



the platelet

MAR 2017

JOURNAL OF THE ITP SUPPORT ASSOCIATION

**FUNDRAISERS
GO THE EXTRA
MILE FOR ITP!**



**ITP RESEARCH, NEWS,
PATIENT STORIES,
AND MORE INSIDE...**

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

In this issue . . .



We are very pleased to report that The ITP Support Association has just agreed to fund three new research projects, as summarised on pages 8 - 10. Following on from these extracts you will see a fundraising appeal, as it is only with your generosity that we can replenish the research fund ready for the next projects that come along.

A number of interesting articles from patients describe their various experiences with ITP and related topics, including pregnancy, and the 'flu jab. We were particularly delighted to receive two articles from children accompanied by some lovely drawings (pg 12). Young or old, do keep your ITP stories coming, they make compelling reading.

Contents

Enclosed with this issue of The Platelet you should receive a booking form for our 20th ITP Convention to be held at the Royal Society of Medicine in London on 13th May. We hope to meet many of you there, and if you haven't been to a Convention before do come along, it's not frightening and people always tell us they feel reassured. In addition to hearing presentations from the experts you'll get the opportunity to talk to them and also to share experiences with others who have ITP. A new feature for this year will be two sessions with Dr Drew Provan who will outline various ITP scenarios and ask the audience to vote on keypads to ascertain their preferences. The results could prove very interesting and unexpected!

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

The ITP Support Association is primarily run by volunteers, with just one part-time paid worker. It is non profit-making and relies upon subscriptions, donations, bequests and fundraising by friends of the Association to enable its operation and to fund vital research into ITP. All donations are gratefully received and acknowledged.

Shirley Writes...

Firstly, I would like to record my personal gratitude to Howard Anderson who has stepped down as an ITP volunteer after 15 years of dedicated service. Howard has been a key member of the Association, not only running our ITP website, and assisting at Conventions, but offering his thoughts and advice on many occasions when difficult issues arose. I'm sure that Platelet readers, especially those who have been to ITP Conventions and met Howard personally, will join with me to wish Howard a hearty thank you for the sterling work he has done, which has been greatly valued by us all.

The trustees (Michael Levy, Derek Elston and I) held a meeting in early January at which we unanimously agreed to appoint Mervyn Morgan as joint CEO with me. Mervyn got off to a flying start as senior administrator, and we felt confident that he was the right person to share the responsibilities of planning, directing, and coordinating operational activities in preparation for me to move towards more of an administration back seat. For the foreseeable future I am very happy to remain as chair of the trustees and continue with various (voluntary) jobs within the Association, including publications editor, liaising with Clinical Centres and responding to patient queries.

Knowing it would be extremely difficult to take a step back from the charity which has become so firmly entrenched in my daily life, I made some New Year Resolutions at the start of the year. My list opens on the screen every day when start up the computer, serving as

a reminder not to go back to my old ways, so since January playing music, exercising, doing household tasks, cooking and giving more time to Frank and the family have been my morning priority, not ITP. A couple of months in to 2017 it is working well, and I can relax knowing Mervyn is sharing the responsibilities.



Since The Platelet Mission became the base for ITP HQ we no longer offer the 'all day, every day' ITP telephone contact line that was available when I ran the Association from my own home, but now the office has settled into a routine there is usually someone present to answer the phone every weekday morning. Messages can be left on the answerphone of course, and emails are picked up regularly with difficult medical queries forwarded to our medical advisors. For people troubled by ITP who need to talk to a fellow ITP patient who understands what they (or their child) are going through, the ITP 'Friends' offer an empathetic ear (contact details are always listed in the pages of The Platelet).

Finally, we are grateful to the ITP patients who put their name forward as willing to complete surveys on various ITP issues when the occasion arises. The patient voice is particularly important in a rare disorder, so if you would like yours to be heard it is not too late to be added to what at the moment is quite a short list.

My ITP & the 'flu jab

by Joan Lee

At the time of my ITP diagnosis in summer 2012, I was already taking immunosuppressants, being 20+ years on from a liver transplant. As recommended by the transplant team, I'd had the 'flu' jab annually. After I had the jab in October 2012, about three months after my ITP diagnosis, my platelet count dived from 167 to 12 in a fortnight. I don't know whether this was the jab, or the change in my immunosuppressants around the same time (see below), or a combination of both. Either way, this experience made me very wary of having the 'flu' jab, and very nervous of catching infections generally for the next couple of years. With common coughs and colds my worries were unfounded – the usual aggravation of a blocked nose, sore throat etc, but no big drops in my platelet count.

About six weeks after my ITP diagnosis, I began taking MMF in addition to the immunosuppressants prescribed by the transplant team which were tacrolimus (Prograf) and a 5mg daily maintenance dose of prednisolone. Two months on from my diagnosis and about three weeks before my 'flu' jab, I was advised (by a member of the transplant team) to stop the tacrolimus. They reintroduced this gradually over the next two months, due to renewed liver rejection problems provoked by its withdrawal. I then continued to take MMF and 5mg prednisolone daily. This combination of

immunosuppressants has kept the liver problems in check and my platelet count has been stable, usually around 150-165, for the past four-and-a-half years. The main issue has been, unsurprisingly given all my immunosuppression, lower than normal white blood cell (neutrophil counts), putting me at increased risk of infection.

After three years of platelet stability I had the jab in 2015 and 2016 with no problems. After a particularly vicious, feverish cold in February 2016 I made my mind up firmly to have the jab from then on. That cold developed into a chest infection and I generally felt very unwell. A blood test at the transplant clinic a few days after this developed showed my platelets dropped from 160 to 114. More seriously, my white cell count was low, with my neutrophils at only 0.5 putting me at increased risk of complications from the infection. They advised me to stop my MMF for a few days and get another blood test done. When I did, it showed my white cells had returned to normal with neutrophils at 2.8. I could then restart my MMF, though on a lower dose than before, reduced from 1g bd to 500mg bd.

Thankfully my platelet count has held up on this lower MMF dose, despite two more colds during 2016, though I've still had some lower than normal low white cell (neutrophil) counts.



American Perspective

Dr Cindy Neunert MD

Columbia University Medical Center

Adherence to ITP therapy

We always start treatment with the expectation that the patient will take the medication according to the directions that we prescribe. Unfortunately, at times patients do not take the medication as advised or stop taking it all together. When this occurs we call it non-adherence. It is hard to believe that patients may not follow up with a plan to make them better. However, it is important for us to sit down with the patient understand why it happened.

There are several different reasons that patients may be non-adherent with medications and/or treatment plans. First, proper consideration was not given to the lifestyle and goals of the patient. Sometimes, as doctors we may think that we know what you need but it is essential that we talk with you to make sure we know how we can best help you. For example, providing a patient who likes to travel with a medication that requires weekly visit to the doctor's office may place unrealistic expectations for adherence from the start. Given the number of different therapies available it is important to make sure you communicate with your doctor any reason a particular medication might not work with your lifestyle and discuss alternatives. Even the best medication will

not work if it can't be taken. The North American Consortium of Pediatric ITP

(ICON) recently looked at how the two thrombopoietin (TPO)-receptor agonists are being used in clinical practice. We wondered if response rates in clinical practice would be different between the two medications due to the differences in how they are given. One TPO-receptor agonist, romiplostim is given by subcutaneous injection once per week (in the US, the injection must be in a doctor's office). The other (eltrombopag) is a daily pill, which requires some restrictions on what the patient can eat and drink in the two hours before and after taking the pill. We questioned if these differences would impact patient adherence and lead to reduced responses. What we found however was that the drugs worked almost the same, likely because patients selected which drug would work best for their schedule in a conversation with their doctor. For example, I have a 10 year-old patient who clearly and honestly stated that he would not take a pill everyday and that was not an option for treatment. If these items are



Dr Cindy Neunert

considered early on then there is greater chance for adherence and successful therapy.

Second, is a lack of understanding of the purpose of the medication. It is key for doctors to ensure that patients are educated about the reason a medication is being prescribed. Additionally, as a patient you should not take any medication if you do not understand what you are taking it for and what to expect while on the medication. A lack of understanding of the importance of medications can often make them seem unnecessary and thus reduce the likelihood of successful adherence.

Lastly, medication side effects can impact a patient's ability to stay on medication. Sometimes medications can cause side effects that appear to the patient to be worse than the actual disease. Dr. Jim George and his colleagues at University of Oklahoma Health Sciences Center conducted a study

where they asked patients and doctors about symptoms of both ITP and corticosteroids. While the doctors felt like bleeding symptoms were more bothersome to patients than the side-effects of corticosteroids, the patients actually reported being much more troubled by side effects of corticosteroids than they were about a risk for bleeding. It is therefore critical to discuss any and all side effects that you experience with your doctor, especially if it might cause you to choose to not take it anymore.

Open discussion with your physician will ensure that the treatments you are prescribed will fit with your lifestyle, that you understand the goals of the medication, and that you are aware of any possible side effects. Through this kind of communication there is greater likelihood that you and your doctor will choose a treatment course that is easy for you to adhere to and will make you better.

Do you know a celebrity?

After our successful ITP fund raising lunch/afternoon in Putney last year, we are looking to hold a similar event this autumn.

Last September's event, on a beautiful day at the London Rowing Club, was hosted by star of 'Midsomer Murders' Neil Dudgeon and compered by Dr Mike Smith, both long-term supporters of the charity. With the help of sponsors All3Media, over £5200 was raised from the day for ITP funds.

We are now looking for another willing celebrity to come forward to step into Neil's shoes and host this year's event.

If you have any ideas or know a famous face who may be prepared to help, please contact me, Debbie Lloyd (debbie.a.lloyd@gmail.com)

Research Funding News...

Three new projects to be funded by The ITP Support Association

Thanks to your generous donations and superb fundraising efforts we have enough accrued in the research pot in this financial year (Apr 16 - March 17) to give grants totalling £53,240 to fund three exciting new projects. This is in addition to £45,000 given in 2016 to support the adult and childhood registries, and savings accumulating to fund the start of the Pregnancy in ITP Registry.

We would like to thank the ITP Support Association for funding our research project "Immune thrombocytopenia, immunomodulation and fatigue". We know that up to a third of patients with ITP suffer from significant fatigue but the reason for this is poorly understood. The goal of our study is to determine whether changes in activity of the immune system are important in causing fatigue. Patients with ITP will be recruited from the immune haematology clinic at St James's University Hospital in Leeds. Patients will complete a fatigue questionnaire and donate a blood sample while their ITP is active, and then repeat this after 3 months. We will analyse how fatigue is influenced by the activity of T and B lymphocytes, which are cells of the immune system involved in the removal of platelets from the circulation. The support association grant will allow us to extend our analysis to include another sub-type of lymphocyte called the natural killer (NK) cell. NK cells can attack virally infected or cancerous cells, but also have a role in regulating the immune system. NK cell abnormalities have been identified in autoimmune disorders

including ITP. NK cell dysfunction has been found in patients with chronic fatigue syndrome, but whether NK cell activity is associated with fatigue in ITP is unknown.

*Dr Quentin Hill,
St James University Hospital,
Leeds*

That's really great news that you are awarding us a grant! Thank you!

People with immune thrombocytopenia (ITP) have a low platelet count because of destruction of the platelet by the immune system. Although we know that a low platelet count makes people more likely to bleed, most people with ITP will not have a serious bleed and many people have no bleeding symptom at all. This is really important when we think about treatment. Although some people do need treatment to avoid a serious bleed, many people with ITP do not need treatment, and the treatment might cause more problems itself. We do not have very good indicators of the risk of bleeding in individual patients. For this

study, we have designed a special MRI scan of the head which can detect very small bleeds in the brain, a bit like the petechia (pink dots) that you can sometimes see on the skin. Our aim is to see whether people with ITP and with specific features or specific platelet counts also have little bleeds in the brain, which could give us a better idea about who needs treatment, and who can avoid treatment altogether.

*Dr Nichola Cooper
Hammersmith Hospital,
London*

We are delighted that the ITP Support Association has chosen to provide funding to support a research project in Bristol entitled: The development of a blood test to predict responses to steroid treatment in patients with immune thrombocytopenia.

This research proposal has been developed following feedback from patients who highlighted the difficulties faced in the first months after a diagnosis of ITP (described by one as a “rollercoaster”). They have helped us develop patient centred priorities for scientific research.

When adult patients are first given a diagnosis of ITP they are usually treated with high dose glucocorticoid steroids (e.g. prednisolone or dexamethasone). These are recommended in guidelines and usually raise the platelet count which is helpful to confirm the diagnosis and control bleeding symptoms. However, the majority suffer significant steroid side

effects (including difficulty sleeping, weight gain, mood swings, diabetes, high blood pressure, stomach irritation and thinning bones). These are sometimes so bad that patients have to stop treatment. The other big problem is that some patients don't respond at all (20%) and others may relapse when the dose is reduced or stopped. Only one in five adults stay well long term without needing another treatment.

The problems faced by patients with ITP mirror those with other autoimmune conditions which as a group are common, affecting 3% of the population. In addition, steroids are part of treatment regimens for other illness such as childhood leukaemias. There is an unmet need to be able to predict which patients will and won't get better with steroid treatment so that only those likely to benefit will suffer the side effects whilst others can receive a more effective treatment sooner.

Long term goal of this research:

- Individualise treatment strategies for patients with ITP
- Avoid the current trial and error approach to ITP treatment
- Avoid side effects of treatments that don't work
- Shorten the time period that ITP is uncontrolled and reduce the harm this causes (bleeding, bruising, fatigue, hospital visits, disruption to life etc).

Recent data from patients in Bristol with ITP and other autoimmune conditions has

shown that immune cells extracted from a patient's blood sample can be treated in the laboratory outside the body with steroids and the responses of these cells differ in patients who get better taking steroid compared to those who don't. This forms the basis of the hypothesis that it is possible to predict a patient's response from a blood test. However, at the moment this laboratory test is not suitable for real world patients in the NHS as it involves specialised research techniques and takes 7 days to get a result. We are collaborating with a group in France who have developed special blood tubes (TruCulture) that have the potential to make this test much easier and give results within 24h. The funds generously donated by the ITP support association will be invaluable to

adapt and test the TruCulture blood tubes for this indication. If successful, then a similar strategy may be useful to predict patient's responses to other treatments.

We would like to say a big thank you to the 50 fantastic patients in Bristol with ITP who have kindly donated blood samples for the preliminary work we have done this year which forms the basis of this project (they are an extremely generous, highly motivated and rewarding group to look after). In addition, we recognise and appreciate the tremendous efforts of the individuals who have worked hard raising funds for the ITP support association to support research like this.

*Dr Charlotte Bradbury,
University Hospitals Bristol*

Research funds appeal

It is only through the generosity of your donations and fundraising events that we have been able to fund the ITP research projects outlined in the above pages.

Please help replenish our ITP Research Fund for future projects!

You can donate by cheque (HQ address pg 2), on line at www.itpsupport.org.uk or by texting ITPA22 and the amount (£1 – £5 or £10) to 70070.

If you would like to support ITP Research by holding a fundraising event we can send you a fundraising pack or sponsorship forms, or you can set up your own fundraising page to collect donations or sponsorship at www.charitychoice.co.uk/the-itp-support-association

None of the research funded by the ITP Support Association uses animals.

ITP – what else to research?

The bleeding disorders research group needs YOU

by Derek Elston

Unless you are new to ITP you already know that as an association, we are committed to research into ITP and its treatment. With your unstinting support, we have been instrumental in funding research into many diverse areas with some very interesting results, all of which have been published on completion.

We are now asking for your assistance once again, but this time with a difference.

Following a proposition by the chairman of the National Institute for Health Research (NIHR) non-malignant haematology group, part of the NHS, a clinical study group into all bleeding disorders was formed under the chairmanship of Professor Michael Laffan. Together with the Haemophilia Society of UK, we were asked to join this group to represent the patients of the two most common bleeding disorders.

Due to the size and complexity of this proposition, it became apparent the group would be better served by forming a Priority Setting Partnership (PSP) in conjunction with the James Lind Alliance.

The requirements of the PSP is to involve patients, carers and clinicians in research priority settings and to identify uncertainties about treatments and prioritise the ones it felt were most important to address. Studies had identified large differences between the

questions patients thought were important and those studied by the health services.

This is now your chance to suggest subjects for research. The study will be web based and will include a questionnaire for completion and return. It is envisaged that it will ask around 10 questions. It will be for UK patients, carers and clinicians only.

The study will be launched on April 10th. It will be formally introduced at our convention in May asking for you, our members, to complete the questionnaire on line. If you are not 'on line' an alternative hard copy facility will be provided. It is anticipated the study will close in September with completion of the survey and publication of the results by May 2018. The top 10 subjects for research will then be presented to NIHR for consideration for research. The remaining subjects for research will then be offered to research organisations.

Further information with the web address will be published in our June edition of the Platelet. I hope you will contribute and submit the important items that YOU consider should be researched. You may like to look at the two web sites below to obtain further information about the NIHR and the James Lind Alliance.

NIHR www.nihr.ac.uk/

James Lind Alliance www.jla.nihr.ac.uk/



Children's ITP Letterbox

My name is Sam Rock, I am nine years old. I have ITP and I have been on the romiplostim trial for about 6 weeks now. I have been extremely lucky and had an excellent response to the medicine. Many people don't have a great response, so

I only had a tiny amount of pain, so don't worry about that.

The good things are that Hamedeh (the lovely person who looks after me) is nice and kind, and she comforts me. She is also good at blowing bubbles + Injections. Also,

when I have high platelets it gives me a nice feeling inside as I can't be told 'you can't do this, you can't do that'. I am also learning a lot of stuff like how they test the platelet level. Hamedeh gives me homework, it may sound boring but it is nice to learn about things like that. Another good bit is when my dad nearly fainted when he gave blood!



I am happy about this, as when I have high platelets my dad does not watch me like a hawk! When I first started the trial I was rather nervous about having an injection in the subcutaneous layer (an injection given between the thin and fat layer of the skin). I also thought that it may not work as other medicines have had only minor affects on me.

The first time I was given romiplostim the injection was rather quick and

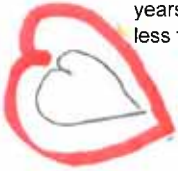
As you may know, there are the downs of the study (for example the injections, although they're not so bad), the long journey, AND THE LIFTS!!!

If you would like to share your ITP story with other Platelet readers please email it to info@itpsupport.org.uk or post it to

The Platelet Mission, Kimbolton Rd, Bolnhurst, Beds MK44 2EL

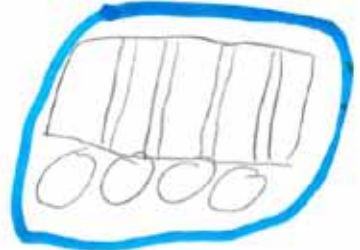
My life with ITP

My name is Bradán Peacock, I am seven years old, and I have had ITP for three years now. My life with ITP is sometimes exciting, sometimes fun and sometimes less fun, due to the nose bleeds I often get with this condition.



Every Wednesday morning I come up to Saint Mary's Hospital in Paddington and I have a blood test and a special injection done.

Also I see my lovely research nurse Hamedeh who takes my bloods and looks after me. She makes me feel really special. Before I set off to the hospital (usually with my Mum but sometimes with my Mum & Dad) my family – Dad, Mum, older brother Finn & older sister Niamh – play a game which is to guess what my platelet count is going to be on that day – which makes it a bit less stressful. Often Hamedeh gets other people in the department to join in with this guessing game too!

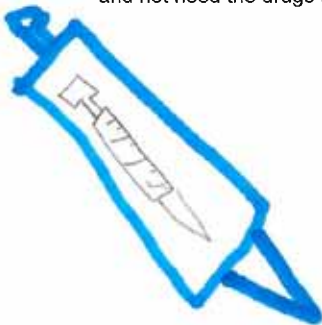


Every 8 weeks or so I have to have a meeting with Hamedeh and my Consultant – Dr Cooper. Dr Cooper is very nice and explains things to me so that I understand completely what is going on. On the days of this meeting with Dr Cooper, Hamedeh needs to take additional blood to be sent to the labs in America for testing. That's what she tells us – but she could really be a vampire in disguise!!!! Haha...

I am no longer worried about living with ITP as I have a brilliant team looking after me, and Mum & Dad are kept informed of everything all along the way. It doesn't really limit my life too much anymore, and who knows, one day.... I might be back to having a really high platelet count and not need the drugs to continue.



That would make me so happy as I would be able to go on trampolines, and to attend wall-climbing parties, but I would be really sad to have to say goodbye to Hamedeh as she is a very important part of my life now-a-days, always makes me laugh, and is delighted when I try to bring the sunshine to my meetings with her.....



Fantastic Fundraising!

We start by recording our enormous gratitude to everyone who made a personal donation with their membership renewal or as a Christmas gift, which included two cheques of £1000! All these generous donations along with the amazing contributions from everyone listed in these fundraising pages and benefactions in memory of loved ones make it possible for us to fund the much-needed ITP research projects outlined on pages 8 to 10. The burden of financing this vital work falls heavily on our charity as there is no state funding for ITP research.

We kick off by reporting on some super Christmas fundraising events. . .

Sarah Palmer raised the terrific sum of £1045 from selling sweet cones, reindeer food and hot chocolate reindeer cones at her son's Christmas fair, and taking donations in lieu of Christmas presents.

Katie Pennington and friends had great fun in December participating in the 12th annual Liverpool Santa Dash, and she raised the grand total of £421.25 with gift aid, for the Pregnancy Registry. The 2016 dash was open to runners, joggers and walkers, with everyone taking part in a Santa suit, which was provided. The course started and finished in Liverpool city centre with a

5K route beginning at the Pier Head on Canada Boulevard in front of the Liver Buildings and finishing in front of the Town Hall at Castle Street. Katie told us "It was a lot of fun! I think there were over 7,000 Santas running for all kinds of different charities.. As the city is big on football, the Santa suits were not only available in red, but also in blue (for the Evertonians!) There was a samba band at the finish line as well as performers on stilts and fake snow! I had to take it easy as I had a pulled hip flexor muscle in my left leg but made sure I sprinted to the finish!" Congratulations to Katie on finishing despite the injury, and we hope she has fully recovered. [Santa Dashes have become a firm favourite in the run-up to the festive season, and if you fancy giving it a try there is a list of 2017 Santa Dash venues at www.santadash.co.uk/]



Katie (2nd right) & Santa friends



Katie Pennington (left)



Shirley's Christmas Concert

their 'local') and a New Year's Eve Supper which she and Frank hosted at the Old School in Bolnhurst. A total of £466 was made for ITP funds.

Shirley Watson organised three fundraising events in December, her annual Christmas Concert featuring her pupils and musician friends, Carols at the Plough (a Sunday afternoon concert given by Bolnhurst Carols Singers at



Bolnhurst Carol Singers at the Plough

And finally for Christmas fundraising we send our thanks to **Denise Money Penny** and her fellow line-dancers in Wrexham who held a raffle in aid of ITP at their Christmas party and raised £87 for our funds.

Simon Tomlinson came up with a novel fundraising idea when he walked 21 miles from Whitby to Scarborough carrying his 7 old daughter **Lily** on his shoulders! Simon told us that Lily has been diagnosed with ITP so raising funds for our charity is close to the family's heart. The total raised via Charity Choice with gift aid was a fantastic £655. Well done to both Simon and Lily, it couldn't have been easy for either of them!



Simon & Lily start out . . .

Congratulations to **Andy McIntyre** on completing the Cardiff Half Marathon again. The race started at Cardiff Castle for a 13 mile route ending at the Civic Centre, and Andy raised a cracking total of £577 for our cause.

Market Bosworth Netball Club very kindly sent us a donation of £170.50. **Nicola Hayes** explained 'Market Bosworth Netball Club is a small club trying to encourage women

of all ages to get back into netball play. Netball is starting to become played more and more and is enjoyed by many, partly because it is exercise in a fun environment but also because of the team working and social side. It's definitely a supportive environment and each



Still a long way to go!



Andy McIntyre

year, our club try to raise some funds (no matter how big or small) for a selected charity which is nominated and agreed on by club members. This year (2016/17), members nominated the ITP Support Association and the charity is close to the club's hearts as I have ITP so I was very touched by the members nominating this. The money has been raised by different methods including a cake sale as a whole club (great hey, netball followed by cake!!) and **Leanne Bond** ran a half marathon and raised money for the club's charity through Charity Choice!



Market Bosworth Netball Team (Nicola 2nd row 4th left)



Leanne Bond

We are grateful to **Simon Gledhill** for raising £75 from an ITP collection tin displayed in his shop, which is part of the Atlas Trading group, a family business. Simon's 10 year old son was diagnosed with ITP last June, and we wish him well.

Last but by no means least, we are, as ever, indebted to **The Charity Shop** for their support, with a cheque for £1000 winging its way to us in December, closely followed by another £1000 in January.

We've had some super photos for our fundraising pages in this issue, not least of all from **Tim Linstead** who raised £80 running a London 10k race in Edwardian swimwear! Many thanks Tim, we think you look fab!



Tim Linstead

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.

£1,070 was received in memory of Andrew Olney

£1,120 was received in memory of Derek Schofield

We thank Mrs Margaret Olney and Mrs J. Schofield for their kindness in remembering our charity.

My ITP Pregnancy

by Hayley Howie

Hayley Howie (nee Keefe) who manages the ITP Support Association's 'instagram' social network page had a baby boy 6 months ago and shares her pregnancy experience with us.

I was doubtful about writing this article as I felt it wasn't helpful, but my husband then pointed out that it may encourage other people who have been putting it off – you will understand why as you read on.

In December 2015 I found out I was pregnant, without even speaking first to my consultant about it. I had been in remission for a good few years and my counts had always bounced around the 90s mark. So thinking this was going to be an absolute nightmare of a pregnancy I got in touch with my doctor. Well, what can I say, other than I was so impressed by our NHS!

It was like the old days with frequent trips to the hospital. Every four weeks I had to see my consultant for bloods, every four weeks I had appointments for the midwife, plus four visits to obstetricians over my pregnancy. I even had an appointment with the anaesthetist to discuss my pain relief options for labour. What I did find reassuring is that every member of staff I spoke to dealing with my pregnancy knew of ITP, even on my very first visit to the midwife.

My counts were never better, always staying around the 125 mark. They kept a close eye on me and wanted to induce me on my due date, as they didn't want baby being too big, causing

unnecessary tearing and bleeding. They said they would have blood on standby just in case.

In the end I was induced the day before my due date and they took my count as soon as I got to the delivery room, 150!!! I was amazed, that meant I could have any form of pain relief I wanted including epidural. But as it turned out I had a straight forward labour.



Baby Nathaniel was born on 31st August 2016 at 10.09pm. Bloods from his cord were taken in accordance with the plan put forward from my consultant. The results came back with platelets at 260. They kept an eye on Nathaniel's count for five days, again in accordance with my consultant's plan. My consultant was even

nice enough to liaise with paediatricians at the children's ward to check his counts as well, and then later informing them they did not need to continue with testing.

Six weeks later I returned to hospital for my count to be checked and I had gone back to my average of high 90s. Advice from my consultant was to just keep an eye on my baby as I know what signs to look out for in the future.

Now we have a happy and healthy baby who is coming on leaps and bounds. So I guess the moral of this story is, it might not always be as bad as you think!

New website coming soon!

by Mervyn Morgan

We have some news, over the winter, at the Platelet Mission, we have been hard at work putting the finishing touches to the new ITP Support Association website making sure that the site can be up and running in the next few weeks.

In redesigning the website we have taken on board many of the ideas and suggestions put forward by our members. Some of the improvements being implemented include an easier members' sign up and renewal process, a members only area, plus the new site is also tablet and mobile friendly.

Sponsorship opportunity

The new website also provides us and you, with a fantastic opportunity, we are looking for individual(s) or companies to sponsor the new website. If you believe you would

benefit from supporting the only ITP Support Group in the United Kingdom then email us your details and we will be in contact.

As a Registered Charity the ITP Support Association will assess any potential sponsor to ensure that there is no conflict of interest with the Association's mission and values.



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Have you heard?

by Anthony Heard

Sadly I don't believe in miracles!

The first article of 2017 and a belated Happy New Year to one and all. Just a quick update on my own purple progress. My last platelet count was 152 on November 7th 2016. I have been on Mycophenolate Mofetil (MMF) since April 2016, and my platelet count has been really good since then. The side effects that I have had from MMF have been nausea, tummy upset, general indigestion and difficulty sleeping. Just like Prednisolone, the MMF has a habit of disturbing sleep patterns but nothing is perfect in ITP world.

This article looks at alternative treatments, herbal and natural remedies for ITP. The first thing to say is that I personally have never tried anything other than conventional medicines prescribed to me by my ITP specialists. I will highlight the many reasons why I personally have opted to tread this path. The drugs that I have been treated with over my ten purple years have been..... Prednisolone, Azathioprine, Rituximab and currently Mycophenolate Mofetil (MMF).

It is certainly not my intention to criticise any fellow ITP sufferers for trying any alternative options. After all, why wouldn't we all at least be interested in learning about anything that would tackle the purple riddler? It is bound to pique our interest especially for those

who have tried numerous conventional treatments without any success. In such circumstances the lure of trying something off piste might be very tempting.

All that said, the following important factors are the ones that I considered to be key in persuading me not to try any alternative treatments including things like Papaya Leaf extract and Aloe Vera juice.

There is no scientific evidence to confirm that any alternative, herbal or natural remedies raise the platelet count in the medium to long term. Platelet counts may well increase in some people in the short term. But it is impossible to tell whether or not the increase is really due to the alternative remedy or just general fluctuations in our platelet count due to changes in our overall health etc.

No official registers are maintained anywhere to record side effects or results which may be caused by alternative, herbal or natural remedies including Aloe Vera juice and Papaya Leaf extract. With conventional ITP treatments full records are kept and updated of any side effects encountered.

There simply hasn't been any research on the true impact of alternative, herbal or natural remedies. The bottom line is that we just don't know.

continued overleaf

There are many dangers in using these types of remedies. It is virtually impossible for us as potential users to actually test/verify exactly what we are taking. We just can't really tell what is in the remedy. Is it what it says it is? With so many unscrupulous sellers especially via the Internet, it's impossible to be totally sure what we are taking.

There are no sure and certain guidelines as to exactly how much of these remedies we should take. Unlike conventional treatments where prescription is supervised by our specialists and our responses monitored carefully.

Surely if it really was possible to raise our platelet counts and control our ITP by taking a relatively simple herbal, natural or alternative concoction then why wouldn't any of the many ITP specialists I have discussed it with in my ten purple years suggest or recommend it?

None of the many ITP specialists I have discussed such remedies with have had any hope that they would work. Their general reaction has been that sadly it is just wishful thinking or clutching at straws.

The very latest research into ITP and its' causes confirms that there is a whole host of very complicated processes going on

in the immune systems of ITP sufferers. It has become increasingly apparent that ITP and the causes of it are far more complex than we have previously thought.

These are the issues that have driven my decision to stick with conventional treatments for my ITP.

Another topic which often raises its' head when discussing alternative ways of treating

ITP, is diet/nutrition. There are many suggestions that consuming certain foods or combinations of them will assist the platelet count or possibly cure ITP. Sadly ITP is a much more complex illness than that. Indeed recent findings from a research team at Hammersmith Hospital/Imperial College London suggest that ITP may be not just one disease but a group of pathophysiologically distinct processes resulting

in immune mediated thrombocytopenia. Somehow we need to understand these processes more. Throwing together a cocktail of ingredients and hoping they solve the purple riddle is tempting but sadly not going to work.

Certainly there is absolutely every reason to eat and drink healthily. By that I mean eating plenty of fresh fruit and vegetables (green vegetables especially like kale, broccoli, spinach), minimising

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the amount of processed foods, eating red meat in moderation, eating less junk food, drinking more water and less alcohol , not smoking and getting plenty of rest/ sleep. It's called common sense. All these things will assist our overall health and well being, including keeping our immune systems healthy and hopefully platelet production plentiful. Drinking too much alcohol for example damages the liver which is responsible for production of the substance Thrombopoietin in our systems which itself regulates the production of platelets in our bone marrow.

So other than following a balanced, healthy diet, I don't believe anything specific will help, as far as we know YET. I say this because specific, conclusive, scientific research has again not yet been done in respect of diet and ITP. There has been some very interesting research done recently by Professor Hunter and his team at Addenbrookes Hospital in Cambridge UK, into nutrition and ITP but it is still ongoing. Details of the research so far are available to read at<http://www.itpsupport.org.uk/itpeating.htm>

In conclusion then, I have made a conscious decision to treat my ITP with conventional medicine. I have decided that there are no miracle cures for ITP. However, I have always had full and frank discussions with my ITP specialists and regularly got second opinions along the way. My thinking is driven by the opinions of the specialists that if the ITP riddle could be solved by a cocktail of herbal, natural,

nutritional remedies, then they would have suggested it by now. The truth is that ITP is very, very complex and because it is so rare we simply haven't done enough research yet to really know with any certainty what such remedies can offer.

The most important thing I will say to conclude is.....Never take anything at all without discussing it in full with your ITP specialist/doctor. Do get a range of opinions from more than one ITP specialist and remember it is YOUR ITP and YOU need to ensure you get as much information as possible to make the best treatment decisions for YOU.

Useful Information ... ITP research ...<http://www.itpsupport.org.uk/research.htm>

Papaya leaf extract discussions <https://healthunlocked.com/search/papaya%20leaf%20extract/group/itpsupport>

Until next time PLATELETS UP!

Best Wishes



We are very grateful for the used stamps that many of you have sent us, but please note:- If your envelope is any thicker than 5ml it needs more than standard letter postage or the excess Royal Mail charge us is more than the money raised from your stamps!

My ITP experience

by Julie Bulpin

I'm 56 years old and have always bruised easily, but late 2014 something changed.

I noticed that the bruises were appearing much more often and without any reason and when I did knock myself the pain would be incredible and the bruise much bigger than I would have expected. My husband said that it looked like he was battering me and that I should see my GP for an explanation.

My GP said that I needed to have a blood test done before he could possibly make any comment or diagnosis. So off I went for a blood test – that was 31st January 2015.

That same evening my local hospital, The Leicester Royal Infirmary, rang to say that the blood test was showing that my platelet count was 8 and that I should come in immediately for more tests. These tests showed that I had the condition ITP so I started a course of 60mg of prednisolone and went back a few days later for another test. My count had gone up to 60 so they reduced the dose to 50mg.

Over the next 2 weeks my count gradually dropped to 10. During this time I did have a cold so that didn't help, as for me, when I have a cold my platelet count always plummets. My consultant then decided to start me on the immune suppressant, mycophenolate, and my levels rose to 119 over the course of the first week. Gradually the steroids were reduced and the Mycophenolate was increased but all the time my platelets fluctuated, although not dangerously low.

The problem with taking all this medication is that it sets off other problems. My potassium levels then began to fall so I had to eat more potassium rich foods and take yet more tablets to make it rise to a safe level.

In May 2015 I had a scan on my spleen to see if it was enlarged. Thankfully it wasn't.

At the beginning of June 2015, after continual fluctuations in my platelet count, my consultant decided to stop the mycophenolate and I started taking another immune suppressant, azathioprine. Two weeks later I was admitted to hospital during the night as I had woken with terrible shaking that I could not control, a feeling of dizziness, sickness and a temperature. They put me on a saline drip and gave me some antibiotics as I appeared to have an infection. I was sent home the following afternoon.

A week later my platelet count was 5 and I was admitted to hospital again for a course of immunoglobulin. After 4 days stay my count rose to 209 and I was sent home. A few days later it had risen to 517 but I was told that it would start to drop down gradually. I was still taking the prednisolone and the azathioprine.

Over the next few months my count continued to fluctuate, the steroids were reduced and the azathioprine was increased to 3 tablets a day. I did notice that over a period of several months my hair began to fall out. Not dramatically but noticeable to myself and my hairdresser.

All was going relatively okay, well as best it does in ITP land! My count fluctuated and I got down to 5mg of steroids. Then in November 2015 my Alt (liver function) test showed that I had a very high reading. This was a side effect of the immune suppressants, so I had to stop taking them immediately.

I had a discussion with my consultant about having my spleen removed. I was adamant that I would not have this done as the scan had shown there was nothing wrong with my spleen and having done some research in to a splenectomy, the percentage success rate following spleen removal in controlling ITP was too low for me to want this. Plus you then had to spend the rest of your life on antibiotics and trying to avoid getting ill. With the uncertain future of antibiotics and their effectiveness, I was not prepared to take this route.

My consultant decided to try the next line of treatment, a relatively new drug – eltrombopag also known as Revolade. Instead of suppressing my immune system this drug makes the body produce more platelets in the hope that your antibodies can't possibly kill them all!

It is now early 2017 and over the past year I have stayed on Revolade (1 tablet a day) and prednisolone (a low dose) and my count has continued to fluctuate, anything from 11 to 278! The steroids have been adjusted accordingly but mainly I take 5mg a day.

I have not suffered any severe side effects from Revolade, no sickness, diarrhoea or tiredness. I sometimes

get a numbness in my hands and my hairdresser says my hair has thickened up again! Although one serious side effect of ITP is the cost of travel insurance!

I know that Revolade is a new drug so the long term effects are not known but if something sort of works for me then I want to stick with it. Anyway I think I am running out of options.

One thing I would say is that you certainly get to learn an awful lot about your body, how it works and what affects different parts, when you have an illness. Up until now I had never been seriously ill, just colds and high blood pressure but having ITP did change my life initially. I had to stop attending my high impact classes at the gym, I worried about getting injured in any way and was signed off work for a while. I have never had a problem with fatigue which I know affects a lot of people with ITP and I am very grateful for that.

Now, nearly 2 years on since my initial diagnosis, I lead a practically normal life. I don't do high impact classes but I do yoga and pilates instead which are great for bone density and flexibility. I was made redundant at the end of 2015 and have not looked for work as I feel that going backwards and forwards to the hospital for my regular clinic appointments would make keeping a new job difficult.

I do hope that one day I can at least stop taking the steroids and I know that ITP, in some people, can just disappear but I will not hold my breath on that one!

NHS: Centre of Excellence

by Rhonda Anderson

To Pay or not to Pay, that is the Question...

Many people who have long term conditions such as ITP wonder if they will get better treatment, clear cut answers, and more reassurance if they pay for their treatment by 'going private' as we call it in this country. Paying does not necessarily give you better treatment, or a doctor who knows more. In fact many of the doctors in my area who work in the NHS by day, populate the local private hospitals for the evening clinics. So in fact, you are getting the very same doctor as you would have seen in the NHS hospital. However, you may shorten your wait and feel that you have got a better deal by paying, but can you really afford it? Private consultations do not come cheap. Sometimes you will get a doctor who does not know much about ITP and you would be better off getting referred to a centre of excellence.

Expert Patient Programme

Unfortunately, long term conditions are hard to treat. One has to learn to live with them. In this respect we are all living with our bodies in the state they are in, and as time goes by we are more likely to acquire the problems of old age. I tutor for The Expert Patient Programme, a Stanford University self management and self care course, which is geared to people with long term conditions and is very helpful for

them to self manage their condition. This means fewer visits to the GP and hospital, and sometimes reduction of medication. This course is free to patients in our area.

Self Inflicted Wounds

People who smoke, drink to excess and who are obese, are draining the system as they are bringing on themselves many life threatening conditions which could be avoided. There is the problem, how to get people to look after themselves so that they are not draining the resources of the NHS through not living a sensible life style. This health education issue will always be with us and is very difficult to deal with.

NHS Funding

It is considered that the NHS needs more money. I am sure it does, but there are also other things that can be done to save money and organise, so that it is streamlined and more efficient.

The NHS, the funding crisis and the too many people trying to access A&E are in the news. What a surprise? It is winter time and Winter Pressures always hit the news at this time of year. The problem is that the bulge which was only experienced in the winter months is now pretty much always with us. We pay less for health care per capita than a lot of other comparable countries. In this country we are very

generous with care and many people access A&E departments inappropriately. Health tourists are users of our very busy hospitals as we offer a standard of excellence that is sought after and often unique.

You may have seen the recent series of TV programmes called 'Hospital' which has addressed some of these issues. It costs £800 per night for a patient to stay in hospital. This is without extra tests etc. I have had experience of paying for hospital treatment myself. When I arrived here from Australia I had to have an ear operation. It was done on the NHS. When I came back again I had to pay up front before the operation, or it would not have been done. I had to get my boyfriend's parents to write me a cheque to post to the hospital before the operation. Then I had the surgeon's fees and follow up clinic visits near Harley Street to pay for. The ironic thing was that it was the same surgeon,

the same hospital and I had the same care, except that he came out from behind his big desk and shook me by the hand as a private patient. The food was better in the hospital, I had the chef come and talk to me about my menu choices and it was all served up on bone china. I also had a private room with bathroom, although it was not that well appointed. I was quite happy to pay for my operation, even though I had been a tax payer in this country before I returned.

GP Organisation

I am always very impressed with my GP surgery who phone me back on the day and offer me an appointment on the day, if I need one. Also my local hospital have excellent staff who give you as much time as you need and work in a most professional manner in the Out Patient Department.

The NHS is a centre of excellence in itself. It is precious, we need to use it wisely.

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.

ITP Global Alliance Update

by Derek Elston

Since the meeting held in Melksham, prior to our convention in September, much has been happening around the world with patient support groups.

There is now a global web site www.globalitp.org which was designed and developed by Nancy Potthast from the PDSA in the states. The intention is to

encompass all those individual groups which currently exist.

It is also intended as a medium for those thinking of starting a patient group, to become affiliated.

In the last three months alone, due to the web site, we have been contacted by a group from Israel and potential new groups in Egypt and Adelaide, Australia. This is all

very exciting. In addition, we have access to many individual patients around the world, who have ITP. Very often these people have no support other than through their own medical centres and they derive much benefit from being able to communicate with others. The most common medium is facebook for those, where no formal group exists.

We currently have 24 countries represented. There is still a long way to go.

Many of our members I am sure, wonder what benefit can be derived from such a global group. The answer is quite simple and can be mirrored to the ERN currently being developed within the European Union and to which we as a patient support

group have contributed. Recently we were asked for advice for a member who was going to Thailand for the winter months. His relative was concerned that should his platelet count drop suddenly, where would he go to be sure of receiving the correct advice and treatment. Fortunately, one of our medical advisors had recently been to Bangkok to lecture a group of haematologists and was

therefore able to provide this information quickly. It is our hope that any of our members travelling abroad, if concerned when they are away, will be able to access the global website and find the contact details of the local support group in that country and ask assistance from them. This is not going to happen overnight. We do however have the support of the pharma

ITP 'Friends'

a listening ear

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companies primarily concerned with ITP who we feel have a very important role to play in the development of the global alliance as they do within each individual country.

We and the PDSA, are already regularly contacted by individual patients from abroad asking advice. These requests come from all over the world which does indicate a need for such an alliance to be established for the benefit of the ITP community. We have

referred a number of enquiries from India to Ajoy Roy in Bengal who is in the process of forming an ITP support group in India.

We are currently considering another 'global' meeting later in 2017 which is likely to be held and hosted by one of the European groups providing funding can be obtained.

We hope to be able to keep you all informed, but do not forget to make a note of the global alliance web site, just in case.



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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