome is little over 50% and for the majority there is no attempt to determine who will respond.

For the latter part of the 20th century the only new treatment available was intravenous immunoglobulin, introduced in the early 1980s. This was particularly effective in raising the platelet count quickly and in many patients was steroid and splenectomy-sparing. It was however a blood product and in the early days was associated with some risk of virus transmission. This is not now the case.

The development and introduction of Rituximab in the early 2000s seemed a 'game-changer' in terms of the early platelet responses, however with experience we now know that only 20% will have responded after 5 years. However, for those who do respond the treatment may offer them many months off all treatment and that is worth considering on an individual basis.

The major innovation was the advent of the thrombopoietins for patient use around 2007-8. The level of response was beyond anything previously seen and this has been maintained over the last 10 years. We have also seen that over this extended period of use the adverse effect profile is very acceptable compared with the alternate treatment options, although continued vigilance is important. It has been generally considered that the use of either Romiplostim or Eltrombopag need to be given long term for a continuous effect but recent studies have shown that nearly a third of patients can be weaned of them and maintain reasonable platelet counts off all treatments. This is being explored further as is their use much earlier in the course of the disease, and in combination with other treatments. While it remains currently expensive as with all treatments prices will fall as more competitors enter the market.

So where does that leave splenectomy? It remains the only curative treatment for a proportion of patients but we know it is not without problems. The use of radioisotope labelled platelets can guide treatment decision-making. For the patient with predominant liver destruction of their platelets, although they may see an immediate increase in platelets post-operatively this is rarely maintained and the response at 5 years is less than 20%. This is the same response rate we have discussed with Rituximab, and more importantly the same rate that is seen with those with liver destruction who have not undergone surgery. Targeted surgery should be offered and this is now increasingly the case in Europe where isotope scanning is available. In those with predominantly splenic clearance of platelets results may approach 90% and is a valuable treatment option. The old adage of saving splenectomy for when the patient has failed to respond to other treatments is only choosing those patients who are most likely to fail and is an approach that cannot be supported.

We increasingly see patients who have favourable splenic studies but prefer to defer surgery while exploring some of the newer treatment options. If your platelets respond to a thrombopoietin to prepare you for surgery why proceed?

We are entering an era where many new agents are being developed that are based on our increasing understanding of immune function and molecular mechanisms and that target the pathways of disease. Many of these are currently undergoing trials and while some will undoubtedly fail, some will not. We wait with great interest and some excitement.

Splenectomy should no longer be considered a routine second-line treatment and should be reserved for carefully defined patients after appropriate study who fully understand the options.

Professor Adrian Newland CBE,
Professor of Haematology,
The Royal London Hospital, Barts Health NHS Trust

My ITP Journey

by Guy Penny

ITP the beginning

In March 2014, I contracted a vicious virus and remember sitting in the sun and feeling all my energy draining away. Later Lavinia, my wife, said she thought I was slipping away before her eyes. I got over it but had no energy. I now realise it was probably the platelet count diminishing, it has occurred several times over the past three years.

I had a call from Dr Brace, my GP, in April 2014 my platelet count had been in the 200s for the previous five years but had dropped to 75. She organised a blood test in May and the count was 53, it was agreed that another test would be done in June.

This time the count was 7 so she emailed The Conquest Hospital and I had an appointment two days later, by that time the count was 4. ITP was diagnosed.

How did I feel?

- Eternally tired
- No concentration
- I stopped socialising with friends
- Very grumpy
- Sat for long spells saying very little

All these are alien to me, I always kept up with friends and arranged a Christmas get together with former work colleagues. My work ethic was hard but enjoyable and I could put in long stints to get things put right. I am NOT a grumpy person and do not recognise myself as saying very little. Each year we visited a different country — that stopped.

How I coped

In 2014, I computerised the accounting system at my daughter's company, it was a difficult and time consuming task not helped by the problem of keeping my concentration on the task. It took twice as long as it should have done, but I needed a task to keep me motivated. If I had not had it then I would have sat and wasted away. The work was completed in four months and I took on a Finance Manager role to bed it down and improve the systems. All year I did not contact my friends.

However, I was on a course of steroids which gave me a lot of energy which I applied to several jobs around the house:

- Gutted the garage and put in a racking system for storage space
- Worked in our woodland to clear rhododendron and cut up fallen trees for firewood.
- Split the logs and filled the log store.

By the end of 2014 my platelet count was 30.

2015 saw little progress with the platelet count and in July it fell to 12. It was at that point I discovered I was on half the recommended dose of mycophenolate, it was agreed that the dosage would be doubled and by August the count was 95. However, each month thereafter it fell away.

In January 2016, I started with the UCLH (University College London Hospital) Haematology Unit. I was asked to run down the steroid in-take and was off them within ten days, with no reaction. But by March I caught another virus and the illness continued through to October. At a meeting, I said that I could not go on and it was decided to stop the mycophenolate and was introduced to eltrombopag. By the end of November, the dosage was halved as my count was 127 and at the beginning April 2017 it was halved again as the count had risen to 221.

I have recovered a lot of my joie de vivre and have started meeting my friends and going out for meals. Almost all have said they were worried when I first took ill and are amazed to see the difference three years on.

Before 2014 if I was asked how I was, I would say "TERRIFIC", now in 2017, once again I can use that expression.

[Ed: Thank you for sharing your experiences with us. I'm sure a lot of Platelet readers will empathise with your feelings in the three difficult years but it is excellent news that you now feel terrific again.]

ITP Patient Day

at Hammersmith Hospital,

W12 Conferences, Du Cane Road, London, W12 0HS
Fri 22 September 2017 from 3pm to 6pm

This is a great opportunity to meet the ITP team at Hammersmith Hospital and put forward questions about your condition. The programme will include guest speakers (both doctors and patients) and there will be time to network with other patients. You will be provided with updates on the clinical management of ITP and current ITP research projects.
Open to patients from any hospital. Carers and family/friends are also welcome.

The number of tickets available is limited so book your free ticket(s) on line at:
www.eventbrite.co.uk/e/hammersmith-hospital-itp-patient-day-tickets-36651545760
or contact

Camelia – email: camelia.vladescu@nhs.net Tel: 020 331 34306

Deena – email: deena.paul@nhs.net Tel: 020 331 38118

A Doubly Happy Event!

by Katie Meloy

After returning from the 2016 PDSA convention in the USA last August, me and my partner were shocked to find out that we were having a baby. We had previously talked about how my ITP could potentially become troublesome and interrupt my year-plus remission if we were to ever try for a baby. The news was a surprise to us both, and at our 12 week scan, it was even more of a surprise to find out we were pregnant with not just one little ITP baby, but ITP twins!

My immediate concern was that my platelets that were happily sitting in the 150s would drop and cause problems for me and my unborn babies, so after speaking to my doctor and midwife, we organised to have 4 weekly blood tests done to measure my platelets. Due to the complications of having identical twins, we had two weekly scans with our fetal medicine doctor to check on the babies' growth.

At 21 weeks pregnant, after maintaining stable platelet counts and having a healthy pregnancy we found out that our boys had Twin to Twin Transfusion Syndrome (TTTS)* and we would need to undergo laser ablation surgery in London to save both of their lives. Luckily my platelets stayed stable making it possible to have the surgery and with only a 33% chance of the boys surviving, thankfully, they pulled through.

Four weeks later, at 25 weeks and 5 days pregnant, my waters broke and I went into labour. I was rushed to the Jessop's Wing in Sheffield where there was space for me and my babies. On arrival the doctors managed to stop the labour, however my placenta was starting to slowly come away from my womb. We managed to hold on until 28 weeks pregnant when I went into labour again and my boys were delivered by emergency C-section. I can only thank

ITP Charity Shop to be sold!

Celina Baxter and Gloria Doyle have been running The Charity Shop since 2009 and have raised a huge amount of money that has gone towards ITP research and the building of our HQ. Sadly they are unable to continue because of Celina's poor health and Gloria's wish to retire (for the 2nd time!) . The shop is being sold as a going concern, but the new owner may not wish to support ITP even if it does continue as a charity shop.

Gloria and Celina send their gratitude for all the contributions from Platelet readers over the years, and they intend to keep the shop running until it is sold.

For anyone interested in buying this business (and flat), tel: 01493 493229 or go to www.rightmove.co.uk/commercial-property-for-sale/property-59615413.html

my body for keeping my platelets stable, whilst betraying me and my boys in their bitter sweet birth. Had my platelets have been low I'm not sure what the outcome of our journey would have been.

Sebastian Thomas Greenwood and Theodore Felix Greenwood were born on the 8th January 2017 weighing 2lb 6oz and 1lb 12oz. For the first couple of days after they were born they struggled to keep their platelets above 10 whilst their tiny bodies thought to be here but they got stronger every day and the rest is history. After my C-section my platelets temporarily dropped to the 70s, however they bounced back very quickly without intervention. Today my boys are doing amazingly well and make me so proud of all of the hurdles they have overcome and continue to overcome.

I am so blessed and thankful for Seb and Theo and even through all the worry and hurdles they are worth it. So my only advice to other women with ITP thinking of having children is to take every day as it comes. You may have a simple happy, healthy pregnancy with no complications; or a pregnancy and birth that is massively impacted by your platelets; you may even have a extremely complicated pregnancy and birth that has nothing to do with ITP. But, no matter what complications you may have to overcome, when you hold that small little person and those tiny little fingers are wrapped around yours, it makes it all worth it.

[Ed:] We often hear people say they feel they are on a roller coaster with their ITP, but my goodness Katie, your pregnancy sounds like a real white knuckle ride in the last 7 weeks! I'm so pleased all went well in the end, and you gave birth to two small but healthy boys. I'm sure Platelet readers will echo my very best wishes to you, your partner and the gorgeous twins.

Twin to Twin Transfusion Syndrome, affects identical twins who share a placenta. TTTS is not related to ITP but is caused by abnormal connecting blood vessels in the twins' placenta. This results in an imbalanced blood flow from one twin (known as the donor) to the other (recipient), leaving one baby with a greater blood volume than the other. This can cause serious problems to both babies.

There is comprehensive information about this syndrome at www.tttsfoundation.org and on Wikipedia and NHS Choices websites.

Fantastic Fundraisers!

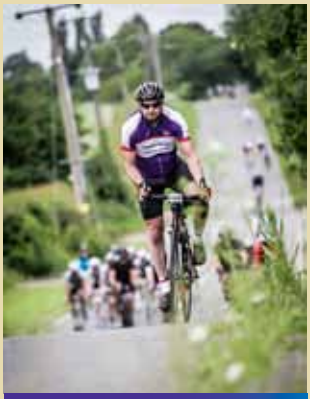
We are extremely grateful to **Ben Simona** of Wates Living Space in Middlesex who organised The Wates Charity Golf Day. Ben explained "We will be playing golf with all our supply chains and hope to raise lots of money for The ITP Support Association". They certainly did, shooting past their target of £3,000 to raise an amazing £4,055. We send our sincere thanks to them all.

Yattendon School, Horley, Surrey has four house teams - Churchill, Pankhurst, Gandhi and Macarthur. Over the course of a year the children and staff organise fundraising events with all profits split between 4 charities, each nominated by a house teams. The children from Churchill house team chose to support ITP. Churchill house chose to support ITP and we were delighted to receive £363.00. Our gratitude goes to all the children and staff for their superb efforts.

The ladies of **Farnham Tangent Club** from Farnham, Surrey have been supporters of The Association for a number of years and very kindly sent a recent donation of £200 from their funds to assist our work. We also received a cheque for £200 from **Kevin O'Shea** in respect of donations by colleagues for his retirement collection. We are most grateful to him for thinking of our charity and wish him a long and happy retirement.

Alannah with her Nanny at the boot sale

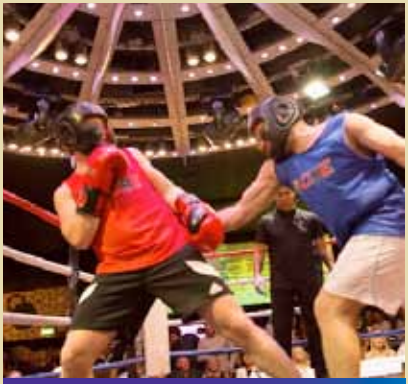
Ella Baxter's 7 year old daughter **Alannah**, who has chronic ITP, designed a poster and collected items to sell at a car boot sale in July, with help of her Nanny. Alannah raised the excellent sum of £150 which she donated to The ITP Support Association. Ella told us 'ITP was diagnosed in 2015 with a platelet count of 2. At the last count the platelets were at 50 so fingers crossed that they will continue to rise, but it's been a very slow process with many ups and downs. Alannah has amazed us with how she has embraced her condition and how she continues to live life with great enthusiasm and humour. She is keen to raise awareness and help other, especially children going through the same thing." Very well done Alannah and Nanny!



Alan Thomas

Alan Thomas raised a cracking £362 for the Association, explaining "I've always been sporty having enjoyed playing football and jogging for many years, but in recently I've taken up cycling (too old for football now!). Having just signed up for my first road race this summer, the Tour of Cambridgeshire Gran Fondo I thought it would be great to raise money for the ITP Support Association, as my nephew Leo suffers from ITP. I am hoping that this will be the start of my fundraising efforts for ITP and look forward to many more fundraising events in the future." We send our congratulations and gratitude to Alan for his very successful efforts both in cycling and fundraising.

Phil Platt also decided to take up something new - white collar boxing. He told us "I decided to step into the boxing ring (something I've always wanted to do) and box for a good cause. The toughest part was the 8 week training and dieting. The ITP Support Association is the charity I have chosen because my 5 year old girl Evie has ITP and I would like to raise money for the care Manchester Children's Hospital has given Evie over the past 12 months." Phil raised a splendid £193 for which we send our warm appreciation.



Phil Platt (in red)

Angela Cox sent £411 in respect of £211 proceeds from her collection box and £200 donation from a fundraising dinner party. We are extremely grateful to Angela for her support, and to everyone who so generously contributed.

A hearty thanks goes to **Patti Pitt** (whose Heartsease folk dancing group chose ITP as their charity of the year) who kindly sent us £80 collected for ITP in lieu of presents for her birthday in June, to **Atlas Trading Group Ltd** in who sent another £70 from their collection tin, and to the **Hope Baptist Sisterhood** for their kind donation of £75.

Last, but certainly not least, The Charity Shop sent yet another wonderful donation of £1500. Once again we record our heartfelt appreciation to Gloria, Celina and the volunteer team.

CONDOLENCES

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

£551 was received in memory of **Elizabeth Budge**

£195 was received in memory of **Mark Reid**

£50 was received from The Music Makers Club of Co. Durham in memory of **Lorna Stobbs**

An Athlete's ITP Story

by Jonny Mellor

Every athlete has their own individual story, with different struggles and triumphs along the way. More often than not these struggles are running related injuries and illnesses, but not always! Like the majority of runners, I've had my fair share of injuries, but along with injuries, back in November 2014 I was diagnosed with ITP.

I was away in Kenya, a country not very well known for their medical facilities, at an altitude training camp that I first started to notice the symptoms, bleeding from my gums and random bruising over my body. Convincing myself it was nothing to worry about I cracked on with training until a few days later whilst having a small blood sample taken for lactate levels during a training session by the camp physiologist, I could not stop the bleeding for over 2 hours. A trip to Iten hospital followed and then down to Eldoret hospital where bloods were taken which revealed my platelet level was at 20. After discussions with the British Athletics endurance doctor, it was agreed that I needed to be flown home the next day for further tests. So unfortunately this meant an early end to my altitude training camp. I had hoped to be returning from altitude with some blood rich in red blood cells, but instead I was leaving with some blood very poor in platelets!

Back on home soil the next day, I had repeat blood tests which showed a further drop in platelets until I literally had none left! Not a very good position to be in and so I was referred to a consultant haematologist for further investigations and management. It was quite a stressful time, because at this stage the cause was very much unknown, and certain conditions which can cause low platelet levels such as leukaemia and HIV needed to be excluded, which added a great deal of stress and anxiety.

Treatment was started straight away, but unfortunately it was not without side-effects. First line treatment was daily prednisolone that had negative side effects including weight gain, loss of bone density (12 months later I was diagnosed with bilateral sacral stress fractures – my first ever bone related

injury at 28 years old). Running was out of the question until my platelet levels were higher, because of the potential risk of bleeding if I were to injure myself out on a run. The treatment, the potential for this to be a life long condition and the lack of knowledge available as to whether I could ever compete or even run again meant it was an uncertain and anxious time, but I had some great support off my family and friends to keep me thinking positive and smiling.

Without going into too much detail, the next few weeks and months probably weren't the easiest of my life! It involved regular hospital tips for various treatments and blood tests to monitor my platelet levels, and the worry as to how this condition could not only affect my running, but also my life!

It's almost three years down the line since I was first diagnosed, I still has monthly appointments with the hæmatologist to monitor platelet levels. I'm on regular treatment and having had the option of either having a daily tablet to take orally or a weekly injection I opted for the daily tablet of Eltrombopag as I didn't fancy a weekly trip to the hospital for an injection or one of my housemates injecting my bottom once a week! I think my housemates are glad I went for that option too! Despite treatment, my platelet levels are still well below normal levels fluctuating between 30-80. After the first few months of uncertainty when I was unsure as to whether I'd ever be able to get back running and competing at an elite level, I'm in a position now where my ITP is well managed. Whilst I'm still not out of the woods, I managed to get back to winning ways within just 9 months of my diagnosis by winning the British 10,000m championships in the May of 2015 and was third in the British 5,000m championships a few weeks later.

Towards the end of 2015 and into 2016 though I was struck down with a series of bone stress injuries that were partly related to the treatment I was taking earlier in the year. Since then I have a stable treatment program that allows me to train properly and I have had some great performances so far in 2017 including a PB 62.23 clocking at the New York Half Marathon and 28.55 for 10km on the road at Schoorl in the Netherlands. The London Marathon didn't go as hoped in April but I plan to run another Marathon again in Berlin this September with a target of 2:14 to aim for qualification for the Commonwealth Games in April 2018.

It's been a bumpy road over the past few years, but I would like to give a huge thank you to all those that have helped me along the way!

THE ITP PHONE APP IS COMING SOON!

To be known as

The ITP Pocket Log,

work is continuing on the ITP phone app which will be launched by the end of September.

How Sick Are You Then?

by Rhonda Anderson

The short answer is, it is very hard to tell. I had an experience whilst on holiday in Krakow this year in June, and I think it is relevant to people who are asplenic as I am. We jog along and nothing happens and we think nothing will ever happen, and that is good, as it is not wise to drive yourself mad with anxiety. However, one must be prepared. Fortunately I was.

The weather was quite hot, we were out and about all day, every day, and I probably hadn't drunk enough water, which I usually do. I had been getting less sleep due to the heat and the hotel bed, although comfortable, not the same as being at home, so feeling tired. The food was tasty, but it was different and much richer with cream sauces, so my tummy was less than happy.

My sister and I were not with our holiday group and went on a river cruise which was fine. I don't get travel sick and the water was very calm. On the walk there I didn't feel 100% well, but it wasn't far and the trip was all sitting down. On the river I felt very tired and a little sick. When we got off the boat I said I needed to sit down. We did so on some nearby steps, then I fainted. I have never before fainted in my life. Through all the blood tests, two bone marrow biopsies, several operations for other things and so on. I am Australian and the heat there never made me faint. Unbeknown to my sister and me, someone had called an ambulance. People were very kind. A couple of ladies who had been on the boat assisted and a young English couple who were walking by. I got into the ambulance and with some repetitions got the message across. Fortunately one of the medics spoke goodish English. They took my blood pressure, blood sugar and blood oxygen levels and said all was OK. The BP must have been a little low as they asked me if I was fit. I said, Yes! I do Yoga! In fact I do have slightly low BP. They asked me if I wanted to go to hospital, but since everything was OK, I thought it was not necessary.

This is where the preparation came in. I asked if I had to pay anything. They said no, but needed identification. I had my EHIC card (The European Health Insurance Card) with me, and after a quick look at it they were happy, and I got out of the ambulance. In fact I had just renewed the card as it ran out before the beginning date of the trip. If you don't know about this free card then it is a good idea to look it up, apply, and have it for all European travel. Things are going to change, perhaps, but for now it goes along as usual.

It was the last night of our trip and the group had a table booked. We went on later and I really didn't want much to eat which was a shame as the food was really delicious. A delightful waiter got me some light food. I asked a nurse if I should take my emergency antibiotics and she advised me to. I always carry Co-Amoxiclav with me. On return I went to see my GP who thought I may have had a urinary infection, but all tests came back negative.

This is probably an appropriate time to revise the advice on taking antibiotics after splenectomy. I did take Penicillin V every day for many years post-splenectomy in 2000. My consultants insisted that I did. Then I got a new consultant and he agreed that I needn't take the antibiotic every day. I was pleased. However, a friend of mine who had a splenectomy a longer time ago, who didn't take antibiotics, has recently been put on them. In America antibiotics are not routinely prescribed for asplenic patients, but they do have an emergency supply. This illustrates how varied the advice is. You must ask your own consultant to see what is best for you because every patient is an individual and your medical team know you.

The NICE Guidelines do recommend lifelong antibiotics. You should also have your vaccinations updated and keep a record. I always have the 'flu jab every year and check if I need anything else topped up, such as Pneumococcal Vaccination which lasts for 5 years. Again there are various opinions as to the frequency of these vaccinations. You can look up on the net more information about all these issues, or ask your medical team and/or pharmacist for advice. The ITP Support Association produces an excellent, comprehensive booklet on splenectomy and living without a spleen.

Fortunately I was prepared with my antibiotics and the health card. Of course I also had travel insurance. I wear a Medic Alert bracelet which is old and this incident has made me realise I need to renew it soon. Also in my purse I have the ITP Emergency Card saying I am asplenic.

I have fully recovered and shall probably never know why I fainted, but 'be prepared' is the moral of the story.

Ed: Comprehensive research-based information on post splenectomy vaccinations and antibiotics can be found at ***https://patient.info/doctor/splenectomy-and-hyposplenism***

Have You Heard?

by Anthony Heard

THE HISTORY BOY

As I have started writing this article on Friday July 28th, it is exactly eleven years to the very day that I was diagnosed with ITP. It still gives me a certain shiver of anxiety thinking back to that awful day in 2006 when my purple odyssey began. Since then there has been plenty of drama, the odd tragic moment, and a fair share of comedy along the way. My very own purple epic !

Like many a milestone, the eleventh anniversary of my ITP diagnosis got me thinking and reflecting a bit on a number of fronts. I have been through quite a few hoops during my purple years. I've ridden the Prednisolone roller coaster five times, the Rituximab merry go round twice and the Azathioprine house of horror once (it made me so sick I couldn't tolerate it beyond three days). But since April 2016 I've been taking Mycophenolate Mofetil (MMF) and it has worked wonders for me. I just wish I'd have got there earlier. But it's always easy with hindsight isn't it ?

All that said, I also realise that my ITP has taken up quite a lot of my time and energy, including, of course writing this very column for nearly seven years. It has also included setting up, posting out regularly and managing all of the ITP Support Association social network forums (Facebook, Twitter, HealthUnlocked, LinkedIn).

I also have my own ITP blog running too, so it has been quite a commitment. That said, I have really enjoyed being involved and hope that I have been able to make a positive contribution along the way to the purple cause.

So you can probably guess by the tone of the last paragraph, that I have decided to step down from doing any further voluntary work for the ITP Support Association from now on. Obviously it means that this will be my last Platelet article and I won't be active any longer on our various social media platforms. To be honest, I have just got so many other commitments and things that I have been meaning to do for ages and really don't want to put off any longer. I will carry on updating my own ITP blog once each month so my personal purple journey will still be recorded if folk want to see how I'm going. The blog is called My Purple Patch and many people have viewed it regularly since I started it last year (nearly 13000 views I think). I hope that it has been useful and informative.

I thought that as September ITP awareness month is now upon us again, I would conclude by setting out some of the key moments in ITP history. After all, our own personal purple stories are just a small part in the long and tricky tale that is ITP. We are all a part of its' history and let us hope we can all contribute to some solutions in the future. Here are some key land marks so far .....

1. After initial reports by Portuguese physician Amato Lusitano in 1556 and

Lazarus de la Rivière (physician to the King of France) in 1658, it was the German physician Paul Gottlieb Werlhof who in 1735 wrote the most complete initial report of the purpura of ITP. Platelets were unknown at the time. The name "Werlhof's disease" was subsequently used until more recent times.

2. In the 1880s several investigators linked purpura (bruising) with abnormalities in platelet count. The first report of a successful therapy for ITP was in 1916, when a young Polish medical student, Paul Kaznelson, described a female patient's response to a splenectomy. Splenectomy remained a first-line remedy until the introduction of steroid therapy in the 1950s.

3. A greater understanding of ITP came as a result of a series of experiments in 1951 by scientists Harrington and Hollingsworth. They confirmed that something in the blood of ITP sufferers was the cause of the low platelet counts being seen in ITP patients.

4. The name given to ITP was changed from Idiopathic Thrombocytopenic Purpura to Immune Thrombocytopenic Purpura from 1951. More recently it has become known as Immune Thrombocytopenia although it is still most commonly known by the letters ITP.

5. Corticosteroids were introduced to treat ITP in the 1950's and a number of other immune suppressing agents like Azathioprine have used since the 1960's.

6. IVIG - Intravenous Immunoglobulin was first used to treat ITP in 1980.

7. The ITP Support Association was founded in the UK in 1995 by Shirley Watson MBE. It became the first support group for ITP sufferers and their families anywhere in the world.

8. The Platelet Disorder Support Association was founded by Joan Young in 1998 to support ITP sufferers and their families in the United States

9. Following research by Professor Julia Newton in 2009 fatigue was finally recognised as a symptom of ITP

10. The International Consensus Report on the Investigation and Management of ITP was published in 2010.

The only way I can think of to sign off for this final time is in the usual way and as ever...

Platelets Up !

Best wishes

That's All Folks !

Anthony will be a huge loss to the ITP Support Association, and on a personal level I will miss his enthusiasm and support enormously. He built up our social media platforms from scratch and has worked tirelessly over these seven years despite struggling with ITP himself. He has made a real difference to ITP patients' lives, and I'm sure the Association wouldn't have our lovely ITP HQ today if it wasn't for Anthony's efforts in plugging our Buy a Brick campaign on social media.

Dear Anthony, you should be very proud of your achievements for the Association and people with ITP, and we wish you happiness and plenty of platelets as you move on to new ventures.

Shirley

Seen at an ITP Clinical Centre?

PLEASE COMPLETE A FEEDBACK SURVEY . . .

The ITP Support Association was instrumental in bringing together leading ITP clinicians in Sept 2011 for the purpose of establishing a network of recognised ITP centres of excellence around the UK. In the six years that have followed, many patients have requested referrals to these ITP Clinical Centres, and the Centre Directors are running a very active ITP Forum which coordinates their expertise to encourage better management, research and clinical trials.

We are now inviting feedback from patients or parents who attend one or more of the ITP Centres listed opposite to assess whether they are meeting your expectations. ITP can be a difficult disease and as we recognise that it is more likely to be patients with problematic ITP who ask for a referral, we are interested in knowing about your overall experience of attending your ITP Centre rather than how successful they has been in raising your platelet count. If you or your child are being seen, or have been seen (even on a one off occasion) at an ITP Centre we would be most grateful if you would complete a survey at: **https://www.surveymonkey.co.uk/r/KHP 7YTD**
If you don't have internet access you can still participate by answering the questions on the survey form opposite and posting it to the ITP office (address on pg 2) . Your answers will be kept confidential – only the result summaries will be shared with ITP Clinical Centres to help them continue to strive towards the highest of standards.

ITP CLINICAL CENTRES

The Royal London Hospital
Manchester Royal Infirmary
QE Hospital, Birmingham
Glasgow Royal Infirmary
East Kent Hospital Trust
University Hospital of Wales, Cardiff
Belfast City Hospital Trust
University Hospital of Coventry & Warwick
University Hospital of Leicester
University Hospitals Southampton
Aberdeen Royal Infirmary
Bristol Royal Infirmary
St George's Hospital, Tooting
Guys and St Thomas Hospital
Norfolk & Norwich Hospital
St James University Hospital, Leeds
Oxford University Hospital
Newcastle upon Tyne Trust
UCLH (University College London Hospital)
Addenbrookes Hospital, Cambridge
Hammersmith Hospital
Derriford Hospital
Royal Manchester Children's Hospital
Evelina London Children's Hospital
Birmingham Children's Hospital
Edinburgh Children's Hospital
Children's Hospital for Wales
Sheffield Children's Hospital
Leeds Children's Hospital
Belfast Children's Hospital
Royal Aberdeen Children's Hospital
Great Ormond Street Hospital
Bristol Royal Hospital for Children

ITP CLINICAL CENTRE FEEDBACK SURVEY

Please complete this survey if you have attended an ITP Clinical Centre (listed opposite) any time since September 2011.

If you've been seen at more than one ITP Clinical Centre please use a separate form for each.

1. *Centre Name* _____

2. Did you specifically ask to be referred to this Centre or the doctor running the Centre? *Yes / No*

3. When did you last visit the Centre? *(month/year)* _____

4. Are you completing this survey as an ITP patient or the parent of a child with ITP? *Patient / Parent of child*

5. What is the name of the doctor in charge of your care? _____

6. Does your doctor have a treatment plan for you? *Yes / No / Don't know*

7. Have you ever had conflicting advice from different doctors in the team? *Often / Occasionally / Never*

8. Is there an ITP specialist nurse in the clinic? *Yes / No / Don't know*

9. Are the staff friendly, polite and attentive? *Yes / No*

10. Are you given time to ask questions or express concerns? *Yes / No*

11. Do the team attempt to answer your questions (bearing in mind much is unknown in ITP) *Yes / No*

12. Are you happy with your doctor's efforts to manage your ITP? *Yes / No*

13. Have you ever felt pushed into having an ITP treatment you didn't want? *Yes / No*

14. Have you ever been refused an ITP treatment you did want? *Yes / No*

15. Have you been given clear instructions about any medications and know that you need to take them as prescribed. *Yes / No*

16. Were you told about any possible side effects from your medication? *(Yes / No)*

17. Have you been offered the opportunity to take part in any clinical trials or studies? *Yes / No*

18. Have you been given a number to ring in case of emergencies or urgent enquiries? *Yes / No*

19. Has the overall quality of care met your expectations? *Yes / No*

20. Were you offered information about the ITP Support Association during your first visit? *Yes / No*

21. If you were referred to the Centre from your local hospital please list up to 3 reasons why you prefer the ITP Centre:-

1. _____

2. _____

3. _____

22. Do you have any improvement suggestions for your ITP Centre?

_____

_____

23. On a scale of 1 to 10 (1 = very poor, 10 = first class) please rate your ITP Clinical Centre? _____

Any comments?

2017 EHA Conference

by Derek Elston

EUROPEAN HAEMATOLOGY ASSOCIATION

ANNUAL CONFERENCE

MADRID, JUNE 22nd – 25th 2017

Near forty degrees of heat is not the most desirable temperature in which to attend any conference, but thank goodness, the heat in Spain is somewhat dryer than here in the UK and the conference centre was air conditioned.

The conference was held at the IFEMA Conference Centre located on the outskirts of Madrid approximately 5 minutes from the international airport.

Again this year, the conference was attended by over 10,000 delegates from all four corners of the world, all with a common interest in BLOOD and the problems that affect us all. Undoubtedly, malignant conditions are more common than non-malignant when it comes to research. Never the less, non-malignancy conditions are equally important and rightly demand attention.

The conference programme was full of sessions endeavouring to cover as many blood ailments as possible. Sadly, with the sheer number of blood conditions, this is not possible to achieve, especially with the advancement of science and research finding derivatives of already known conditions.

There is always a very large representation from the pharmaceutical companies and the advocates booth was visited by many of our old friends from Novartis, Spire and Amgen.

This year there were more than 450 talks or sessions spread over the four days of the conference supplemented by poster sessions. Presentations are given by members of the EHA from many different countries on their specialist subjects and allows the opportunity for delegates to question the presenters on their research and findings. This is a most valuable medium for all to learn the latest information available and to 'network' with others in different countries.

The poster sessions, held at the end of the day, present in a visual format results of research and drug trials. These are usually prepared by a group of specialists in their particular fields who are on hand to discuss the available information.

Dr John Grainger,(UK,) one of our own paediatric advisors, presented a poster on the long term efficacy and safety study of Romiplostin in children with ITP. His co authors were Prof. Jim Bussell (USA); Dr Nichola Cooper, (UK,) Dr Michael Tavantino (USA); Prof. Victor Blanchette (Canada); Dr Jenny Despotive (USA); Dr Alexy Maschan (Moscow); Dr Nancy Carpenter (UK); DR Mellis Eisen (USA); Dr Bhakti Mehta (USA). A truly international collaborative survey with the aim to assess platelet response in

children with ITP receiving Romiplostim.

The result for year one on an open label study of Romiplostim, indicated that there were NO new safety signals. NO effects of Romiplostim were observed on the bone marrow in the subjects of patients with bone marrow biopsies. Data would be extracted and analysed in year 2 and 3 rather than cut. Future data extracts taken from years 2 and 3 of the study will be the largest on Romiplostim in children with ITP, with an accumulation of 79 years exposure to data. This will provide more information on platelet response, dosage, requirement and safety.

Prof James Bussell (USA) was part of a team from the USA; Poland and Czech Republic with a presentation on platelet disorders and a trial study on Fostamatinib. This was undertaken on 150 patients all with chronic, long term ITP with counts under 30. The study concluded that this new drug substantially improves platelet counts with pre-treated, severe chronic ITP patients of long term duration. If this drug is approved, it could be an important alternative as a single therapy in certain situations.

In respect of patient advocacy, EHA have embraced and promoted the importance of patient involvement and participation in their international conferences. I am very pleased to have been a part of this development over the last few years representing ITP internationally, together with advocates representing other conditions from all over Europe. We have witnessed patient advocacy growing in importance, and this year the patients' advocates were granted 2 separate business sessions on the Saturday morning, in addition to a capacity building session for advocate members on the Thursday at the start of the conference. The first session was entitled *Innovative Clinical Trial Designs, Adaptive Pathways and Patient Involvement*. This session lasted an hour and a half with speakers from France, Germany, USA and the UK.

The second session on the same day, which was specifically related to myloma, was entitled *Pregnancy During and After Treatment: Myths and Reality*. Speakers were from Germany, UK and Spain.

At both sessions, the halls were full with clinicians and other delegates. One session over flowed into an adjoining room. This emphasised the change in attitude of many medical personnel who may have needed persuasion that patients' voices should be heard and had an important role to play.

Patient Mentors

a listening ear . . . . . .

Rhonda Anderson
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The advocacy group has grown and flourished. The future is now firmly set in the programme for EHA conferences. The work group, which comprises one representative from each condition, is to be re-organised into a more formal group with structure and we hope some secretarial assistance from The Hague. It is also hoped there may be some funding to assist patient groups to attend.

Steps were taken this year to unify the patient's booth in the exhibition hall and comprised one long table top for literature and a back cloth printed with the logos of each medical condition represented. The booth was situated in a predominant position in the exhibition hall and would have been passed by most of the delegates at some time during the convention on their way to collect their lunch box or visit another booth.

Thankfully we had some leaflets left from last year in Copenhagen which our good friend Davy from Copenhagen had stored and transported to Madrid. In addition, Mervyn prepared a QR code which was firmly attached to the desk for delegates to scan onto their phone or tablet. This enabled them to have access to our web site and to register their interest in ITP and then later, to log on and download any information they may require. It attracted much interest from the other advocates for the way forward especially when space was limited.

Overall, it was a very good conference even if there was not very much content specifically for ITP. Who knows, maybe next year there will be more.

Derek Elston
(ITP Trustee & EHA Patient Advocate Workgroup Member)

(Ed: Derek Elston attended on a self-funding basis and was not supported by the ITP Support Association)

Don't forget – SEPTEMBER IS ITP AWARENESS MONTH!

Please help our campaign:–

- To increase awareness in any way you can about ITP and the symptoms
- To increase awareness in schools so that parents of children with ITP bruising are not subjected to accusations or suspicion of physical abuse.
- To increase awareness amongst health professionals (GPs , paramedics, A&E staff, midwives, dentists etc) to improve medical care for people with ITP
- To increase public awareness through fundraising events to raise money for more vital ITP research to improve the lives of those with ITP.

AllTrials Campaign Update

The AllTrials campaign was launched in January 2013 calling for all past and present clinical trials to be registered and their results reported. They were deeply concerned that whilst the clinical trials producing positive results are routinely reported many negative ones are not, yet this information is equally important. If doctors and researchers are unaware of what was done and found in these trials it could lead to bad treatment decisions, missed opportunities for good medicine, and trials being repeated. As ITP patients have been involved in various clinical trials the ITP Support Association was pleased to support this campaign and sign the petition.

In May of this year AllTrials reported a huge step forward with major global funders and international non-governmental organizations agreeing to adopt the The World Health Organization's strong standards on clinical trial transparency. This means all clinical trials they fund or support will be registered and the results reported.

AllTrials continued their campaign by carrying out the first ever review of the clinical trial registration and reporting policies of the largest pharmaceutical companies. They report that it was not straightforward to do as company policies are often vague, ambiguously worded, internally contradictory and difficult to interpret. Their review results were published in the British Medical Journal in July, summarised as follows:

"Most of the largest companies, though not all, have some sort of publicly stated policy about registering and reporting results from current trials.

However, only around half of all the companies we looked at had policies that applied to trials carried out in the past.

Policies commonly fail to refer to trials on unlicensed treatments or to phase 4 trials. This means there is a loophole that thousands of trials may be falling through."

When emailing their supporters with news about the publication of this review AllTrials declared that they are now moving from policy to practice stating:

AllTrials is now able to identify the mass of unreported trials and over the next two years we will be pursuing them. We're advising anyone sitting on an unpublished trial to move quickly to get the results reported, before we get to it.

If you would like to know more about this campaign visit the AllTrials website at http://www.alltrials.net/

ACUTE ITP IN A DOG

We received an email from the distressed owner of a 7 year old basset dachshund cross in Canada. The dog had just been diagnosed with ITP a week after red spots suddenly appeared all over her belly, combined with a loss of appetite and lethargy. Bruises arose daily for 2 weeks and her platelet count was under 24. A week later, just as suddenly, her platelet count shot up to 354!

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 your donation to be earmarked for ITP Research)*

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