MAR 2019

the platelet

JOURNAL OF THE ITP SUPPORT ASSOCIATION

itp
Immune Thrombocytopenia

ITP NEWS, PATIENT STORIES, ADVICE . . .

AND MUCH MORE INSIDE !

THE ITP SUPPORT ASSOCIATION TEAM

Charity Registration No:1064480

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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.

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

Shirley Writes

Over the last couple of years a number of tributes and thanks have been included in The Platelet. This edition is no exception as Professor James George and Frank Watson both step down from their very different supportive roles within the Association, and Dr Paula Bolton-Maggs retires as chair of the ITP Forum.

Back in 2007 at the ITP Convention in Oxford I chaired a post-convention meeting with our speakers – a truly impressive array of expert ITP clinicians (Professors James George, George Buchanan & Dr Dee Terrell from the USA, Professor Victor Blanchette from Canada, and from the UK Professors Adrian Newland & Sir John Lilleyman, Drs Drew Provan, Paula Bolton Maggs, John Grainger & Roberto Stasi). During the discussions I clearly remember them expressing concern that most of their number were working towards retirement during the next decade, and they wondered if many young haematologists would have enough interest in ITP to follow in their footsteps. As predicted, most have indeed retired but they need not have worried! ITP has certainly been fortunate, and a quick glance opposite at our list of medical advisors will assure Platelet readers that ITP is in safe hands with the next generation of expert clinicians.

I have now decided to step down from the Association totally. Since taking part-retirement I am increasing my involvement with music and music arranging, and feel it is time for me to move on from the obligations of the charity. I will, of course, continue to have an interest in ITP and will be working with the ITP Forum. I am extremely grateful to all the volunteers and medical advisors who helped me build up the Association to a charity so well respected worldwide, and to all the patients and family members who have become friends over the years. I hope you will still keep in touch. While Frank and I move on to pastures new, we wish the Association team and membership well.

Front cover photos:

Millie Floyd *(see pg 11)*

Jimmy Gledhil *with the Jimmy Curzon 11 & Tommy's All Stars*

Contents

American Perspective

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

How do ITP patients know what's the right thing to do?

Understanding medical disorders and choosing the right treatment (or, maybe, choosing no treatment) is difficult for patients. It may be impossible. How can you cope with this?

Understanding medical disorders and choosing the right treatment is also difficult for doctors. However we can talk with our colleagues, we can read medical journals, we read textbooks, and much more than either of those, we now go online to read the summaries of medical journals and textbooks. Doctors are commonly specialists. For example, they may only see patients with heart problems. Or they may be surgeons who only operate on patients heart problems. Or they may be pediatric surgeons who only operate on children with heart problems. And so on. These specialists are comfortable with their knowledge as long as they stay within the boundaries of their specialty.

Patients, of course, can have serious problems affecting any body system. They can have anything. How can they learn about their illness and how to manage it? Patients can also go online, but they may be overwhelmed by a tsunami of information, most of it not relevant to their own questions, some of it misleading, some not true. Often the information is commercial, pushing whatever the company is selling. Often patients become confused, and they may become frightened.

Of course the normal, accepted source of information for a patient is her (or his) doctor. The ideal situation is for her and her family to have a comfortable conversation with her doctor, who can answer all of her questions. But this rarely happens (does it ever happen?). Doctors have tight schedules. The appointment times are limited, often to only 15 minutes. Doctors may not be good listeners. So what can a patient do?

For patients with a diagnosis of ITP, you know the answer, because you're now reading the March 2019 issue of The Platelet, the publication of The ITP Support Association. This issue, like all issues of The Platelet, is full of practical information.

Patients tell their stories, and this is a huge help for other patients, assuring them that they're not alone. The ITP Support Association is an ideal organization because it brings together hematologists who are experts in the care of ITP patients and ITP patients who have become experts in their illness. This combination of different perspectives would be ideal for understanding any illness. You're lucky that you have the ITP Support Association.

How did the ITP Support Association begin? It began because 25 years ago Shirley Watson was frustrated. Her young son had severe ITP that had not responded to treatment. She talked with her doctors. But she had many more questions. Nothing seemed certain. She could have stopped there, but she recognized that her problem was a common problem because ITP is not a common disorder. Shirley is not only very intelligent and insightful, she is determined. How she rounded up the best of England's ITP experts, I don't know. I do know that in 1996 she contacted me and asked for my help, for providing an American perspective for ITP. I remember that saying "No" didn't seem to be an option. I see adult patients; I asked George Buchanan, who sees children, to help. He couldn't say "No" either. And then we began the American Perspective in each issue of The Platelet, beginning in June 1997.

This has been one of the best experiences of my career. The Conventions have been memorable. The shared goal of providing the most important and most practical advice and insights has been as rewarding for me as it has been for you. And now it's time for me to retire from The ITP Support Association. My gift to you are two American hematologists, Spero Cataland, who manages adults, and Cindy Neunert, who manages children. With them you are in good hands.

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 through facebook at www.facebook.com/ITPSuppAssoc or by texting ITPA22 and the amount (£1 – £5 or £10) to 70070.

You can also support ITP Research by holding a fundraising event!

Professor Jim George – an appreciation

Dr Jim George is the George Lynn Cross Research Professor at the University of Oklahoma where he was chief in the Hematology-Oncology section from 1990 to 1999. He has had an interest in platelets throughout his entire career looking at their structure and function and covering those with either congenital or acquired disorders. Over the last two decades however he has concentrated his efforts on patients with thrombocytopenia, where he has made seminal contributions in both immune thrombocytopenia (ITP) and in thrombotic thrombocytopenic purpura (TTP). He has a reputation of collaborating widely and his publication list runs into the hundreds. He has covered many aspects of the disease from epidemiology through causes, treatment options and outcomes and including comprehensive studies on drug-induced thrombocytopenia. He was instrumental in the production of the first Guidelines on the Treatment of ITP in 1996 for the American Society of Hematology (ASH) which helped regularise patient care and he became the ASH President in 2005. This was a very appropriate accolade for his industry and eminence and well deserved.

Prof James George & Prof Adrian Newland

The Association was very fortunate to gain his support at our inception and he has been assiduous as a medical advisor, in attending and speaking at the Conventions and in his regular contributions to the 'Platelet'. There is no doubt that his interest and quality input were crucial in helping the Association establish its credibility as a national voice for patients with ITP and I, for one, am grateful for his friendship and involvement over the years. The Association will find ways of maintaining our links with him but wish him well as he moves, in his 80s, into something approaching retirement. We know he will not give up entirely and I am sure patients with thrombocytopenia will continue to benefit from his lifetime of experience.

Professor Adrian Newland

In the very early days of The ITP Support Association those contacting me often asked if there might be a cure for ITP in America. The local library (pre-Google days) found me the address of the American Society of Haematology (ASH). I wrote explaining that I had formed an ITP support group and asked who was the USA's leading ITP haematologist. ASH forwarded my letter to Professor James George who had been chairing a committee to produce the American ITP Guidelines. How surprised and delighted I was to receive a parcel in the post a couple of weeks later which contained a copy of the American Guidelines and a lovely letter from Jim offering to help in any way he could. And over the past 23 years help us he did indeed!

We corresponded for a couple of years, and first met when Jim came to speak at our 2nd Patient Convention in 2000, accompanied, as always, by his wife Katie. During his talk he referred to 'our support association', and so he has called it ever since, showing his deep commitment to our cause. His staunch support has been wide-ranging – answering patient queries, advising on difficult cases, checking the medical text in our booklets and website for accuracy, speaking and chairing discussion groups at many conventions, writing peer reviews on research funding proposals, and providing an empathetic ear and sound advice for non-medical issues within the charity. In short he has been a true friend and mentor.

Jim's first American Perspective essay was published in a very basic 8 page Platelet and this column, shared then with George Buchanan and now with Spero Cataland and Cindy Neunert has appeared in every edition since. It has been a great privilege to publish these articles, full of information and advice yet written in plain English so we could all understand the medical complexities. On behalf of everyone at the Association and Platelet readers everywhere we send a resounding and heartfelt . . .

THANK YOU JIM!

Shirley Watson

Katie & Jim George (right) with Frank Watson, 2002 Convention

Round up from ITP HQ

by Mervyn Morgan, CEO

Local ITP Group Meetings

We recently held the first Local ITP Group Meeting of the year in the Ancient Stannary Town of Ashburton in the heart of the South Devon countryside, close to the edge of Dartmoor. We must say a big thank you to ITP Support Association member, Sally Rhodes, who stepped forward and volunteered to organise a suitable venue and refreshments for the meeting. I had the pleasure of representing the Association at the meeting and welcomed everyone to the first (we hope) of many such Local Group Meetings in Devon. Feedback from the meeting was excellent and has resulted in a tremendous amount of interest from people wishing to come along to the next meeting. In fact, the date for the next Devon Local Group Meeting has already been scheduled: Friday 1st March, 7:15pm start at St Andrew's Church Hall, Ashburton, TQ13 7DD. There is parking at the hall, however, if this is full then you can park on the forecourt of the residential home next door (St Andrew's House). This will be an informal meeting with tea/coffee and an opportunity to chat and talk about each other's experiences with ITP and possible fund-raising opportunities. Dates for this and future meetings will be published on the ITP website. We are also in the process of arranging other Local ITP Group Meetings around the country, and are currently in the early stages of planning meetings in West Sussex, Cheshire, and Edinburgh. Dates and venues will be published on our website when finalised. If you would be interested in volunteering as a local ITP Meeting Organiser, please email mervyn@itpsupport.org.uk (or ring ITP HQ on 01234 376559 if you don't have internet access)

Sally Rhodes (left) and the Devon Group Meeting

Dublin ITP Patients' Meeting

The ITP Support Association is pleased to announce that it has been asked to organise an ITP Patients' Meeting in Dublin. The event, which is being supported by Novartis, will be open to ITP patients, family and

friends and will take place on Saturday 13th April at the Ashling Hotel in Dublin. The programme will include talks from several specialist speakers plus the opportunity for delegates to put their own questions to our expert panel. Tickets will be available from our website at www.itpsupport.org.uk.

Facebook Fundraising

During September 2018 we added the option on our Facebook Page to allow followers to support the Association by making contributions to the charity. In all honesty, we had no idea of how successful this would be, but I must say it has exceeded our wildest expectations. As we go to press with this edition of the Platelet, we will be passing £8,000 raised via Facebook in just five months. A big thank you to everyone who has contributed. Remember, if you donate to the Association via Facebook we receive 100% of your contributions

You can become a Facebook Fundraiser by going to our Facebook page at www.facebook.com/ITPSuppAssoc and clicking on the Fundraisers +Create tab

BT MyDonate

Many of you would have read in the press that British Telecom are closing their BT MyDonate platform in June. There are thousands of charities up and down the United Kingdom that have been using BT MyDonate to raise much needed contributions and the MyDonate platform was one of the best around. However, with its closure the ITP Support Association will be moving to a new donation platform which will be used in addition to Facebook. Please keep a lookout for updates on our website and in The Platelet. We would also like to thank everyone who has used the BT MyDonate to donate to our charity.

RAISE MONEY FOR ITP WHEN YOU SHOP ON LINE

at no extra cost to you!

You shop directly with the retailer, same goods, same prices, but by signing up (for free) on Easy Fundraising and Amazon Smile a 0.5 percentage of whatever you spend comes directly to ITP at no extra cost to you.

Go to *www.easyfundraising.org.uk/causes/itpsupportassociation* and use the links on the easyfundraising site to take you to your chosen retailer. You'll get access to hundreds of exclusive discounts and voucher codes. Join the 53 supporters who have raised £518 for us so far!

Got to *https://smile.amazon.co.uk/* and enter ITP in the search box to sign up to supporting our charity whenever you shop on Amazon.

UK ITP Forum Update

by Dr Quentin Hill (ITP Forum Chair)

2018 saw the retirement of Dr Paula Bolton-Maggs, who has been chair of the Forum since it was established in 2011. Paula trained at both Cambridge and Oxford Universities, taking up consultant posts initially as a paediatric haematologist at Alder Hey Children's' Hospital in Liverpool and then as a consultant in adult haemostasis and thrombosis at Manchester Royal Infirmary. Her final appointment was Medical Director of the UK national haemovigilance scheme, Serious Hazards of Transfusion (www.shotuk.org). She has had a long-standing interest in ITP, contributing to the influential international consensus report on the investigation and management of ITP (2010). Paula was a regular speaker at ITP Support Association conventions where she excelled at leading the question and answer sessions, creating a relaxed atmosphere with a blend of enthusiasm, common sense and humour. During her chairmanship, ITP Forum membership has more than doubled in size. It has developed a website, on which it published a template for better perioperative care for ITP patients. It has facilitated peer to peer discussion of difficult ITP cases, established a nursing forum, supported clinical trials, and established collaborations with the British Society of Haematology (BSH), NHS England and NICE (National Institute for Health and Care Excellence). Paula cared deeply about achieving the best outcomes for those affected by ITP, and made a huge contribution to the raising of standards of care in the United Kingdom in the fields of coagulation, transfusion and ITP. For that, I would like to thank Paula on behalf of the Forum and wish her a very happy retirement.

With a big gap to fill, the Forum decided to elect an executive committee in December 2018. They immediately invited the current editor of the Platelet, Shirley Watson to be part of that committee as a patient representative and are delighted that she has accepted. The Forum will next meet on the 3rd of April 2019 at the annual BSH scientific meeting in Glasgow.

Ed: The other members of the ITP Forum Executive Committee are Dr Quentin Hill (Chair), Dr John Grainger (Secretary), Dr Drew Provan, Dr Gillian Lowe, and CNS Louise Taylor (Nursing Representative).

The Ups & Downs of ITP

by Millie Floyd

From left to right: **Friends Libbie and Erin with Millie**

My name is Millie and we found out I had ITP when I was 3, so I have had it 8 years. We realised something was wrong because I came home from nursery with lots of bruises, but the nursery hadn't seen me hurt myself.

There are ups and downs of having ITP, let's start with the 'ups'. The good things are that I can do things like bowling, swimming, riding a bike and dancing. I have been on a 'plane on holiday too. I do nearly everything my friends do. My best friends and I did a 'Pretty Muddy' run last year to raise money for Cancer Research. The doctors and nurses that have looked after me are all really nice. They know me and my family really well. The 'downs' are that I can't do some things like contact sports in P.E. and I've never been able to try ice skating or trampolining. I didn't like the steroid tablets when we tried that. Also, I couldn't get my ears pierced until we had spoken to a special doctor in Oxford, who knows ITP better. Saying that, I did get my ears pierced just before Christmas, and it was fine!

It may be annoying and upsetting at times, when the bruises are bad or I feel especially tired, but it doesn't stop me from being a normal 11 yr old. I still have the same friends that I met when I was 3 and they are used to my ITP. They have always looked out for me. I am just as normal as them, with one extra thing. Starting secondary school recently was good because apart from the teachers nobody knows about my ITP, and I'm happy with that.

I think that I am lucky because some people are affected much worse than me. My platelet count is normally between 10-15 so I am very lucky to not have stayed in hospital once! If you have ITP don't worry, you will find a way to manage it. I do not know anyone with ITP, but it would be really nice to speak to another child who has it.

[Ed: Please contact me (shirley@itpsupport.org.uk) if you would like to be put in touch with Millie].

Your questions answered...

Q I have a question triggered by Dr Drew Provan's reply to the enquiry about bone marrow testing, on page 22 in the December 2018 edition of 'The Platelet', in which he mentioned the taking of regular blood films for all patients on a TPO.

I have been receiving Romiplostin injections at our local hospital almost every week for the past two years, when my platelet level has been under 250. Apart from having blood tests each week to monitor a full blood count and check on liver and kidney function, I am not aware of a blood film ever having being taken and have not been advised about any results.

Could you please advise how frequently these investigations should be made and what the results of these films would indicate.

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

A *I think many people have blood films checked but often the doctor will not mention the result specifically. For our patients on TPOs, we see them every 2-3 months and tend to get a "registrar" blood film i.e. we like the film to be reviewed by a medic so that any changes related to fibrosis can be picked up and then this might trigger a bone marrow test being done. But as I say, the blood film may have been done in your case but they may not have shared the result and only tend to do this if there is an abnormality picked up.*

Q 1) When taking a course of Rituximab treatment (4 infusions) how long will the platelets remain at safe level. Do the platelets drop suddenly or gradually fall?

2) What is the safe level of platelets for a person suffering with ITP.

Dr Drew Provan replied:

A *These are very difficult questions to answer. The platelets may remain safe for months or years but it is very difficult to predict in an individual patient.*

Safe platelet count is another tricky question. For younger people a platelet count of 20 may be fine but for older patients (over the age of 60) it would be safer to have a higher count. But this all varies from patient to patient and no two people are the same!

Q I have suffered with depression and have taken Citalopram daily for the last 10 years. I have read about the connection with ITP and

depression and I was wondering if you had any up to date information on this, and any advice on other suitable medication, or any case histories of other people who suffer with depression and are ITP patients.

Can I take this opportunity to thank you and your team for all the work that's been done to inform and support people living with ITP like me. It's been invaluable.

Professor James N. George
of University of Oklahoma Health Sciences Center, USA replied:

A I believe that patients who have ITP are at greater risk for depression than people without ITP. But when depression occurs, it is not different from depression in anyone else. There are multiple effective medications for depression. My recommendation for this patient is that he needs a psychiatrist. Psychiatrists whom I know are expert at managing depression. They know the full spectrum of medications and other supportive therapies. They can provide the help that he needs.

Q I had a splenectomy in 2004 which was reported as a case history in the Platelet some year ago. Since then I have taken daily penicillin.

I have always had fairly frequent urine infections for which I have been prescribed antibiotics. This year I have an infection which does not respond to any antibiotic, obviously because I have taken so many in the past. Do you think the continuous use of penicillin could have contributed to this resistance?

Urologists seem to have no answer to this problem. I am 84 years old.

If you would like a question answered by one of our medical advisors please email shirley@itpsupport.org.uk or write to Shirley Watson c/o The Platelet Mission, Kimbolton Rd, Bolnhurst, Beds MK44 2EW

Dr Jecko Thachil
Consultant Haematologist, Manchester Royal Infirmary replied::

A Recurrent urinary tract infections is not uncommon and requires urologist input. In this case, I would also seek the expertise of a microbiologist who can suggest the best antibiotics. I am not sure whether long-term penicillin would have contributed.

Q My son who is 3 has had chronic ITP since last September and I was just wondering when platelets are really low does it affect behaviour? When they drop very low my son always seems on edge and unsettled and has a lot less energy.

Dr Cindy Neunert
Columbia University Medical Center, New York, USA replied:-

A The question asked here is an excellent one. It is often hard to understand behavior changes in children and having ITP may change behavior for several reasons. First, simply living a health condition that requires lab work and trips to the doctor can impact a child and family's quality of life. Second, some of the medications that we use to treat ITP can cause behavior changes, such as corticosteroids. Lastly, we have learned that many patients with ITP experience fatigue and have less energy when the platelet count is low. We don't fully understand why this is but based on patient surveys of fatigue we know that a significant number of patients report this as part of their ITP. As always it is important to talk about this with your doctor, so they can also make sure that there is nothing else causing the changes that you mention.

Shingles vaccine query

I am not sure if this subject has been aired previously or of its significance.

Because I have reached the age of 70, when I visited my local surgery for my Influenza vaccination in early November 2018 I was offered a shingles vaccination, which I accepted. Before the vaccination was administered I was asked to confirm by reading a warning card that there was no medical reason why the vaccination could not be administered. It was obvious from the text relating to anticoagulants and blood disorders that it "might" not be advisable for me to be vaccinated. The nurse administering the vaccination told me that she would make a check with my GP and inform me of the outcome. No response was received so I contacted the Haematology help line at the Royal United Hospital, Bath for advice. In the interim I was advised by my GP that it was perfectly safe to could accept the shingles vaccination. Before I attended for the vaccination I was contacted by a consultant haematologist from Bath (I have bloods monitored six-monthly) who advised that she had reviewed my blood test results and under no circumstances should I accept the shingles vaccination.

She stated that the shingles vaccination contained a live virus and that being vaccinated could compromise any future treatment that I may be required to undertake.

I reported our conversation to my GP whose response was "I never knew that - you learn something new every day".

Needless to say that my patient record, at my insistence, has been annotated with the relevant information.

Ed: In the Dec 2016 Platelet Professor Newland wrote an article about the shingles vaccine, reprinted opposite.

SHINGLES VACCINE AND ITP
by Prof Adrian Newland

The Shingles vaccine is available through the NHS to patients who are certain ages between 70 or 79 and there are specific dates in which their birthday must fall (see explanatory NHS poster opposite). It is not licensed for people under 50. (It should be available privately at the cost of approximately £200) The vaccine will reduce, but not completely prevent, the risk of developing shingles, or recurrent shingles in those who have previously had an episode.

Who can have the shingles vaccine?

The vaccine itself is a weakened form of the zoster virus that causes Chicken Pox or Shingles. Itself it will not cause either of these infections although may cause some blistering at the site of the injection. It cannot be given to patients who are in any way immune suppressed and is contraindicated for patients on steroids, and any other form of immunosuppressant chemotherapy. It would be fine for someone who has had a splenectomy in the past provided they are off all other treatment.

Can the vaccine trigger ITP?

The vaccine itself is very unlikely to cause thrombocytopenia. In the very rare case, were it to occur, it would be transient as with other vaccines.

Professor Newland added:-

'We usually recommend that there should be a gap of 6 months after receiving immunosuppressants before receiving immunisation with a live vaccine, in view of the risk of developing a mild form of the condition being immunised for. Shingles when immune suppressed can develop into full blown chicken pox and can have significant mortality, although it isn't common. The risk of developing it post immunisation is higher while on chemotherapy than developing it de-novo.

For non-live vaccines the gap can be shorter but the risks here are of a sub-optimal response. '

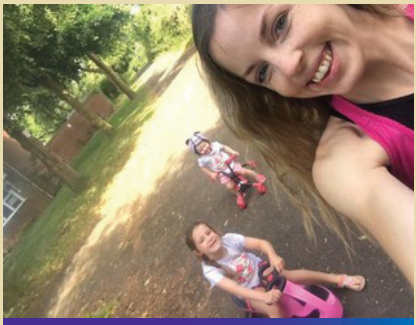
Ed: With regard to your query about the vaccination compromising future treatment, a shingles leaflet published by NHS Scotland ***www.nes.scot.nhs.uk/media/3412891/Shingles contraindicationsupdate_Oct 2015toHPSCONSULTATION_1 1320.pdf*** *states:* The risk and severity of shingles is considerably higher amongst immunosuppressed individuals and therefore eligible individuals anticipating immunosuppressive therapy should ideally be assessed for vaccine eligibility before starting treatment that may contra-indicate future vaccination.

Eligible individuals who have not received the shingles vaccine should receive a single dose of vaccine at the earliest opportunity and at least 14 days before starting immunosuppressive therapy, although leaving one month would be preferable.

Long term stable low dose corticosteroid therapy (defined as no more than 20mg prednisolone per day for more than 14 days) is not considered sufficiently immunosuppressive and these patients can receive the vaccine.

The leaflet also recommends leaving a gap of 12 months ***after*** *rituximab before receiving the shingles the vaccine.*

Fantastic Fundraisers!


Grace Harris, training

Grace Harris has been fundraising for us on BT My Donate. She told us 'Our 20 month old daughter Dottie was diagnosed with ITP in March 2018. Day to day Dottie is full of life and energy and she fills our lives with joy and happiness! Grace works for Old Rectory House featuring The Orangery, at Ipsley, Redditch and wrote 'Earlier this year 3 of our AMAZING chefs decided to get in shape, so between lunch and dinner service everyday they are out in the grounds doing HIIT Training sessions, going for runs and cycles. They wanted to set themselves a challenge and a goal to work towards so they entered the Winter Wolf Run 2018, Stanford Park. They very kindly offered to do the event in order to raise awareness and funds for the ITP Support Association, at which point I asked if my sister and I could join them as we have been looking for an opportunity and a challenge to support this fantastic charity. I also took part in the Birmingham Half Marathon on Sunday 14th October 2018 and completed it in 1 hour 57 minutes on a very wet and windy day. The funds raised from this will also go towards the ITP Association.' Congratulations to Grace, her sister, and the 3 chefs at The Orangery, Ipsley for successfully competing in these challenges, collectively raising an astonishing total of £1,527.


Dottie Harris

Rachel Bishop energetically participated in a two hour Zumbathon in aid of The ITP Support Association with the intention of raising awareness and funds as her daughter Arya has been diagnosed with ITP. Rachel certainly achieved her aim, raising an incredible £905. We were pleased to hear Arya is doing well.

The Burford Trust most generously gave us a second donation of £500 following one given in September 2018 for which we are delighted to record our gratitude.

Sincere thanks once again to **Atlas Trading** for another £80 contribution received at the end of the year from their very successful collection box.

Jimmy Gledhill

We were thrilled to discover that **Jimmy Gledhill** had organised a charity football match for his son Jimmy. The proceeds totalling an impressive £700 were donated to The ITP Support Association. We send our sincere thanks to Jimmy for arranging such a successful event, and to both teams; the Jimmy Curzon 11 and Tommy's All Stars for their involvement in this game. *(See photo of the teams on front cover)*

Buckingham Covers donated £500 following **Neil Dudgeon** (of TV's Midsomer Murders fame) signing Christmas covers for the company. We are extremely grateful to them, and to Neil for nominating our charity to receive this super contribution.

Neil Dudgeon

We were delighted to receive donations in celebration of birthdays. Win McGhee (ITP Supporter) let us know that her cousin, **Stella Oliver**, held a birthday afternoon tea and included a raffle for ITP which raised £170. Many thanks Stella, hope you had a wonderful birthday! **Anne Pryke**, who has been a supporter for many years sent a donation of £100 in lieu of buying a friend a birthday present. We send our thanks to Anne and her friend who we hope enjoyed her birthday.

The Allen family fundraisers!

Jasmine Allen and her family were busy fundraising before Christmas. First of all they dressed up in Christmas outfits and found sponsorship to run 5k. Then they made little craft boxes, sewed sock toys

Hand made by the Allens

and made Christmas decorations which they sold alongside ITP merchandise at Jasmine's school Christmas Fayre and finally her Daddy boosted the donations by selling the remaining items at his workplace. In total they raised a worthy £124 - what a great family effort!

Finally we send our thanks to **Paula & Laurence Freeman** who sent a £50 cheque donation having recently celebrated their Golden Wedding Anniversary. Says Paula, who has been an ITP member for more than 20 years, "my husband and I recently celebrated our Golden Wedding Anniversary and would like to donate £50 to your funds to mark the occasion." The delightful picture (right) shows Paula and Laurence holding a painting of a photo taken on their wedding day in June 1968. Our congratulations to you Paula and Laurence, and we wish you many more anniversaries to come.

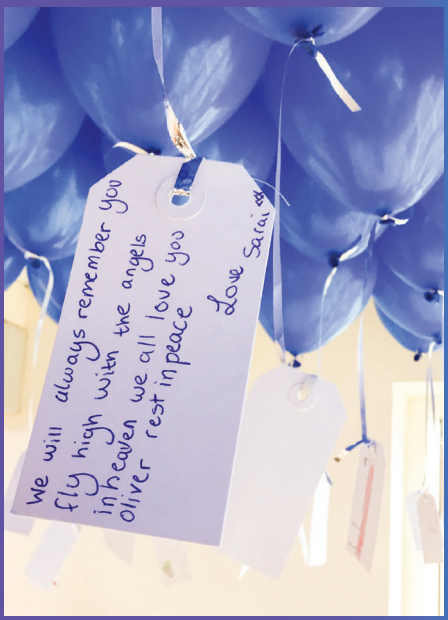
Paula & Laurence Freeman

Olly Fickling

West Denton Primary School in Newcastle gave us the tragic news that their pupil Olly Fickling, aged 6, had died from ITP. The school have raised £619 for ITP in memory of Olly and have sent us these moving photos of their balloon release day which gave the children the opportunity to say their own goodbye messages in a beautiful and emotional afternoon following his funeral. We send our very deepest sympathy to Olly's family, particularly Marie and brother Bradley, and to all his teachers and friends. Our sincere thanks goes to the staff, pupils and parents at West Denton Primary School for their generous support of our charity.

Paediatric ITP specialist Dr Cindy Neunert said '*ITP remains a difficult diagnosis for both families and doctors due to the wide range of bleeding symptoms that children can experience and the recognition that no child is the same. Fortunately, in pediatric ITP significant bleeding is extremely rare. Despite this we recognize that these events may occur, and we continue to strive to find ways to prevent and treat them.*'

In Memory of Olly Fickling



A Surprise Weekend

by Peter Hinchley

2018 was the year when my wife Pauline and I reached our 80th birthdays, she in February and I in October. We thought it would be nice to have a joint celebration in the warmer weather, so on a beautiful sunny day in July, our son and daughter-in-law hosted a "Prosecco Afternoon Tea" in their large garden, where thirty family and friends enjoyed a wonderful afternoon of eating, drinking, chatting, and dancing.

My birthday passed in early October, I felt good, healthy, energetic, pleased with myself that at this age my only health concerns were minor and did not interfere with my daily life. I was going to the gym 3 times a week - look after your body and it will look after you. Life was good - or so I thought.

On Friday 23rd November, having been for my third gym visit of the week, my wife Pauline and I prepared for prospective house purchasers who were coming to view our house on the Saturday and Sunday, The following morning, I noticed a blood blister in my mouth. Nothing to worry about - they happen. Our first viewers came as expected. But as the day passed I had a strange feeling that the blister was getting larger, and I seemed to have a few more. On preparing for bed, Pauline noticed a small red rash on my lower back. On Sunday morning, I had more blisters in my mouth, and my thighs were peppered with red spots. Purple bruises were appearing on my arms. Our second house viewers came, and seemed to like our house, which was encouraging. The day passed as normal but once again by evening the spots were spreading. Pauline suggested that a visit to our surgery would be a good idea. Apart from the visible symptoms, I felt absolutely normal and well, but I reluctantly agreed.

Monday, 26th. November we began our breakfast, and as soon as the surgery opened, I telephoned and told the receptionist that I had a rash and a few blisters. "Come in and have it checked" she said. "Better be safe than sorry". At 11.00am I sat in front of my doctor, and showed her my mouth and rash. Without hesitation she asked me to return to the waiting room while she made a phone call. Very mysterious! After a few moments, I was called back into the consulting room. "Go immediately to York District Hospital, and take an overnight bag with you - you may have to stay for tests," This was a shock - I had thought a cream or tablets would be prescribed.

At 1-00pm I was admitted to hospital as an emergency. An immediate blood test was carried out and while waiting for the result, I was handed tablets to take, which I soon learned were 60 mg prednisolone and

40 mg omeprozole. Shortly after, a bed was available, and I was moved in. The tests had shown that I had a platelet count of only 3, and the diagnosis was severe Immune Thrombocytopenia. I had never heard of it!!

Worse was to come. The next day, my platelet count had dropped to 0, where it remained for 7 days, despite the high-dose steroids. Tranexamic acid was added to my medication, but the next few mornings my hospital pillow was more red than white from my nocturnal nose bleeds. Because of my poor response to the steroids, it was decided to put me on a course of rituximab, A very unpleasant bone marrow biopsy confirmed ITP as the problem. On my 7th day, my platelet count rose to 1, then 2, then back to 1,then to 5, then back to 4! On my 18th day, I had the second rituximab infusion. That afternoon, my consultant informed me that my count was now 6, and it would be safe to discharge me. I would be able to come into hospital as a day patient for the third and fourth rituximab treatment. From what I had now learned about my condition, a count of 6 seemed still pretty low, but I was pleased to be going home, as Christmas was only 11 days away.

I have now finished my rituximab, and my steroids are gradually being reduced, but I have had very unpleasant side-effects – mainly insomnia, severe fatigue, and bad muscle pains. I am seeing my consultant for monitoring every two weeks, and my platelet count increased to 20, 55, 70, and 77 at the last check. Better than before, but my consultant would like to see it higher.

I began this tale with the title "A Surprise Weekend" I certainly did not expect to wake up with a rash on Saturday, and be hospitalised on Monday!

Having researched ITP, I found The ITP Support Association, and sent off my subscription immediately. I hope that this tale of an older newly diagnosed recruit may be of interest.

Raise money by donating your scrap car in aid of ITP!

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.

My ITP Story

by Carolyn Phillips

My name is Carolyn, aged 57, and I live in Essex. It was in early May 2018 when the problems started. I had severe pelvic pain which came on suddenly, first on the left then tended to move to the lower abdomen. It simply would not go away but I just put up with it for a few days taking paracetamol. Finally I decided to ring 111 and was given an out-of-hours doctor's appointment due to it being on the early May bank holiday. The doctor was very concerned with my racing heart rate and quite high blood pressure so I was told that I should go to the nearest A&E. My husband drove me there, where I was very swiftly given an ECG. Many questions followed, blood tests, abdominal X-ray, and ultrasound scan, whilst they tried to diagnose what was wrong. I was admitted to a surgical ward and given a CT scan that night. I was told that I had an infection, sepsis in the pelvic area and that I had a large mass behind my uterus with some leaked fluid, possibly blood and pus, and that I was anaemic. Antibiotics were started together with iron tablets and pain killers. More blood tests followed.

A bed was found for me in the gynaecology ward two days later, where I was monitored and told that I had low blood platelets. ITP was not mentioned at this point. Whilst in hospital I began to have slight bruising which I thought was due to all the blood tests and being prodded and poked. I also had a slight bloody nose, but not streaming, and a few blood blisters in the mouth. However there was a problem with counting my platelets. They kept clumping. I was discharged from the hospital after 5 days, the infection had cleared up with oral antibiotics so they were happy for me to go home. I had an appointment made for an MRI scan a few weeks later. At this point I was very anxious to know what they would find.

A follow up appointment was made to see the gynaecologist and haematologist to discuss the results which revealed a large mass behind uterus. This meant an operation to remove it as soon as possible, not knowing

whether it was cancerous or not. It would be at another hospital who specialise in this. It was at this point that my haematologist mentioned ITP as a possibility for my blood issues. My liver and spleen felt normal upon examination but I still had mild bruising.

Although an operation was needed urgently it couldn't go ahead if my platelets remained low. As they were about 26 but needed to be above 80, I was given 2 days of IVIg which gave me headaches. I was then given eltrombopag, first at 50 mg for 3 days then increased to 75 mg thereafter, and I was still on 2 iron tablets a day.

Great news! The treatment raised my platelets to roughly 80 and therefore on the 18th June 2018 a few days later, my operation for a total abdominal hysterectomy and removal of both ovaries and tubes, together with the tumour took place. The left ovary was found to be contorted which meant that the blood supply to it had become cut off, hence the infection. It was a success, everything went to plan but I would have to wait 2 more weeks for the results of whether it was cancerous or not.

Recovery was going well when suddenly all went downhill. My blood pressure dropped and I became semi conscious. I was found to have an intra abdominal bleed so had to be opened up again to repair this and had to be given a few units of blood and plasma. A drain and catheter was inserted. More antibiotics were given. However, all this happened while they still couldn't get accurate readings of my platelet levels. My bruising was becoming darker and I still had slight bleeding from nose.

The next evening I had to have another procedure, a CT angiogram, arteriogram and venogram but no bleeding site was identified. I was feeling very rough at this point, and had no food, sleep etc. I was wired up to some inflatable booties to help my circulation as I wasn't allowed to have blood thinning injections. Soon after I began to get my appetite back but then suffered another setback. Very loose stools revealed I had C.diff bacterial infection so had to be put into isolation with a change of antibiotics.

Eventually my catheter and drain were removed, my appetite came back and I even enjoyed the hospital food. At last! Finally I could escape after 12 days of being in hospital and was able to go home. I was still on medication, 75 mg eltrombopag, iron tablets, antibiotics and painkillers if needed. My platelets were 30 on discharge having been down to 14 at one point during my stay. Clumping made counting difficult but I was made aware that any future blood tests should be made using a thromboexact tube (magenta top).

More follow up appointments took place for staple removal and blood tests, x-rays etc. My large vertical abdominal scar was healing up nicely as it should.

continued overleaf

After a couple of months my platelet levels were 114 so I was weaned off the eltrombopag and no longer required iron tablets. I was told that the clumping issue is called pseudo thrombocytopenia.

Now after 6 months I have had another blood test. My platelet levels were 40 but with clumping, this could mean more (perhaps 50, 60 or 70)if looked at and counted under the microscope. My haematologist is happy with this saying that they are at a safe level. I have been warned not to take aspirin or ibuprofen and only to call him if I have bleeding issues or any concerns. He wants to see me in 1 year's time for a blood test, so I've just got to watch and wait.

Here's hoping for a healthy 2019!

[Ed: We second that Caroline, and wish you well. As your story is more complex than the typical experience of most ITP patients, we are grateful to Dr Will Lester for supplying an explanatory comment]

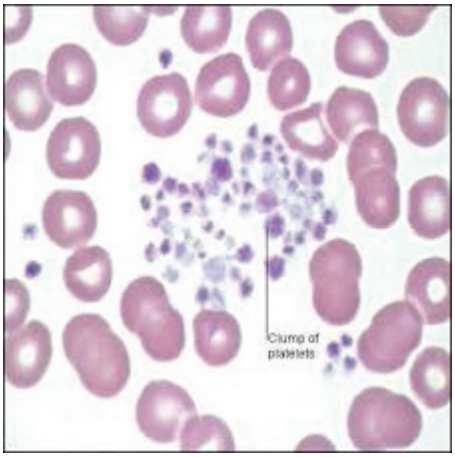
Thank you for sharing your experience, Caroline.

The case raises an interesting issue – can we always trust the platelet results from the automated machines we use in the laboratory?

The automated blood platelet count is produced as part of a laboratory test called the 'full blood count' (a useful website for understanding blood tests is LABTESTS ONLINEUK – see *https://labtestsonline.org.uk/tests/full-blood-count-fbc*)

If the automated platelet count is unexpectedly low then the laboratory staff would usually make something called a 'blood film'. This is where the blood is spread thinly across a glass slide, dried and then stained with special chemicals to show up all the cells (red cells, white cells and platelets). A biomedical scientist and/or a doctor will then look at the blood film using a microscope. A key question is whether this result is true. The diagnosis of ITP requires a true low platelet count but where all the other cells appear normal. It's very important that the laboratory doesn't give out false platelet results because that could lead to unnecessary distress and even unnecessary treatment. One of the reasons to get a false low platelet count (pseudothrombocytopenia) is that the platelets are 'clumping' together. This can be seen down the microscope with large clusters of platelets stuck together. The machine cannot count these clumped platelets properly. The commonest cause is something called 'EDTA clumping'. EDTA is contained in the tubes used to collect blood for a full blood count. The platelets are not clumped when inside the body but only when they enter the tube. The EDTA causes a change in the shape of proteins on the platelet surface and reveal a hidden site to

which some people have made antibodies (proteins made by the immune system which stick on to bugs to help clear infection). ITP is usually associated with antibodies against platelets but the antibodies that cause EDTA clumping are different because they only work in blood mixed with EDTA but not while the blood is still in the body. The way to get around this and to get a genuine platelet count is to take the blood into a different tube that doesn't contain EDTA. The usual option is to use a citrate tube which will have a different coloured



top. The reason we use additives like EDTA and citrate is to stop the blood coagulating in the tube (ie forming a big lump of solid clot) as the automated machine can only give results on anticoagulated liquid blood.

This case is particularly complicated because it sounds like there is a combination of true ITP with genuine reduced platelets in addition to platelet clumping – a 'double whammy'. Using a different blood collection tube can usually get around this problem but sometimes there can be clumping for other reasons. Trying to test the blood as soon as possible after it's taken can sometimes help. There are also rare inherited bleeding disorders like type 2B and platelet type von Willebrand Disease which can give abnormal platelet results (sometimes with some platelet clumping) and bleeding.

Key messages

1. An unexpected low automated platelet count should always be confirmed on a blood film. If the patient is bleeding then it's probably genuine but if there's no bleeding, it could be 'fake news'
2. Always repeat a blood test where there are results that don't match with the patient's medical condition
3. If you are one of the people who has EDTA platelet clumping, it's always worth reminding your health care professionals and phlebotomist to take a full blood count in two different tubes (EDTA and citrate) so that you get an accurate result
4. It's important that a haematologist is involved at an early stage when things are a bit unusual. Although I would say that!

Dr Will Lester,
Consultant Haematologist,
University Hospitals, Birmingham

ITP Registries – Update

As of 31/12/2018, we have consented 3,366 patients to the UK Adult ITP Registry. We are happy to announce that we have extended the study recruitment to include specific data collection in women who are pregnant with primary ITP; Inclusion of pregnancy data requires consent to both the Adult ITP Registry and the pregnancy sub-study. These data will help further our understanding of management of patients with primary ITP during pregnancy and provide information on best management practices.

We have made some significant changes to our online data collection system to help enable hospitals to enter data more easily and efficiently. The feedback has been overwhelmingly positive so far.

We presented an update for the delegates at the annual ITP Patient Support Association back in October. It was a great opportunity to promote the Registry to the patients and update our progress to the Support Association, who have been supporting us over the years.

We are in the process of expanding the registry to more hospitals. At present, there are over 70 sites actively recruiting in the registry and we are hoping to increase this further to help boost recruitment.

Recruitment to the ITP registry has been extended until 12th June 2020. Be sure to contact your local hospital to get involved and help the registry.

by Dr Vickie McDonald,
Consultant Haematologist,
Royal London Hospital, Whitechapel

The paediatric ITP registry continues to recruit well with now over 2000 children and recruiting an estimated 75% of all new cases across the UK. We are currently updating the data collection process for the registry which was originally designed in 2005 on internet explorer 6. The new design will make data entry easier and ensure we have high quality data to analyse. This update has only been possible by the ongoing funding through The ITP Support Association and an additional donation by a very generous parent. The update should be ready very soon and we will provide further details in due course.

This year we plan to analyse data around the use of second line therapies and how their use is changing. We also plan to analyse changes in quality of life following interventions. The results of these analyses will be part of a future update.

by Dr John Grainger,
Consultant Paediatric Haematologist,
Royal Manchester Children's Hospital

(See opposite for recruitment chart)

Letterbox

Dear Shirley,

I have recently had two episodes of ITP, since November 2018. First diagnosed in 2012, whilst living in Warwickshire, I was treated in Coventry at Walsgrave Hospital where there was a specialist haematology unit. Now living in Winsford , Cheshire, and being treated at Leighton Hospital, there is no haematology unit. As an out patient for last two years I was seeing the haematologist at Leighton, who is based at Stoke University Hospital.

What is frustrating is that the haematologist does not have admission beds at Leighton Hospital, and I am admitted under a general medicine consultant who then makes a referral to a haematologist for them to advise on my treatment. I was in 3 days before being seen by a haematologist.

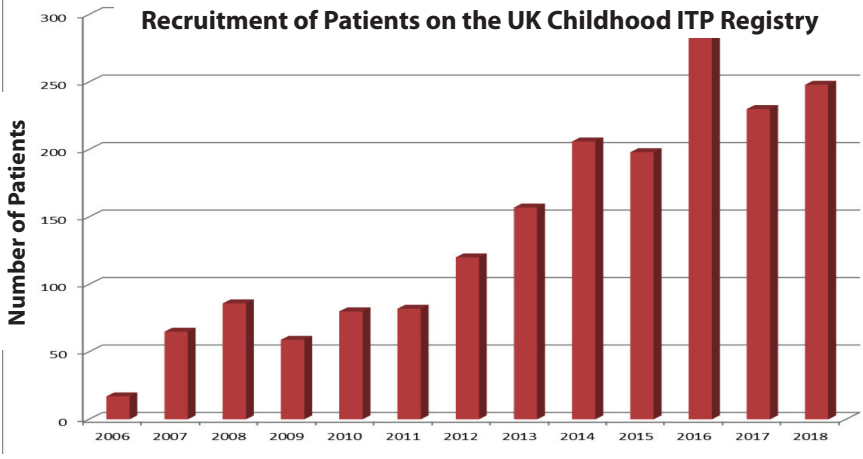
I have no other option but to attend A & E when signs occur as there is no direct access to haematologists. Once the haematology team get on board they do plan the appropriate treatment although it seems they have to get the immunoglobulin approved first because of the cost.

I'm about to start rituximab (which also had to be approved) as they feel I am not responding to first line treatments this time. I live about 20 miles from Royal Stoke, Chester and Manchester Hospitals who all have haematology units. Should I go to one of these units, when the acute signs appear?

I would be interested to hear other ITP patients' views, especially if they live in my area.

Steve Humphreys

Ed: This situation certainly doesn't sound ideal, Steve. Of the 3 hospitals you mention, Manchester is an ITP Centre, and we would suggest you ask for a referral there to see Dr Jecko Thachil.



Friends & Family Test (FFT)

by Rhonda Anderson

Have you ever heard of the Friends and Family Test? Well you should have done! But if you haven't, it probably isn't your fault. If you have accessed almost any NHS service, you should have had the opportunity to fill in a feedback form that is called the Friends and Family Test. It should be readily available at your GP surgery, out patients departments, hospital services, dentists and other NHS service points.

Why so many 'shoulds'? Let's concentrate on GP practices. It is a contractual obligation for GP practices to collect FFT Data from their patients. Some practices seem to ignore it altogether. At others it is very difficult to come across a form, so therefore, you may never have been alerted to its existence. You are not alone if you use the NHS regularly, and have never heard of FFT, or indeed seen a form, or been asked to fill one in.

Since it was initially launched in April 2013, the FFT has been rolled out in phases to most NHS-funded services in England, giving all patients the opportunity to leave feedback on their care and treatment. Since 1 December 2014 GP practices have been required to implement the Friends and Family Test (FFT). Therefore at every visit to your GP you should be able to find a form readily available so you can give your feedback on the service, by filling in a very easy tick box set of questions and also write comments.

So what does it entail? This is the initial FFT question:-

"We would like you to think about your recent experiences of our service. How likely are you to recommend our GP practice to friends and family if they needed similar care or treatment?"

The responses are: 'Extremely likely'; 'Likely'; 'Neither likely nor unlikely'; 'Unlikely'; 'Extremely unlikely'; or 'Don't know'

On average, nine out of ten people say they would recommend the service they used to their friends and family.

Following this there may be more questions and finally a space for you to write your own comments. It is designed to be very simple and easy to use for patients to give feedback.

Is it useful, helpful and valuable to collect this information? The NHS thinks so by,

- *Putting patient experience on the map where previously it hadn't been.*
- *Giving everyone a voice in a way the national surveys don't.*
- *Supporting staff in reinforcing the good job they do.*
- *Giving staff evidence on where changes need to be made.*
- *Providing swifter and more granular data than the surveys, which is particularly important at a time of major change such as in primary care at the moment.*

This focus on patient experience provides an opportunity for improvement in big ways and small ways. We have seen many examples over the years, from initiatives for quieter wards at night and improving the dining experience through to initiatives to dramatically reduce patient fasting times before operations, and projects to enhance end-of-life care for both dying patients and their loved ones.

(The above italicised paragraphs were copied from websites for accuracy and official wording.) You may say well all that was obvious wasn't it, and patients have been highlighting these points for years, but having FFT actually made them do something about it that has been documented, so in that respect it has been useful, helpful and valuable for improving patient experience.

Next time you access an NHS service, look out for the FFT form and take a few minutes to fill it in. This is an opportunity for you to have your voice heard. You may be full of praise, or you may be critical. No matter what, it is really important that you have your say. It is a quick and easy way for you to express your opinion. If you do not think it is detailed enough, then do write in. If you do not tell them, they will never know. The patient voice is really important and needs to be heard in order to improve services. Praise is also always needed to boost the morale of the hard working people who look after us in the NHS. Do support them with your praise.

I would love to know how many people had heard of the FFT before reading this article, and also if you have participated in giving your feedback since (email: rhonda.anderson@virgin.net)

For more information visit: *https://www.england.nhs.uk/wp-content/uploads/2014/07/fft-gp-summ-14.pdf*

and: *https://www.england.nhs.uk/fft/*

Patient Mentors

a listening ear .....

Rhonda Anderson
0208 504 2688
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Derek Elston
0151 625 8213
derek.elston@itpsupport.org.uk

Dave Farrow
01664 852218
davidfarrow40@yahoo.co.uk

Frank & Shirley

Thanks to Frank!

Read all about it, read all about it! Frank Watson retiring . . .

Yes it's true folks, Frank is retiring. Since 1995, when Shirley founded The ITP Support Association, Frank has been "the power behind the throne". I do not believe I know anyone as practical as Frank. His self taught skills of bricklaying, plumbing, thatching and the rest, he gained from endless studying of manuals that he borrowed from the library. He needed these skills initially to renovate, all on his own, the derelict thatched cottage that is now "Synehurste", their lovely home. So, when in 2014, the Association purchased the derelict Bolnhurst Mission hut, it was a "no brainer" as to who would be demolishing the old hut, clearing the site, and laying the concrete ready for the new building to be erected. Again it was Frank, together with his friend Tim King, a maintenance engineer, whom Frank met whilst they were both working at 3M, who fitted out the new building. This involved installing the insulation, plumbing, the electricity, air conditioning and fitting the internal walls, doors and toilets. In fact everything that makes the building what it is today. There is no doubt that without Frank's and Tim's input the Association would never have been able to afford a builder to do that work. Ever since the building was opened, Frank has been responsible for its maintenance including laying 5 tons of additional gravel to top up the car park. When, as a result of this work, Frank had to undergo a hernia operation, and also now with painful hips, Frank realised that at the youthful age of 78, there were some things he should not be undertaking. Sadly now ITP need a younger volunteer to take over maintenance duties. So Frank, enjoy your retirement, [you've certainly earned it] and don't let Shirley give you too many jobs to do!

Michael Levy
ITP Hon. Treasurer 2011 - 2018

Ed: In addition to the building and maintenance of ITP HQ Frank has helped out at every convention, proof read each edition of The Platelet, folded thousands of ITP Christmas cards and packed them in tens before we changed to ready packaged ones 3 years ago, stapled together all the hundreds of booklets printed in-house, and in the very early years stapled and enveloped up The Platelet to post to all the members. Not least of all he took on many household and family duties freeing up my time during evenings and weekends to run the Association. In short, I couldn't have done it without him!

Shirley Watson

News & Views

Major overhaul of GP Services

NHS England has announced that GP services are to undergo a major overhaul as part of a new GP contract. This 5 year contract was agreed between NHS England and the British Medical Association GP committee. The new deal will see an investment of £4.5 billion to enable improved access to GPs, an expansion of services and longer appointments.

It is planned that by 2024 there will be 20,000 extra staff working in primary care so that GPs have more time to see the patients who need them most. In future GP practices will be supported by pharmacists, physios, paramedics, and social-prescribing link workers who will connect patients needing practical and emotional support with appropriate community groups or services. In addition there will also be more practice nurses and GPs available.

In December nine million extra appointments became available with GPs offering evening and weekend appointments. From April all patients with access to the internet should be able to order repeat prescriptions on-line, and for every 3000 patients in their practice GPs will have to make one appointment per day available to be booked through the NHS 111 service.

For more information visit *www.england.nhs.uk/gp/gpfv/investment/gp-contract/*

Meanwhile BBC News have carried out a survey of GP availability around the UK. Results showed a near threefold difference between some areas giving unequal access to patients. Swale in Kent has only one GP for every 3,300 patients whereas Rushcliffe in Nottinghamshire has one GP for just 1200 patients. The Royal College of GPs says that England alone is 6,000 doctors short of the 40,000 it requires. A map of the UK showing the survey results can be found at *www.bbc.co.uk/news/health-46912055* . The good news is that the number of GP trainees is at an all time high.

The Patients' Association Surveys

If you would like to take Rhonda Anderson's advice in getting your patient voice heard, do join The Patients' Association. Membership is free and it gives patients the opportunity to play their part in making sure that everyone can access high quality health and social care services when they are in need. Their national helpline service offers information and advice, and they run regular surveys to truly understand patient opinions *www.patients-association.org.uk/*

ITP Nurses Meeting

Novartis are organising an educational meeting for ITP Nurses in May. Nurses should contact their local Novartis representative for more information.

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