JUN 2018

the platelet

JOURNAL OF THE ITP SUPPORT ASSOCIATION

itp
Immune Thrombocytopenia

ITP NEWS, EXPERIENCES, ADVICE, EVENTS AND INFORMATION . . .

THE ITP SUPPORT ASSOCIATION TEAM

Charity Registration No:1064480

HONORARY PRESIDENT
Shirley Watson MBE (founder)

TRUSTEES
Professor Adrian Newland CBE (Acting Chair)
Derek Elston
Xenia Norman
Colin Williams

OFFICE STAFF (part-time)

Chief Executive
Mervyn Morgan

Office Administrator
Liz Gooch

VOLUNTEERS

Platelet & Publications Editor
Shirley Watson MBE

Treasurer
Michael Levy FCA

Social Media Platforms Manager
Hayley Howie

Group liaison officer
Derek Elston

Building & Grounds Maintenance
Frank Watson

Patient Mentors
Rhonda Anderson
Dave Farrow
Derek Elston

THE ITP SUPPORT ASSOCIATION HQ
The Platelet Mission
Kimbolton Road, Bolnhurst, Beds.
MK44 2EL (UK)
Tel: 01234 376559 (manned most mornings)
Web: www.itpsupport.org.uk
E-mail: info@itpsupport.org.uk

MEDICAL ADVISORS (Adult ITP)

(Prof. Adrian C. Newland CBE
MA FRCP FRCPath

Prof. James N. George
MD FACP(USA)

Prof. Spero R. Cataland
MD FAAP(USA)

Dr. Drew Provan
MD FRCP PRCPath

Dr. Jecko Thachil
MRCP FRCPath.

Dr. Will Lester
MBChB(hons), BSc, MRCP, FRCPath, PhD

Dr. Nichola Cooper
MA, MBBS, MD, FRCP, FRCPath

MEDICAL ADVISORS (Childhood ITP)

Dr. John Grainger
MBChB MD MRCP FRCPath

Dr. Mike Richards
MA BM BCh DM MRCP FRCPath

Dr. Cindy Neunert
MD MSCS

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

In this issue . . .

It's a bumper issue this time with five patient stories showing just how different each individual's ITP journey can be. We report on the patient afternoon in Cardiff *(pg 16)* which was very well attended, and announce the next patient afternoon to take place in July in Bedfordshire, at ITP HQ *(pg 11)*.

As we approach the summer months we have a timely update on travelling with romiplostim *(pg 21)* and practical advice from two ITP patients on how they manage this.

Dr Will Lester writes on how older ITP patients having routine screening tests for bowel cancer can avoid false readings and Professor Jim George reports in his American Perspective column that lower platelet counts in pregnancy are normal.

We have news from the ITP Forum and Clinical Centres *(pg 12)*, Rhonda Anderson recounts her experiences on the NHS Quality Improvement programme *(pg 30)* and Derek Elston reviews the PPTA meeting and 'How is your day?' initiative *(pg 28)*. So many people use this phrase in everyday conversation without realizing how difficult the day can be for some people living with a chronic disease, such as those requiring blood plasma as a treatment.

Finally, thank you to everyone who sent their good wishes on my semi(!) retirement from the charity.

Front cover:

Rhonda Anderson receives her QI facilitators certificate of achievement (pg 30)

Neil Dudgeon & Annette Badland on Pointless (pg 15)

Tayah Callender (pg 18)

Contents

Round up from ITP HQ

by Mervyn Morgan, CEO

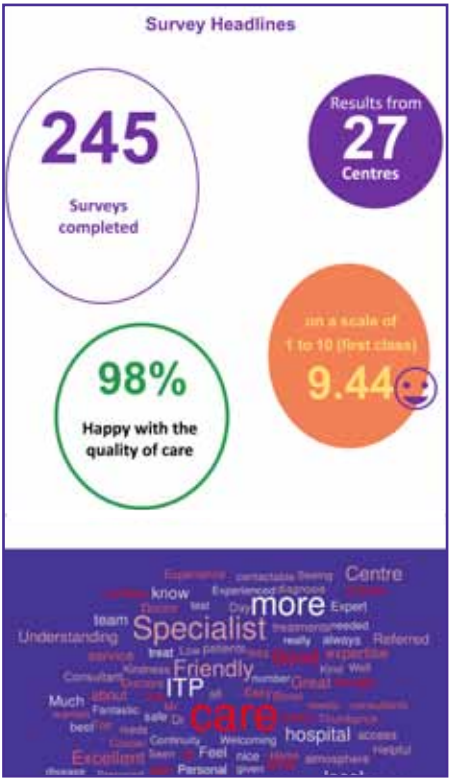
News from the ITP Office

The spring is always a busy time at the ITP office as we process new memberships and renewals of our existing members. However as many more members are joining via the website the administration is much improved.

We have also been processing the results of the ITP Centre Survey which went out towards the end of 2017. Having received back the last of the surveys from the Centres in April and spending the time since collating the results, it is almost complete, but before we share results with the membership on our website and in a future edition of the Platelet we will give the Centres first look at the detail. I have included some of the headline results opposite.

Work is also underway with the planning for our Annual Patient Convention, which is being held at Chester Racecourse in October. You can book tickets on our website at www.itpsupport.org.uk. Chester is a beautiful city with some wonderful history, so why not book tickets for our convention and stay a few days to sample the sites that this historic city has to offer.

We are also pleased to announce that we will be hosting the ITP International Alliance meeting the day before our convention with representatives from ITP organisations attending from all corners of the globe.



We also had a mention on National TV recently thanks to friend of the Association, Neil Dudgeon, (star of Midsummer Murders) who was appearing on the quiz show, Pointless Celebrities, along with his quiz partner Annette Badland. They reached the final only to miss out on the jackpot by 1 point! Neil very kindly dedicated his £250 winnings to the ITP Support Association.

Screening for bowel cancer

by Dr Will Lester

A patient has asked us whether it is worth sending in a sample for bowel cancer test, or whether it will give a false reading of blood present because of ITP. This is an interesting question. First, it's worth giving some background information on bowel cancer screening

Bowel cancer is a common type of cancer in both men and women. About 1 in 20 people will get it during their lifetime.

Screening is offered in the UK to people who are 55 years or older. It can help detect bowel cancer at an early stage, when it's easier to treat. It can also be used to help check for and remove small growths in the bowel called polyps, which can turn into cancer over time.

Depending on your age, there are two types of tests – a flexible camera test (colonoscope) or a home testing kit that requires a small sample of poo. If blood is detected in the sample (often called faecal occult blood or 'FOB' for short) the camera test or a suitable alternative is recommended.

Does ITP affect the FOB* test? It makes sense that if a person is having bruising and bleeding on the outside (eg on the skin and in the mouth) then the same thing could be happening on the inside, within the intestine, where small amounts of blood could mix with the stool to give a positive FOB test, even if it's not obvious to the naked eye. Very little is published on FOB results in patients with ITP. In a study of just over 50 children with either newly or relapsed ITP with a platelet count less than 10, about 1 in 5 (20%) of those tested had a positive FOB result[1]. It's possible that in older adults with severe ITP, a higher proportion would have a positive stool compared to children. We don't actually know how high the platelet count needs to be to prevent a positive FOB test due to ITP alone and it may differ between patients. However it's reasonable to surmise that if there's no external bleeding, internal bleeding is also less likely.

I would suggest a pragmatic approach:

1. An FOB test is more likely to be positive if you're having a flare of ITP so if possible, do the test when things are more stable.
2. You can't assume that a positive FOB test is due to ITP so further investigations may still be required.
3. If colonoscopy is recommended, it would be prudent to have a reasonable platelet count (eg over 50) in case biopsies or polyp removal is required. You should inform your haematologist beforehand in case treatment needs to be given to improve the platelet count.

[1] *Flores & Buchanan. Am. J. Hematol. 91:287–290, 2016*

* The new FOB test is now known as a FIT test (faecal immunochemical test).

American Perspective

Professor James N. George MD
University of Oklahoma Health Sciences Center

ITP, Platelet Counts, and Pregnancy

When platelet counts of women with ITP decrease during pregnancy, it has been assumed that the ITP has become more severe. Greater severity of ITP during pregnancy is consistent with observations that other autoimmune diseases, such as systemic lupus erythematosus, may become more severe during pregnancy. However our recent research suggests that decreasing platelet counts during pregnancy in women with ITP may not mean that the ITP is more severe. The platelet counts of all women decrease during pregnancy. Therefore the platelet counts of all women with ITP will also decrease.

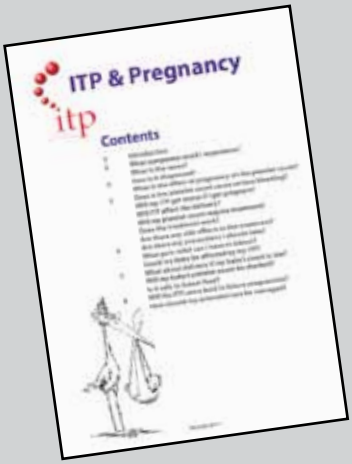
Our research began with the goal of looking at platelet counts of healthy women with uncomplicated pregnancies. Our goal was to find out how many women have what is described as "gestational thrombocytopenia" or "incidental thrombocytopenia of pregnancy" and try to determine its cause. These low platelet counts in healthy women with uncomplicated pregnancies are not a disease; they are merely a transient "condition", just as pregnancy itself may be described as a "condition". In 4568 women with uncomplicated pregnancies, platelet counts were already significantly lower than normal at 8 weeks of pregnancy. Throughout their pregnancies, the platelet counts continued to decrease until delivery, when 10% of women had platelets counts less than 150 (our lower limit of the normal range). These women with platelet counts less than 150 are the women with the "condition" described as gestational thrombocytopenia. Then 7 weeks after delivery, their platelet counts were normal again. The average decrease during pregnancy was 17%. The platelet counts of all women decreased at the same rate throughout pregnancy; the platelet counts of each woman decreased about 15-20%. There are multiple normal changes throughout pregnancy that contribute to the lower platelet counts. I discussed these in my American Perspective in the March 2016 issue of The Platelet.

529 of the 4568 women had a second uncomplicated pregnancy during the years of our study. Women who had a low platelet

count during their previous pregnancy were 14-times more likely to have a low platelet count again, compared to women who had not previously had a low platelet count. This happens because our platelet count level is genetically determined. Our platelet counts are always at about the same level throughout our lives. While the typical normal range for all people is 150 to 450, the platelet counts of each individual do not go up and down throughout this entire range. Each of us has our own narrow range. For example, my platelet counts during the past 30 years (measured when I had a routine health exam) have averaged 203; their range has been 163-243, but almost all (83%) of my platelet counts have been between 190 and 220. Someone else will have lower platelet counts; others will be higher. And that's where they stay throughout our lives. This is the reason why it is the same women who have low platelet counts, "gestational thrombocytopenia", with each of their pregnancies. Their platelet counts when they are not pregnant are probably always close to 150, the lower limit of normal. During their pregnancies, their platelet counts will naturally fall below 150. Women whose platelet counts are higher, such as 250, when they are not pregnant will not fall below 150 during their pregnancies.

This also explains what happens during pregnancy in women who have ITP. In our study 24 women had ITP. Their platelet counts were lower than the women without ITP and during their pregnancies their platelet counts decreased at exactly the same rate as women without ITP. After delivery. I assume that their platelet counts increased, like the women without ITP.

What does this mean for women with ITP who become pregnant? It means that their platelet counts will decrease during pregnancy. At delivery their platelet counts will be about 15-20% lower than they were before pregnancy. This is not more severe ITP. This is normal. (I'll say this one more time: this is normal.) This normal platelet count decrease happens in all women and in every pregnancy. Of course I understand that some women may have severe ITP and their ITP may become even more severe during pregnancy. But I believe that this is uncommon.



If you would like to know more about ITP in pregnancy, gestational thrombocytopenia, or pregnancy whilst in remission from ITP, The ITP Support Association has an informative booklet compiled with the assistance of leading ITP specialists and obstetricians with a special interest in bleeding disorders.

Letterbox

I have suffered with the carpal tunnel syndrome for years and have managed to get by with the occasional Hydrocortisone injection when necessary. This has now been withdrawn from me and leaves me with only the option of having surgery on both of my wrists. Please can you ask Platelet readers who have had this surgery with low platelet counts for their opinions?

In the past whenever surgery has been spoken about on various consultations the surgeons have never wanted to perform surgery.

Paula Freeman

I am being pushed by my family to try diets to help platelet count. They have persuaded me to try a gluten free diet. But after 2 weeks my platelets have dropped further to 8. I shall keep going a bit longer.

On the internet papaya leaf has a good write up and number of followers. Is there any evidence, even anecdotal, that it would be worth a try?

My 3½ years of ITP have been a roller coaster. High dose steroids sent me loopy. On third relapse I refused steroids and tried eltrombopag. We finally got what we think is the correct dose but then I suffered joint pains, visual disturbance etc. I switched to Nplate about 3 months ago but am not having much success with it, though my consultant suggests it might kick in yet so it is worth persevering. At least I know now that I am not alone in my frustration.

Once again my bruises give me a fetching piebald horse look! Thanks for all the support from the group.

Heather Bruce

My daughter was diagnosed with ITP aged 10 in 2014. She suffers badly with fatigue so misses lots of school and has virtually no social life.

She has had steroid treatment and IVIg in the past and is now using eltrombopag. She has never met anyone her age with the condition, and being a teenager, now 15, turns to the internet for information.

Her friends are very supportive and help with school catch up but don't realise how difficult and isolating it can be with ITP and the associated fatigue.

Jess would love to have contact with other teenage sufferers to share stories and advice, and feel part of a 'community' that understands things.

Do any Platelet readers know of an ITP teenage on-line group?

On a personal note I would like to praise you as the founder, and all who work with the ITP Support Association, for the amazing hard work you do to help and support people with ITP. We have been members since Jessica's diagnosis and have found lots of useful information from the Platelet and your website, thank you.

Helen Farmer

My 7 year ITP roller coaster ride

by Katie Hackman

I was diagnosed with ITP in 2011 for which I was given steroid therapy.This was tailed off, but I relapsed in July 2011 and was again given a very high dose of steroid. This was tailed at a slower rate this time. I again relapsed in Feb 2012.

I was then given a second line treatment of Rituximab which was complicated by reactive arthritis, and I was hospitalised due to this.

As third line treatment I was then recommended to have a splenectomy which I had in Feb 2013. After about 6 weeks I started to notice the tell tell signs of my ITP returning. The splenectomy had not worked.

For fourth line treatment I was given romiplostim but due to erratic blood counts was then put on to a fifth line treatment, eltrombopag. I had an allergic reaction to this so was put back on romiplostin, my sixth line treatment.

My blood count was still erratic so my consultant contacted Dr Drew Provan whom I then went to see. He prescribed mycophenolate (Feb 2014) , which I have been on ever since and have been very happy on. The dose has been tailed slowly. Recently I was recommended to reduce to 250mg morning and night from 500mg in the morning and 250mg in the evening. After 5 days I started to feel extremely tired and all my joints very sore. To start with I thought I was getting the flu. I did a little research on Mychophenolate,withdrawal symptoms . I decided to up my dose to my original and in a few days was fine again.The symptoms were similar to when tailing steroids.I have asked if I could have the liquid form of mycophenolate but have been told it was to expensive so is not possible. I have tried several time to go down to the dose recommended by my consultant but have been unable to due to the side effects. I am now taking 375mg in the morning (cutting 500mg to get this dose) and 250 in the evening and feeling fine again.

My local consultant is concerned that I have been on mycophenolate for a long time which could have adverse effects in later life which I fully understand but I have been feeling very well on mycophenolate and am able to lead a full and active life and am reluctant to change this.

I have listened to my consultants since the onset of my ITP and as a result I do not have a spleen and my adrenal glands no longer work due to the high dose and prelonged period on steroids. (I take hydrocortisone each day, 10mg in the morning, 5mg at lunch and 2.5 in the evening).

I'm currently waiting to see Dr Provan for a review of my ITP management.

Dr Provan commented on the long term use of mycophenolate as follows:–

We have had patients on this for many years with no problems. Patients after transplantation are on mycophenolate for life.

ITP (probably!) saved my life

by Xenia Norman

It was bad enough getting used to a diagnosis of ITP without a mole just above my left breast taking on a life of its own. It was larger than my other moles (at just under 1cm) raised and itchy. With a sinking heart I saw the GP. "You have absolutely nothing to worry about" she said, "but if you're really concerned you can see a dermatologist". I went home and photographed the mole, saved the picture onto the computer and tried not to think about it. I failed. Over the next few weeks it became known as "My Scary Mole" and eventually I went back to the GP and asked to see a dermatologist.

He was charming and said "You have absolutely nothing to worry about but if you're really concerned I can do a biopsy". Well, I felt a bit of an idiot but after worrying away for another couple of months I opted for the biopsy. The result came back and I was re-assured "You have absolutely nothing to worry about." The pathologist gave it a clean bill of health. But the dermatologist had said he would take it off if I wanted. So, another couple of months went by while I tried to convince myself everything was OK. I failed. I went back to the GP and asked to have it removed. Only to be told that cosmetic surgery was not available on the NHS and I would have to go privately.

A private dermatologist seemed a big move so another couple of months passed while I spoke sternly to myself about how silly I was being. I failed and eventually I claimed on my husband's health insurance and trotted off to Harley Street. "You have absolutely nothing to worry about" said the private dermatologist, "but if you're really concerned you can see a plastic surgeon." I felt I really had to pull myself together and hear the messages of re-assurance I was getting. I failed. I opted to see the plastic surgeon. He said (no not that) "If you were my sister I would tell you not to do it. It will leave a horrible scar". I felt I had taken this as far as I could, and the saga might have ended there if I didn't have carpel tunnel syndrome. It was so severe that I needed an operation.

This is where the ITP comes in. To have that operation I needed to raise my platelet count. To do this I had to have IVIg and steroids and the mother and father of all headaches – even with the prophylactic. Well I thought I might as well make the most of this and have My Scary Mole removed at the same time. I remember just before the operation I found the picture I had taken nearly 18 months ago and saved on the computer. The mole had grown from a single round into a clover shape nearly three times the size.

When I went to have the stitches removed the plastic surgeon said, "I am really sorry, but it was a malignant melanoma and I need to take a much wider safety margin". "My platelets", I wailed but undeterred he went ahead and managed somehow. The private

dermatologist rang up and apologised and sent all the samples off to a Top Man to be reviewed. We discovered that the melanoma had been there in the first biopsy and had been missed. We also discovered that since the biopsy the melanoma had more than tripled in depth. That is when they get dangerous.

I asked for a referral to the Marsden and they said that there was no chemotherapy available for melanomas; (I think there is one now that can help a little). With my depth of melanoma, the follow up was for life. However, ten years on they said the risk was now seen as negligible and signed me off. So, you see, if I hadn't had ITP I would never have had the IVIg. And without the IVIg I would never have the mole removed. And, given that surgery is, virtually, the only treatment for melanoma, I have to conclude that having ITP (probably) saved my life.

ITP Patient Afternoon

on **Friday 13th July** from **1.30 - 4.30pm**

The ITP Support Association invites ITP patients and parents of ITP children to attend an ITP Patient Afternoon at

The Platelet Mission,

Kimbolton Rd, Bolnhurst, N. Beds MK44 2EW

This informal free (ticket only) event will provide an excellent opportunity to share experiences, develop friendships and talk to the ITP specialists from the two ITP Clinical Centres:–

Dr Martin Besser (Addenbrookes Hospital, Cambridge)
Dr Emmy Dickens (Addenbrookes Hospital, Cambridge)
Dr Emily Symington (Addenbrookes Hospital, Cambridge)
Dr Nichola Cooper (Hammersmith Hospital, London)

The afternoon will include some short talks, discussion group, QA session to put your questions to the expert clinicians, refreshments, and social time to chat with other patients/parents:

Tickets are available (free of charge) from ITP HQ

web: www.itpsupport.org.uk Email: info@itpsupport.org.uk Tel: 01234 376559

News from the UK ITP Forum

by Dr Quentin Hill (Secretary to the ITP Forum)

The UK ITP Forum is collaborating with the British Society of Haematology on a good practice paper to provide guidance to clinicians on how patients with ITP receiving steroids should be managed to prevent osteoporosis (OP). The writing group was very fortunate to have the involvement of two international experts in the care of patients with osteoporosis Professors John Kanis and Juliet Compston. We have written this good practice paper because there is little in the ITP literature about this topic and we hope that it will lead to a better awareness of the steps that need to be taken. The paper is currently undergoing review by the British Society of Haematology task force and once approved, will be available to download from the BSH guidelines website https://b-s-h.org.uk/guidelines/. A link will also be provided from the UK ITP forum website.

The UK ITP forum has now adopted the logo above and are very grateful to its designer, Neville Watson.

University Hospital Birmingham are recruiting patients to a study looking at a new therapy for patients with difficult to treat ITP (PRTX-100). This is an exciting development and results of the study have the potential to change treatment pathways. In addition they are taking part in the FLIGHT study which asks which treatment is best to give first in newly diagnosed patients.'

News from ITP Centres

University Hospital Birmingham are recruiting patients to a study looking at a new therapy for patients with difficult to treat ITP (PRTX-100). This is an exciting development and results of the study have the potential to change treatment pathways. In addition they are taking part in the FLIGHT study which asks which treatment is best to give first in newly diagnosed patients.

Dr Nichola Cooper and her team at Hammersmith Hospital had a paper accepted in the British Journal of Haematology on the antibody work that the ITP Support Association funded. They also submitted a poster to the EHA (European Hematology Association) on the MRI ITP study and reported that the bone marrow work is progressing well, both of which projects were also funded by the ITP Support Association.

The UK ITP forum, established in 2011 is a working group of health care professionals with a special interest in the care of patients with immune thrombocytopenia (ITP)
The recently revised forum website www.ukitpforum.org has a complete list of ITP Clinical Centres

Your questions answered...

Q *My daughter has been diagnosed with ITP since last year and we would like to know the medical answers please.*

1. *Does hayfever affect the platelet count.*
2. How can someone know that their platelets are dropping?
3. What is the lifespan of patients with ITP?

Dr Nichola Cooper
Senior Lecturer & Consultant Haematologist, Hammersmith Hospital replies:–

A 1. We don't have any data about hayfever affecting the platelet count to be sure.
2. As long as there is no bleeding the actual platelet count does not matter really. So knowing the actual platelet count is not as important as the symptoms of bleeding, or tiredness (which some people also suffer from).
3. This can be very variable between people, so it can be difficult to say.

Q *I have suffered with carpal tunnel syndrome for years and have managed to get by with the occasional hydrocortisone injection when necessary. This has now been withdrawn from me and leaves me with only the option of having surgery on both of my wrists. Please can you ask your readers for their opinions from those who have had this surgery with low platelet counts. In the past whenever surgery has been spoken about on various consultations the surgeons have never wanted to perform surgery. If this goes ahead I will be put on steroids for a few weeks to bump up the platelet count and then hope I don't bleed too much, as I understand the wrist is very vulnerable.*

Dr Drew Provan
Reader in Autoimmune Haematology Barts & The London School of Medicine replies:

There is no reason why someone with ITP should not have carpal tunnel surgery. It probably needs the platelets to be 80 or more and she could have IVIg before the surgery (e.g. 5-7 days beforehand).

Q How many ITP specialised ITP Treatments Centres are in the United Kingdom?

Shirley Watson
(Platelet Editor) replies:–

A *There are 22 Adult ITP Clinical Centres, 16 Paediatric ITP Clinical Centres and 1 Adolescent ITP Clinical Centre for 13 - 20 year olds. They are listed with links to each Centre at www.ukitpforum.org/index.php/en/itp-clinical-centres on the ITP Forum website.*

Q *In the March 18 issue of The Platelet Dr John Grainger's answer to a question on cow's milk intolerance included the statement "Severe inflammatory bowel disease is definitely linked with ITP and any history of chronic tummy pain or diarrhoea needs to be investigated by a gastroenterologist. Would he be willing to explain a bit more please, for example is it just two autoimmune diseases running concurrently, or does one condition cause the other?*

Dr John Grainger
Consultant Haematologist,
Manchester Children's Hospital replies:-

A Inflammatory bowel disease can cause immune thrombocytopenia. We would call this secondary ITP. Sometimes the bowel disease may not have been diagnosed when the patient presents with ITP.

Q *I have a 2 year old boy who has had low platelets for around 8 months now, he has now been referred to the chronic ITP specialist at GOSH. Can you please advise if it is common to have ITP for this long in toddlers? And when do they usually outgrow it?*

Dr John Grainger replies:–

A Children as young as a few months of age can have ITP. This may follow a vaccine when typically it usually resolves quicker than non vaccine related ITP. Once ITP has persisted for over 6 months the registry data suggests that 25% will resolve in the next 6 months. Once the ITP has persisted for 12 moths we refer to this as "Chronic" ITP. For children with chronic ITP about 10-20% will recover from their ITP each year.

Research Funds Appeal

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

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.

You can also support ITP Research by holding a fundraising event.
Why not set up your own fundraising page to collect donations or sponsorship at https://mydonate.bt.com/charities/itpsupportassociation

Fantastic Fundraisers!

Our congratulations and warmest wishes go to Corinne and Bill James who recently celebrated their 25th wedding anniversary. As their grandson Evan has ITP they very generously requested donations to the ITP Support Association in lieu of presents. A fantastic total of £645.96 (including gift aid) was raised by their family and friends, and we send our gratitude to one and all.

The Red Socks Charitable Trust made a much appreciated donation of £1,000 to be used for ITP equipment. A hearty thank you goes to one of our supporters who was familiar with this Norfolk based charity and most kindly nominated our Association to receive a contribution. Red Socks raises funds from Country Fairs and makes grants to charities particularly relating to children in East Anglia and Derbyshire where funds are raised. Once the ITP trustees decide which equipment to purchase in relation to children with ITP needs Red Socks will be informed of how the money has been spent.

Corinne & Bill James celebrate 25 happy years

Our thanks go to the Peter Clare Focus Group who sent £146.15 donation in memory of Peter Clare, and also to Atlas Trading who donated £71 in March and a further £78 in May, raised from their collection box they hold in the company's shop.

Regular supporter Valerie Hambelton, who has ITP, sent in a super £450 of which £250 was raised with the help of photo shoot vouchers donated by LDN photography. The vouchers were sold for £20 with all funds donated to ITP. Valerie's son Mark and partner Ann-Marie own the photography studio. The other £200 was raised by a sale of crafts made by the talented people who live at Catherine Baird Sheltered Housing Scheme. Our sincere thanks go to Valerie, Mark and Ann-Marie, and all the craft-makers at Catherine Baird Housing.

Once again we send our warm thanks to Neil Dudgeon, star of Midsomer Murders for being brave enough to appear on a Celebrity quiz show to raise money for our charity. On this occasion Neil appeared on Celebrity Pointless (see front cover) and nominated our Association to receive the £250 charity donation.

ITP Patient Day in Wales

by Colin Williams (ITP Support Association Trustee)

On a very wet Friday afternoon about forty people braved the elements to attend a Patient Day at the University Hospital of Wales in Cardiff. About 10% came from Bristol with the vast majority coming from different parts of Wales. It was pleasing to note that a number of parents brought their children. In addition there were present a number of junior medical staff and specialist nurses.

For those of us with blood conditions it was, however, a little strange to find the event was held in the Seminar Room of the Obstetrics and Gynaecology Department !!

The afternoon commenced with presentations from 2 haematologists specializing in adult ITP, Dr Rachel Rayment (Wales) and Dr Charlotte Bradbury (Bristol), together with paediatric haematologists Dr Philip Connor (Wales) and Dr Emma Phillips (Bristol). After the clinicians, Shirley Watson, the ITP Support Association Honorary President spoke, explaining the history of the Association and encouraging patients to form local groups. This was welcomed by the attendees, many of whom mentioned that they would look forward to getting together again".

Key points made by the speakers were :

1. Within medicine ITP is amazingly rare. The Cardiff area has only 6-7 new cases a year whilst the Greater Bristol area with a population of almost a half million has only 20-30 new cases each year.

2. Prior to the appointment of all the speakers ITP was managed by a wide variety of haematologists with consequential variable management. In both Cardiff and Bristol ITP patients are now looked after by the speakers who have a special interest in ITP.

3. On presentation there are quite a range of different symptoms reported by patients in addition to the standard bruising resulting from low platelet counts.

4. With children there is a tendency for ITP to present in an acute form at commencement but with the appropriate management many become well quite quickly. Clinicians therefore have to be careful not to over treat.

5. Due to its rarity as a medical condition only a limited amount of research has been undertaken into ITP to date and not very much has been shown to be conclusive with the result that there is a little "crystal ball gazing" in determining treatment. The cause of ITP remains idiopathic. Over the years research projects undertaken have provided a considerable amount of knowledge about the immune system and ITP as one of the medical conditions associated with its dysfunction. Clearly therefore we hope that continuing research will contribute to an ever better understanding.

6. A large number of patients report adverse reactions to prednisolone which generally has been the first line of treatment. Consequently the haematologists in Bristol and Cardiff are collaborating in new research to ascertain if Prednisolone given in conjunction with Mycophenolate (MMF), as the first line of treatment, would be both more effective and satisfactory.

Following the presentations people broke into two groups, one for adults and one for children, to enable patients to put their questions directly to the haematologists present. This was really beneficial in view of the time taken.

As always with these events thanks must be extended to the organisers, speakers and attendees for all their effort put into a rewarding afternoon.

Case History: Tayah, age 5

Tayah Callender *(see front cover photo)* was 23 months old when she was diagnosed with ITP in March 2013.

A week or so prior to her diagnosis, Tayah developed a haematoma in the centre of her chest. As I undressed her for a bath I noticed a large lump and bruise on her chest and thought that she must have had some form of accidental injury at day nursery. The following morning I took Tayah to the GP and raised my concerns with the nursery as I did not accept that they had no idea as to how Tayah had come to have such a large bruise. I informed the GP that it was my belief that she must have fallen on to something like a toy. I was reassured by the GP that she would be OK and the haematoma would resolve itself.

We've heard of being wrapped in cotton wool !

Tayah then came down with a norovirus one evening and was unable to keep any fluids down. I noticed a few small bruises on her torso but didn't think too much of them and told myself perhaps they had been caused by her twin whilst playing. As the day went on she started to become lethargic and larger, darker bruises were suddenly appearing out of nowhere. At this point I became worried that she might have meningitis. We went straight to the GP, who advised me to go to the hospital. I was well aware that her symptoms and position of her bruises could give concern about potential physical abuse. When we arrived at the hospital, we were taken to a single room. I noticed the doctor pull out a child protection body map where he proceeded to mark out her bruises on the sheet. I informed the doctor that I was well aware that it looked like she may have been physically abused but that was certainly not the case and there was clearly something medically wrong with her. I urged them to look for a medical reason before they initiated any child protection process as due to my educational and employment background, I knew this would remain on Tayah's file regardless of the outcome. The doctor agreed and advised that if tests did not reveal a medical cause the child protection process would need to be initiated. I agreed that I would fully expect and accept such actions at that point but would raise a complaint if they

did not investigate medically first. Whilst waiting the bruises kept coming. The doctor advised that they thought it may be something worse than meningitis, which at that point I couldn't think of anything worse – that was until I heard the word leukaemia! Within 20 minutes of the blood test being taken we had our diagnosis of ITP. With a platelet count of 1 she had this condition which, despite my best efforts I could not remember what it was called. But I remembered a friend of mine recently mentioning that her little girl had been diagnosed with a rare bleeding disorder that sounded very similar. Nobody could really tell me much, except for the fact that it was rare and risks of a platelet count that low were significant. I messaged my friend who confirmed it was the same condition, but she too knew very little about it. Despite Tayah being very unwell due to the norovirus I remained optimistic as I knew my friend's little girl appeared to be fine and her prognosis appeared to be good.

I was told that 3 out of 4 children spontaneously recover within 3- 6 months. Then out of the remaining children that don't spontaneously recover during this time 3 out of 4 will go on to fully recover within a year. However as Tayah's counts remained in single figures any bump to the head meant an overnight stay in hospital. We have continued to have open access to the children's assessment unit and were usually seen very rapidly. As she was a wobbly toddler with a very active twin brother, avoiding bumps was very difficult at best. Needless to say, we spent many nights in hospital. When Tayah didn't recover as expected I was advised she would be referred to ITP specialists in Cardiff. At this point the eltrombopag petit trial was underway. As Tayah suffers with nose bleeds she was prescribed tranexamic acid, she also tried steroids and rituximab but none of these had any effect. Her platelets remained at single figures, with the exception being a slight rise to 17.

Whilst on steroids the side effects were certainly not worth the extra 8-9 numbers on the platelet count. Tayah had one significant nose bleed that we couldn't stop. This was by far the worst experience of my life. It started around midnight whilst she was sleeping, there was blood all over her bed so I knew she must have bled for some time before waking. Although the bleed was more trickling than gushing I could see that it was not stopping despite our best efforts. As my husband had to stay with the other children I had to drive to hospital myself whilst trying to pinch her nose (In hindsight an ambulance would have probably been the better option), but knowing the delay this may have had I wasn't willing to wait. At the hospital the doctors didn't seem to be overly worried, but I made it clear that if I wasn't concerned we would not be there at that time of the morning. She had been bleeding for quite some time and I knew how much blood was left in her bed. The trickling nose bleed appeared to be starting and stopping, Tayah asked to go to toilet complaining of tummy ache and the

next thing I knew she was vomiting blood everywhere. I heard a nurse say 'make the call' but apart from that everything was a blur. I was shaking uncontrollably falling backwards into someone else's cubicle covered in blood. I recall being sat on a seat by a nurse who was trying to calm me whilst others were working on Tayah, I could see oxygen masks and fluids being Injected into her and could hear the nurse directing me to look at the monitor that was showing her heart beat. The nurses were amazing, but the experience of that night still affects me to this day.

I didn't think I could continue the way we were, some nose bleeds a lot more difficult to stop than others and always seeming to occur during the middle of the night. We don't sleep much as we keep checking she's not having another nose bleed. She is constantly tired and does sleep more than her twin. She doesn't have the energy levels of others her age but she is very bright and has been moved up a year for her reading and spelling (or as she says "top of the class"). Her school are brilliant and accommodate her needs ensuring she can continue to play safely and join in the activities that the others do, albeit it with caution and a lot of supervision.

Tayah started eltrombopag, during May last year. I was not optimistic that we would experience any success, after all nothing else had worked to date.

However I have been pleasantly surprised. We have not achieved any life changing results as such but we have had an improvement. This does of course fluctuate and we did recently take a dip back down to single figures. Her counts are now often around 30 – not great considering what normal is, however this is fantastic for Tayah. The little girl who has always been in single figures has finally found something that gives her a boost. In terms of managing her health needs this has been invaluable. Yes we do still get nose bleeds and require rituximab, but these are nowhere near as lengthy as they were, and much to Tayah's delight we don't have as many bruises.

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

All the nurses and doctors at Cardiff (and community nurses) are amazing with her. She doesn't like going to the hospital for blood tests but soon forgets all about them when she finds a whoopee cushion in the bravery box and is always eager to return to the hospital to make sure Louise (play therapist) has got one of her artistic creations on the display board.

Throughout the whole ITP journey Tayah has been brilliant. There are activities that she can't do and as she's getting older this does bother her but we are optimistic that this could change now she is on eltrombopag.

Travelling with Nplate

James Collins wrote to us asking:–

My wife, who is Spanish, and I travel overland and by ferry from the UK to the Canary Islands ,a journey of 6/7 days, where we remain for up to 2 months. We are supplied with 3 preformed plastic packs of Romiplostin which we keep in a cool bag with frozen ice blocks. Whilst hotels and ferry companies are usually very helpful there is never ever a guarantee that the fridge temperature is below 8 degrees C therefore it can be a bit traumatic trying to keep the packs at the right temperature and the cool bag is not necessarily the best solution. We have been searching for a suitably sized cool bag fitted with a monitoring thermometer without success (there are such cool bags for diabetic patients but they are too small).

In order to reduce the bulk I have been looking at the possibility of separating the Romiplostin vial and water vial from the rest of the components in 2 of the preformed packs and putting all of the temperature sensitive components in one pack thereby reducing bulk. I've put my idea to Amgen but they are reluctant , for obvious reasons, to advise. I wonder if anyone on your team could comment please.

We sent his query to Dr Hitan Patel at Amgen. He replied that coincidently Amgen had recently submitted new data to the European Commission and were awaiting approval to update their advice that Nplate (romiplostim) may be temporarily removed from the refrigerator for a maximum period of 24 hours at room temperature.

Amgen duly received European Commission approval for the stability variation. The amended text is as follows:-

*"Nplate may be removed from the refrigerator for a period of **30 days** at room temperature (up to 25°C) when stored in the original carton."*

Dr Patel advised us that the patient leaflet will be updated accordingly.

We conveyed this information to James Collins and in due course he replied:–

In the light of your email I have spoken with Amgen about the viability of carrying the powder and water separately from the remainder of the standard pack and apparently it is possible, provided that:–

a) The powder and water are kept securely in the original plastic container (I find I can fit 3 sets without difficulty)

b) The plastic container is returned to the original cardboard carton to avoid light damage.

c) That the revised stability provision be followed.

Obviously the rest of the paraphernalia will need to carried separately.

Advice on carrying prescription drugs abroad can be found here (including taking a doctor's note): *https://medicaltravelcompared.co.uk/travel-insurance-guides/taking-medication-on-holiday.aspx*

At our recent Patient Day at Cardiff University Hospital the topic of travelling with Nplate was raised in the discussion group. Barry Catton, who has ITP, gave the group some very useful advice which he kindly recorded in writing for us as follows:

As a diabetic on insulin I have been challenged with the same issue of trying to keep my insulin cool when travelling. I have therefore used a product, as have many diabetics, called FRIO. I attach a couple of links below that provides background and information. In respect of the Romiplostin I tend to use the Eye Drop Wallet or Injector Wallet products as these are a sensible size but has a small black waterproof pocket / pouch. They are reusable and only require soaking in water for about 3 to 5 mins to work.

FRIO: *https://friouk.com/*
FRIO Medical: *https://friouk.com/product-category/medical/*
Eye Drop: *https://friouk.com/product/eye-drop-wallet-3-bottles/*
Injector Wallet: *https://friouk.com/product/injector-wallet/*

Our thanks to James Collins for his question and following up the Amgen update with further advice, and also to Barry Catton for sharing his successful method of carrying romiplostim (Nplate).

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.

£500 was sent by Mrs Morpeth in memory of her dear husband **Cec Morpeth**, who died on 19th April 2018 as a result of a freak accident in which he sustained a very serious head injury which was exacerbated by his ITP.

A pecuniary legacy of £1000 was gifted from **Dr Margaret Lowrie**'s estate and sent by her daughter, Helen. Dr Lowrie was an ITP member for several years, and compiled ITP medical papers and articles having been a scientist.

Tribute to Val Sizer by Shirley Watson

Valerie Sizer left her estate to be divided between a number of charities. The ITP Support Association received a £6,290.92 legacy although Val did not have ITP, nor knew anyone with it! She had been a client of Keith Lewis, our first Platelet Editor, who by profession is a piano technician. He had mentioned to Val about his volunteer work for the ITP Support Association and she later sent a donation of £100. With my thanks I sent a programme of a recent pupils' concert I had held in aid of ITP and we corresponded ever after, often about things musical. When her arthritis halted her piano playing she sent a big parcel of duet music for Keith and me to play. I never met her, but she was most generous in her ITP donations. I was deeply touched when I heard that our charity had received a legacy.

News & Views

ITP Registry Website

The Adult ITP Registry website *http://www.ukitpregistry.com/* has been totally revamped and includes an *Adult ITP Chat Forum* and a *Comments* section. You can also find a list of collaborating centres to see if your own hospital is participating in the Registry (which is part funded by the ITP Support Association)

EHA Congress

The European Hematology Association will be holding its Annual Congress in Stockholm from 14th-17th June with over 10,000 haematologists and patient advocates from all over the world expected to attend. Once again there will be a shared "patient advocacy hub" in the exhibition area. A total of 11 organisations, including the ITP Support Association, will display their logos and leaflets at the booth.

Long term plan for the NHS

The Secretary of State for Health and Social Care, Jeremy Hunt, has outlined his priorities for the forthcoming long-term plan for the NHS, which includes an integrated NHS and social care system, major efficiency savings by adopting new technology, and meeting performance targets for elective surgery and waiting times in A&E.
The first formal announcement is expected to coincide with the 70th anniversary of the NHS on July 5th.
[Ed – I'm biting my tongue very hard not to write an adverse comment here after my personal experience of waiting 9 hours for an ambulance to arrive for my elderly brother-in-law who collapsed at Christmas, and then being told by the paramedic that it wasn't worth taking him to hospital because the ambulances were queuing up in the car park!]

ITP Patient Convention

on **Saturday 27th October, 10 - 5pm**

at **CHESTER RACE COURSE**

Cheshire, CH1 2LY

Entry by ticket only: £25 members, £40 non-members

web: www.itpsupport.org.uk Email: info@itpsupport.org.uk Tel: 01234 376559

My Everlasting ITP Story

My everlasting story of ITP from a gibbering wreck to a thankful man recovering from years of uncertainty

by Professor Chris Kemp

I have suffered from Idiopathic Thrombocytopenia Purpura for over two decades. Initially my platelet levels stabilised at 38,000 after dropping to below 6000 when first diagnosed. I was diagnosed whilst in Israel giving a paper on cognitive musicology at the university there and was training for a marathon at the end of the month.

I returned to my hotel room after running to find that I had acute diarrhoea and sickness. Later on in the evening blood started to emit from both ends and I had to get a taxi to the hospital in Jerusalem which was not a pleasant experience. They would not admit me to the hospital until I had run my credit card through the machine and the psychological trauma of the whole experience was extremely upsetting. Once in the hospital they found the cause of my condition and gave me some tablets to sort it out. However, they ran a series of tests and one came back showing that I had an extremely low platelet count. This was the first time that I had ever heard about platelets and it was pretty disturbing and devastating.

They wanted to keep me in for observation for seven days and it was very difficult as I was on my own in a foreign country with no access to anyone to help. Luckily one of the doctors convinced the others to send me home and BA were supposed to set everything up for me to have a guided journey back to the UK. When I arrived at the airport no one knew anything about this and refused to give me any support at all and I arrived home in cattle class in the usual manner to be met by my very upset wife.

I went straight to the GP the next day and I was sent to the John Radcliffe hospital in Oxford where I underwent a series of tests. The doctors in Jerusalem said it was most likely that I either had AIDS or leukaemia which added to my distress. After waiting six very disturbing weeks for the results of the AIDS test it came back negative and I then had lumbar punctures taken and various tests for cancers of the blood. The service from both the John Radcliffe and the MK Hospital was exceptionally good and I made good progress.

As you may know the cause of this rare condition is unknown but it is thought that I had caught a virus between running two marathons which reduced my immune system coping mechanism which was then attacked by an unknown virus which caused my white cells in my body to destroy the

virus. However in the destruction phase the particles of the virus stuck to my platelets and the white blood cells then attacked my own platelets thinking that they were the virus. So my own body was attacking itself.

For years I lived with a low platelet level. Four years ago after suffering an internal haemorrhage in my legs after pulling a muscle in my groin playing tag rugby, I was rushed into hospital and given a high level of immunoglobulin which took my levels from 4000 up to 120,000. My specialist went mad; not because I had played non-contact rugby but because I had not thought about the possibility of a kick in the head or other injuries which could have occurred, which of course I had not thought about. At the time I had not had any treatment for this condition and this relapse came after back to back trips to the US and Australia.

My specialist then decided that they would try the only three known procedures at the time to stabilise the condition. The first was the use of steroids which failed miserably, made me fat and impossible to live with. The second was a drug called Rituximab which also failed with absolutely no effect. The third was to have my spleen removed through a splenectomy and then to manage the outcome after this which should increase the platelet levels or make them manageable. Without the splenectomy I was given little chance of reaching my 60th birthday as there were no other known treatments for the condition at the time.

I again had to undergo an AIDS test (the third since I had started on this road to recovery, such is the mystery of the change from analogue to digital records) but unlike the other two the results were quick but the wait was just as agonising because no matter how much you think you have avoided the spectre of AIDS you can never be 100% sure. After a botched nuclear scan where the dye in the radioactive element caused inconclusive results I developed a skin condition that took three months to clear. Funnily enough the skin condition baffled the greatest medical minds in dermatology and it took my cancer therapist to tell me that she had seen this before twice and that it was an allergic reaction to the dye used in the procedure. I then returned to my specialist.

At this point there were several new drugs which were available on the market in a test phase. I was asked if I would like to try romiplostim, a new drug. As you can imagine I accepted (she still has the bite marks on her arms) and I have been taking romiplostim for 30 months. This is, as you may know, a man-made protein based thrombopoietin drug, which has raised my platelet count to an acceptable level of 80,000-130,000. This has meant that although ITP cannot be cured, through permanent weekly injections with the drug I can maintain a safe level of platelets.

However, romiplostim does have its side effects, the main one which I suffer from is insomnia, which means that I only get

between three and five hours sleep a night. Long haul travel severely affects me and I no longer work in destinations where the time difference is longer that seven hours and I usually makes four hours the limit. I have been to the sleep clinic, to cognitive behavioural therapy sessions and used other methods, none of which have worked and thus I still struggle to get a decent rest. Unfortunately I am a workaholic and after leaving my Pro-vice Chancellor post at a university five years ago I have created a very successful consultancy business in crowd management, security and safety and I am thankful to my specialist and the Macmillan nurses for their brilliant support. However, I struggle with not sleeping every night.

One very sobering thought from being under the Macmillan nurses for over a year was that I realised just how lucky I was only having ITP, as some of those I saw in the unit were so poorly it made me feel humble that I was getting treatment alongside them.

I have a lot to be thankful for and I have never let ITP beat me. My family, friends and work colleagues that know about my condition have been so supportive. However, if anyone knows of a real cure for insomnia, do please let me have it as I would be eternally grateful!

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.

My ITP Journey

by Leslie Briggs

Well it all started very strangely for me. While undressing for bed my wife noticed hand sized bruising on my stomach several times. She asked me what had happened but I replied that I don't know how I had done it. As it wasn't sore or raised, I went on about my life. One day while I was with the diabetic nurse I casually raised the issue of my bruises although this wasn't the place for this topic. The nurse said she would do a full blood count and so that was that.

Next day I got a phone call from my doctor who started to quiz me about how I was feeling and how did I come to have that blood test. He then asked me to have the test repeated, which I did, and it showed I was extremely low with my platelet count. I was admitted to hospital where I was asked numerous questions about my lifestyle choices. I am just a simple married man, haven't had illegal drugs and my wife was my only partner. It just so happened that a haematologist was having a clinic at my hospital and he came to see me and performed a bone marrow aspiration, to rule certain diseases in or out. I have to say I was worried, my results came back and I was diagnosed with ITP, which of course I never had heard of.

I was discharged from hospital and attended haematology clinics. My blood count was never above 10 and at one time was 0 ! I was prescribed azathioprine but it didn't have any effect. I was offered steroids but declined them. So for years I was living with ITP on a blood count of 10 or less and doing quite well on this watch and wait approach.

During that time I had to get a tooth extracted and I was taken into hospital and given IVIg to raise my platelets for the extraction. I think they got up to around 60 but that was short lived.

My health deteriorated with me going into atrial fibrillation. My cardiologist wanted to protect me from a stroke, and wrote to a colleague of hers in haematology who reviewed my case and suggested that I could be given romiplostim and subject to platelet counts above 50 I could then be given warfarin.

I have been on romiplostim for several months now and my platelet count is around 70. I am also on warfarin and again doing really well. I am finished supervision for self administration of romiplostim, so I feel the health service has been on the ball from my initial conversation with the nurse to cardiologists and haematologists working to find a way to treat me.

How is Your Day?

PPTA CONFERENCE, BUDAPEST, 13th – 14th MARCH 2018 by Derek Elston

This year was marked by the 25th anniversary since the formation and founding of this global therapeutics association of which we are a stakeholder. It was founded around an actual need that representation would make possible relationships both with regulators and patient groups. PPTA are always asking "how can we help more patients?"

Paul Rosenthal PPTA's general counsel says, "when PPTA holds conferences and stakeholder meetings, it's great to see the industry and patients working together for a common cause. That's been driven by these factors – the transparency, the sharing of scientific data, the voluntary standards, and the continuous striving by the industry to improve and to make sure its products are safe and effective."

We all know how important and effective IVIg (intravenous immunoglobulin) is for treating ITP but how many of us know where it comes from and how it is treated before it is used?

Plasma collected from donors is the clear, straw coloured liquid portion of blood that remains after red blood cells, white blood cells and platelets are removed. Donors need to meet stringent criteria before being considered for plasma donation. The process takes around one hour. Having harvested the plasma, the real process starts and can take up to 12 months from the time of donation until the therapy is ready to be administered to patients.

Firstly, the plasma is tested for viruses known to transmit infections by plasma before it is frozen. Freezing can last up to a maximum of 60 days. It is pooled with other collected plasma and further tested before it begins the fractionation process. This process extracts therapeutic proteins from the plasma which include clotting factors; antibodies; A1PI (alpha1–proteinase inhibitor) ; albumin; speciality therapies. These plasma protein fractions are purified further to remove unwanted proteins and cleared of potential viruses by additional manufacturing steps before being packaged. A very detailed production with regulation and quality control throughout.

Donors are the key to success of patients with rare, life threatening disorders or in the case of ITP autoimmune disease. It takes 130 donors to treat ONE patient with a primary immunodeficiency disease: 900 donors to

treat one patient with an Alpha-1 antitrypsin deficiency and 1200 donors to treat one patient with Haemophilia. In addition to the rare genetic conditions such as bleeding disorders, plasma proteins are also used to treat a whole host of other conditions including autoimmune conditions like ITP and surprisingly, neurological conditions.

Patient advocacy is a most important element with the PPTA led initially by the haemophilia community and is a major driver of patient issues. It has been joined by IPOPI (International Patient Organisation for Primary Immunodeficiency's) established in 1992. This was followed in 2004 by PLUS (Plasma Protein Users Group) of which The ITP Support Association is also a stakeholder. Their modus operandi is to take action when patient communities are targeted by government cost saving measures, and commenting on EU health policy developments. It was also instrumental in getting IVIg back onto the WHO list of essential medicines.

The conference itself was, as usual, extremely interesting with a variety of informative presentations from international concerns. One of the best was from NICE on their Highly Specialised Technologies Programme.

Patient Mentors

a listening ear . . . . . .

Rhonda Anderson
0208 504 2688
rhonda.anderson@virgin.net

Derek Elston
0151 625 8213
derek.elston@itpsupport.org.uk

Dave Farrow
01664 852218
davidfarrow40@yahoo.co.uk

Being the 25th anniversary of PPTA, Kedrion Biopharma, an Italian company, and only one of a few companies who specialise in the production and distribution of plasma products worldwide, kindly hosted a reception for delegates. This was held at the Italian Embassy in recognition of the contribution they make in Europe through their Hungarian production facility. The reception was attended by the Italian Ambassador to Hungary and allowed delegates to network in a convivial atmosphere.

"HOW IS YOUR DAY?" is a global initiative that unites people worldwide who benefit from plasma protein therapies and highlights the important role of plasma donors in saving and improving patients' lives.

Visit www.howisyourday.org and share the content via your professional and personal networks.

The whole two days of conference; the PPTA stakeholders meeting and also PLUS proved extremely informative with exceptional presentations, networking with medics, pharma representatives, presenters and the other stakeholders. We returned back to the UK feeling exhausted but better informed and sadly, without the opportunity to explore the historic city of Budapest.

Quality Improvement in the NHS

by Rhonda Anderson

As a volunteer tutor for the Expert Patients Programme (EPP), with North East London Foundation Trust (NELFT) I was invited with 2 other tutors to take part in NELFTs QI programme (Quality Improvement in the NHS). This was a great privilege as we were treated as staff and given our own personal mentor. Mine was a lovely lady called Trish and she used to come to my house to help me with my QI project. I certainly couldn't have done the project without her help and support and that of my fellow EPP colleagues. Getting to grips with the associated technology was a whole steep learning curve of its own.

EPP is a 6 session course, to assist patients and their carers, to live with long term conditions. It is an evidence based programme and many benefits for patients and health care professionals have been demonstrated. Through various means I aimed to get increased referrals in Redbridge through GPs, as they see the most patients with long term conditions, who could benefit from this free service.

The thrust of QI is to make a small change that has a big effect. There is a process to go through, and in the end we had to give a five minute presentation to our fellow QI cohort in order to pass and get our certificate and badge. All the way through we attended five whole day sessions once a month and had meetings with our mentors in between to see how our projects were developing.

Everyone did a project that affected them in the workplace, such as reducing pressure sores, reducing the time to resolve queries in HR, reducing drug use in psychiatric units, and social media aspects of improving EPP uptake.

My project aim was to increase GP referrals to EPP within Redbridge by 10% by May 2018. The rationale behind this is that EPP helps patients to self-manage long term health conditions. The baseline data was not great, as there had only been two GP referrals identified in October 2017 and no more since then.

In fact, doctors or healthcare professionals do not need to refer patients, they can go via the self-referral route. However, this means they first need to know that the free service is available. A new information leaflet is in preparation, but there have been major delays with its production and we hope it will be rolled out very soon and available in GP surgeries. We are also working on a poster.

One of the most difficult tasks has been stakeholder engagement. As a non-staff member perhaps this was more difficult for me. Requests to have meetings with the Health Care Professionals at my own GP surgery, did not come to anything, although there was interest from the Diabetes Nurse, through my contact with her on the Patient

Participation Group , (PPG). Apparently the GPs did not agree to me contacting patients in the surgery and having the Practice Nurse point people in my direction, so I could give them verbal and written information. After this disappointment, I approached another GP practice, through the Practice Manager, and was invited to present EPP to their PPG. They may provide a room and want local courses for their patients. They have shown great interest and I await contact for further steps.

In QI you then have Plan Do Study Act (PDSA) cycles which work alongside the project changes you wish to make. So far I have not been able to test the change ideas, as progress has been very slow. I have to rely on other people, the Stakeholders, to act. This has inhibited the progress of introducing EPP to Patients in GP surgeries in Redbridge.

Trish Reynolds (mentor) & Rhonda

QI needs to be measured, but this was going to be difficult without the leaflets and the co-operation of GPs. I was not personally able to measure anything. For my presentation I got full marks for everything, except the measurement.

This is the learning I discovered during the process. It is a challenge for a volunteer to convince clinical staff of the value of EPP. As a volunteer I had no control over the production of the EPP leaflet and had to use other means of publicity. Issues of confidentiality were contentious, and a barrier to publicising EPP to patients directly, in GP surgeries. I had to be very proactive in approaching GP surgeries, which was not always welcomed by them. Change in the NHS is slow for many reasons, and I had to hold onto my impatience.

Persistence finally got one GP surgery on board, but I am still waiting for follow up, and the first EPP course to be arranged locally for the benefit of patients and staff alike.

It was a challenge that is ongoing. It shows how slow the NHS is to change and take up ideas that are really simple and free. There is always the call for more money to be spent, but even the things that are there are not always used, and it is a great shame that EPP is not rolled out in every GP surgery in the country for the benefit of patients and the NHS.

Having said that, it was really heartening to see the projects that were more 'successful' than the EPP ones. Staff engaged with their peers to make a small change that made a big difference. This may have been in administration or clinical areas. Quality Improvement is the way to go, and NELFT have seen improvements in CQC ratings, staff engagement and morale, all of which are excellent measures of project success.

I am thankful that I was invited to be part of this process and look forward to future developments in the uptake of EPP from GP surgeries.

USE THIS FORM TO:–

- **MAKE A DONATION***
- **CHANGE YOUR ADDRESS**
- **JOIN THE ITP SUPPORT ASSOCIATION***
- **RENEW YOUR MEMBERSHIP SUBSCRIPTION***
- **DISCONTINUE RECEIVING THE PLATELET**

* or do this on line at www.itpsupport.org.uk

Please tick 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 enclose £10 to renew my membership annual 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)*

Let us keep in touch – *please tick the appropriate box*

☐ Opt in to receive updates
please circle preference: email telephone post

☐ Opt out

Name _____ Tel_____

Address _____

Postcode_____Email_____

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

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