



the platelet

SEPT 2018

JOURNAL OF THE ITP SUPPORT ASSOCIATION

**ITP CENTRES
SURVEY RESULTS,
NEWS, EVENTS,
ADVICE,**



**RESEARCH UPDATES, CONVENTION DETAILS
AND MUCH MORE INSIDE . . .**

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In this issue . . .



. . . we kick off with a report looking at the problems of living with ITP, and these are reflected in the questions asked of our medical advisors, Dr Drew Provan and Dr Jecko Thachil, (pgs 8 & 26). Prof. Cataland discusses how a better understanding of types of ITP could lead to more effective use of treatment (pg 6), 3 ITP researchers give updates on their projects funded by the ITP Support Association, and in News and Views (pg 21) you can find a link to a round up of the latest research on gut bacteria implications with various conditions including autoimmune disease.

A review of the patient afternoon at ITP HQ (pg 16) includes Dr Besser's outline of great improvements in outpatient management with the new electronic patient record system at Addenbrookes, Cambridge, and one of his patients explains how he has found this beneficial (pg 19).

Results of the survey that those of you who attend an ITP Clinical Centre completed a while ago are summarised (pg 10) and show how well these are fulfilling a role as Centres of Excellence. University Students are given timely advice by a GP (pg 15) as many prepare to move away from home for the first time.

Mervyn whets your appetite for the Convention in October and invites your stories for ITP September Awareness, and finally, Rhonda reports on the progress of the Patient Participation Group of which she is a member.

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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 Toll of Living with ITP

A report from the I-WISH collaboration

New research reveals the toll of living with ITP. Experts suggest that ITP affects nearly 10 in 100,000 adults.¹ Currently, there is no cure for ITP;² a disease that causes the blood to not clot properly due to low number of platelets³ and sometimes resulting in life-threatening hemorrhaging.⁴ This means a confused, overactive immune system hunts and destroys platelets, putting patients at risk of bleeding spontaneously. People of any gender can have ITP, but it is twice as common in women than men.⁵

A particularly interesting discovery from a recent survey, the ITP World Impact Survey (I-WISH), found severe fatigue to be the most difficult ITP symptom to manage for about two-thirds of people living with the disease and has the greatest negative impact on their lives.⁶ Additionally, the survey found a solid one-third (36 percent) of those with ITP reporting their disease has a high impact on their emotional well-being and 28 percent saying the disease caused them to miss work.⁶

“Severe fatigue, in particular, was reported by many patients as the most difficult to manage symptom of ITP;” said Nichola Cooper, MD, clinical senior lecturer, Hammersmith Hospital, Imperial College London, and chair of the I-WISH Steering Committee. “This is an important message for health care providers treating patients with this rare disease; ITP is about more than bruising and risk of bleeding.”

For most of us, experiencing an occasional bout of being extremely tired is remedied with a good night’s sleep and maybe some strong coffee in the morning. But for some people with ITP, that feeling of being overwhelmingly tired is so constant and pronounced that it surpasses all others in the daily management of the disorder – impacting work, home and social lives.

The ITP Support Association hopes that I-WISH might be the catalyst to greater understanding and empathy, resulting in new programs and services to better support the ITP community.

I-WISH is a collaboration among global ITP experts, patient groups (including Shirley Watson and Mervyn Morgan from the ITP Support Association) and Novartis, and is one of the largest surveys of ITP seeking to understand the real-life impact of the disease. In addition to the survey, the I-WISH Steering Committee developed the ITP Life Quality Index (ILQI), a ten-question tool to help quantify and monitor the quality-of-life impact of ITP on patients. Using this tool, clinicians can better monitor symptoms beyond bleeding and rely on more than platelet counts when treating people with ITP.⁷

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ITP Nurses' Education Day

There are now 22 ITP Clinical Centres for adults and 17 for children spread around the United Kingdom from Aberdeen to Derriford, and Belfast to Norwich. Working within these are 23 ITP nurses that we know of, many of whom are haematology Clinical Specialist Nurses (CNSs). Siobhan McGuckin, CNS at University College Hospital in London has taken the initiative to arrange a Nurses' Education Day to give them the opportunity to meet, swap experiences and share best practice in order to further improve their dual role of supporting ITP patients and doctors in clinics and wards. Although the meeting is primarily aimed at ITP Clinical Centre nurses any spare places can be filled by nurses working in ITP clinics in other hospitals. Do please pass details of this event to ITP nurses in your clinic.

Date: **Tuesday October 30th**

Venue: **Royal College of GPs, London**

Speakers include: **Dr Nichola Cooper, Dr Drew Provan**

More information from: **siobhan.mcguckin@nhs.net**



American Perspective

Professor Spero Cataland MD
Columbia University Medical Center

ITP and New Treatments: The view from your side of the pond

As I begin to write the latest installment of the American Perspective, I am on the way home from attending the 64th Annual ISTH Scientific and Standardization Committee (SSC) Meeting that was held in Dublin, Ireland. As always, it was an excellent meeting with expert presentations and interactions with colleagues in the field of hematology. While I had several things that I wanted to accomplish, at the top of the list was to learn more about some of the newest treatments for ITP. While I certainly learned a great deal at the meeting, the session on ITP was particularly interesting.

I thought I would be writing about fostamatinib, and new targeted therapy recently approved by the United States FDA for the treatment of chronic ITP. Fostamatinib works by blocking the destruction of antibody coated platelets, thereby leading to an increase in the platelet count. I also thought I might talk about avatrombopag, another drug recently approved drug by the FDA that could be considered very similar to romiplostim or



eltrombopag. Avatrombopag works in a similar way as romiplostim or eltrombopag by boosting the bone marrow's production of platelets.

Because existing treatments already work so well for patients, I was not sure exactly where these new treatments should fit in our treatment plans for patients with ITP.

On the last day I sat in on what turned out to be an excellent and interactive session on ITP. Several experts presented lectures on different aspects of ITP, but I was particularly struck by the last lecture given by Dr. Philip Choi, a haematologist and ITP expert from Australia. In giving an excellent overview of the pathophysiology of ITP, he asked an interesting question. He asked how it was possible to really talk about the treatment of ITP and novel therapies, before we know how to diagnose ITP? On the surface this might seem like a strange question, but the point he was trying to make is that

not everyone has the same "ITP". There are potential mechanisms of disease that can involve decreased production, increased destruction, with the destruction of platelets occurring in different ways. Different parts of the immune system can be involved in the autoimmune destruction of platelets in ITP including both B cells and T cells, as is evidenced by treatments that target both B and T cells being effective in the treatment of ITP. The spleen is thought to be the major site of destruction of antibody coated platelets, but not all people respond to splenectomy supporting the hypothesis that the clearing of antibody-coated platelets can occur in places other than the spleen.

Maybe in order to properly treat patients with ITP, we need to be able to "diagnose"

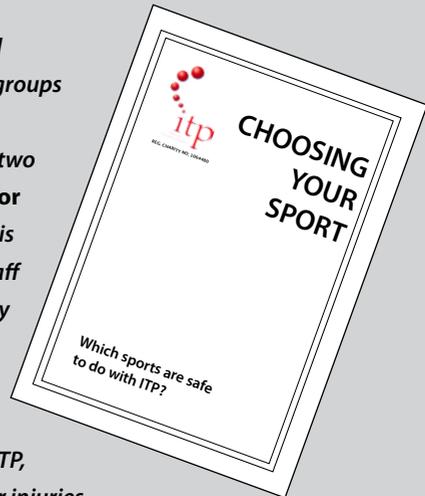
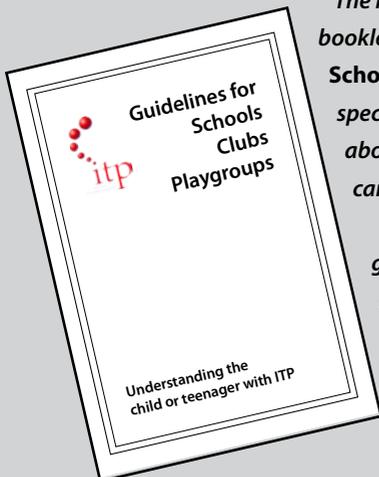
exactly the cause of their ITP as put forth by Dr. Choi. With the addition of both fostamatinib and avatrombopag to the list of potential treatments available to physicians, we now have even more treatments that target different mechanisms of disease in ITP. By knowing which mechanism or mechanisms are causing an individual patients' ITP, we may be able to more effectively and safely treat patients with ITP that require therapy. Ongoing and future research will need to focus more on the development of testing that may be able to more accurately assess what is causing each individual's "ITP" to best know how to approach the treatment. If one looks at ITP in this new way, the potential utility of these new treatment options becomes more readily apparent.

September is the month when many children and teenagers move to new schools, toddlers start playgroups and adults enrol at gyms and sports clubs.

*The ITP Support Association has two booklets to help. Our **Guidelines for Schools, Clubs and Playgroups** is specially written to explain to staff about ITP to assist them in safely caring for a youngster with ITP.*

***Choosing Your Sport** gives advice on which sports are safe to play with ITP, and how to cope with minor injuries.*

Both are free to Association members (SAE appreciated)



Your questions answered...

by **Dr Drew Provan** (Reader in Autoimmune Haematology, Queen Mary University, London)

Q I'd like to know what's expected of us as an ITP patient when surgery or biopsies are planned. Are we expected to get blood tests and if necessary arrange treatment to get a good count in time ourselves, or should the doctor arranging the procedure do this?

In my experience doctors from other specialties often don't respect ITP and don't understand that a good count two months ago doesn't necessarily mean there will be a good count today. I find it an added stress to always have to be worrying about my platelet count. I feel that the doctors should be aware and arrange for blood tests which is far easier for them to do than for me to do.

One example of several that have happened to me. In July 2017 I had surgery to remove a lump from my neck. At an appointment beforehand the surgeon said that he knew about my ITP and it would all be fine. From what he said and what he wrote in the letter to my GP it sounded as if he had it all in hand. But I heard nothing else from him so got myself a blood test at the Haematology Day Unit the day before so that I would know on the day what my count was. I got them to look at the blood results and my count was 37. They were surprised and didn't then know what to do as it was too low for surgery. They consulted with haematology and were told that I should have a platelet infusion during the surgery. All

went ahead satisfactorily although there was much delay. However, was it in fact my responsibility to have got myself tested a couple of weeks beforehand and get treated or should they have assisted with this?

A *Depressingly this sort of thing happens all too often. The responsibility should not be that of the patient. The surgeon, dentist or whoever is performing a procedure on a patient with ITP should inform the patient's ITP consultant of the intended procedure and the date of the procedure. It is only if we know these things that we can plan the appropriate action. For minor procedures we normally recommend the platelet count of 50 or greater and for major procedures such as hip replacement we recommend a platelet count of 80 or more. For dentistry we recommend 30 or greater.*

We have several ways of achieving this and we generally use IVIG or sometimes a small dose of dexamethasone a few days before. But all of this is dependent on knowing the actual date of the procedure. So the surgeon and the haematologist should be contacting each other and arranging everything in advance of the patient having the procedure.

I was very sorry to hear that this patient was put in a position where his/her platelet count was too low for the procedure although s/he was aware that there was a specific threshold for the procedure. As a result s/he ended up

having a platelet transfusion which is less than ideal and not what we would have done had we known that the procedure was taking place.

I guess to make sure this kind of thing does not happen, the patient may have to say to the haematologist have you heard from the surgeon? And likewise when the patient sees the surgeon they may have to say have you informed the haematologist of this procedure so they can initiate treatment if necessary.

In medicine, whenever there are complaints from patients, it is almost always related to poor communication between healthcare professionals and patients.

Q I was diagnosed with ITP in 2015 when my count was around 43. I was given steroids and they went up to 90ish and then I was given steroids to cover my holiday in America in April 2016.

Last year in July I was found to have breast cancer and my platelet count prior to biopsy was 7 - the steroids didn't work this time so I ended up having Intratect before my biopsy and again before my surgery. Further steroids didn't work and then I had Rituximab at the same time as my radiotherapy which didn't work. High dose steroids after this didn't work, twice. I was then put on Eltrombopag started on 50mg per day then 75mg per day and my platelets went up to 43 but then I reacted against it so it was stopped. I am now on weekly Romiplostim but there has been a lot of confusion over the dose and what I should be on and currently my platelets are still only 6. Apparently the dose can be increased a few more times yet.

I was just wondering if anyone else

has struggled like this as I am getting a bit concerned that I don't seem to be responding to anything.

A *It is a shame that steroids did not work this time but we do see this in some patients where previously steroids are effective but then when we try them again they don't work. It is also a shame that you did not respond to IVIG which normally brings the platelet count up very nicely but this was not the case with you.*

Eltrombopag has worked to a certain extent although your platelets only went up to 43. Now you are on Romiplostim and the dosing is very straightforward normally. I'm not sure how many micrograms you are receiving but we start at 3 µg per kilogram weekly and then increase every week until we achieve the platelet count we are aiming for. The maximum dose of Romiplostim is 10 µg per kilogram so you may not be on your maximum dose. The easier way to do this would be to start with one vial weekly and then if that is not enough increase to two vials and then eventually up to 3 vials. Since you responded to Eltrombopag I am hopeful that you will respond to Romiplostim but you may need to increase the dose over the next few weeks until you reach the maximum dose. Once you are on 10 µg per kilogram you need to stay on this dose for four weeks and then if there is no response after four weeks then we can say the drug has failed. Drugs like Eltrombopag and Romiplostim have incredibly high efficacy rates of around 80 to 90% so the chances are you will respond to Romiplostim given time and also once you are on the correct dose for you.

ITP Centres: Survey Results

by Shirley Watson

In September 2017 we invited patients being seen at ITP Clinical Centres to complete a survey. We wished to assess whether these patients, who include some of the most refractory and difficult ITP cases, felt that Centres were achieving their aim of providing a specialist ITP service with top quality care. Your responses exceeded our highest expectations!

When the on-line survey closed we continued to collect paper surveys until the end of March 2018 and received a total of 245 responses. We don't know how many ITP patients are actually seen at the ITP Centres, and hope that this number represents a good proportion of them. 23 responses (<10%) were completed by parents of a child with ITP.

The Centre Directors must be warmly applauded for receiving an overwhelming 'yes' to the questions 9, 10, 11, 12 & 19, which shows how extremely well they and their staff are communicating with patients, answering questions and managing this very difficult and unpredictable disease. As there is no single defined treatment path for ITP, and patients all vary in symptoms, severity and response to drugs, it was encouraging and surprising that the number of patients who had received conflicting advice from doctors in the team was recorded as Never 204, Occasionally 36, Often 5.

We would have preferred to see that 100% of ITP patients had a number to call in case of emergencies (Q18), and we could hope for a small improvement in patients knowing whether the doctor has a treatment plan (Q6) and being told about side effects of medication (Q16), but our big disappointment was that a third of patients had not been told about the ITP Support Association on their first visit. We will certainly be working with the relevant ITP Centres to improve this area of communication, as our range of publications on so many ITP issues can back up the excellent work of the ITP clinics in answering questions and addressing concerns. Conversely, the Centres should be actively encouraging membership of our charity as it is our members' donations and fundraising contributions that enable us to fund ITP research projects carried out at ITP Centres!

The table opposite shows patient responses to the straightforward 'yes / no / don't know' questions.

The final survey question asked patients to rate their ITP Clinical Centre on a scale of 1-10 and again the responses show a very high satisfaction level (1 = very poor and 10 = first class) Ignoring the 6 people who skipped the questions, over 96% of patients rated

	Question	Yes	No	Don't know or skipped
Q6	Does your doctor have a treatment plan for you	190	21	34
Q8	Is there an ITP specialist nurse in the clinic	156	5	84
Q9	Are staff friendly, polite, and attentive	245	0	0
Q10	Are you given time to ask questions or express concerns	242	3	0
Q11	Do the team attempt to answer your questions	242	3	0
Q12	Are you happy with your doctor's efforts to manage your ITP?	243	2	0
Q13	Have you ever been pushed into an unwanted treatment	234	11	0
Q14	Have you ever been refused a treatment you wanted	232	10	3
Q15	Have you been given clear instructions about taking your medications as prescribed	225	12	8
Q16	Were you told about possible side effects of your medication	213	19	13
Q17	Have you been offered the opportunity to participate in clinical trials?	162	77	6
Q18	Have you been given a number to ring in case of an emergency or urgent enquiry?	225	19	1
Q19	Has the overall quality of care met your expectations	238	4	3
Q20	Were you told about the ITP Support Association during your first visit?	160	79	6

their Centre between 8 and 10, as can be seen in the table overleaf (pg12).

Lastly in the survey patients were given an opportunity to make suggestions for improvements at their Centre, or to make a general comment. There were many

appreciative remarks, and although the main culprit of adverse comments was long waiting times, the majority of patients felt this was due to lack of NHS resources or funding, not the Centre's bad management. A selection of improvement suggestions and comments are given overleaf.

Clinical Centre rated 1 – 10	Number of responses
10	164
9	38
8	28
7	3
6	2
5	3
4	0
3	0
2	0
1	1
skipped the question	6

A selection of suggestions:-

(edited for brevity)

'Give documentary info about the ITP Support Assoc at the first consultation. I just happened to find a copy of "The Platelet" amongst other leaflets on the general table.'

'Once our 6 yr old has been examined by the doctor, it would be nice if a play therapist could play with her, so that we could discuss more things that concern us, out of her ear shot.'

'Facilities to do a blood count there and then and get immediate results, as used to happen at my local hospital.'

'Better communication with the pharmacy!'

'Email / Skype appointments for follow up of blood tests would reduce time off school'

'More doctors to reduce clinic waiting times which can be over 2 hours.'

'If having a platelet crisis I should be able to contact the doctor rather than going through other departments.'

'Need of bigger space due to how busy the Centre is.'

A selection of comments

'I wish GPs knew about ITP Centres and referred patients there. I know about them only through the ITP Association.'

'I feel I'm getting good treatment advice, but it's very chaotic there and the clinic has been moved to an area with no windows and very hot in the summer months. Printers sometimes fail when the doctors try to print blood request forms etc. Very frustrating for them as time is wasted running back and forwards to different rooms!'

'I have received excellent care and advice from both of my consultants and can contact a specialist nurse by phone if necessary. I feel very strongly that we manage my ITP as a team and I never feel as though I am having treatments forced on me. I feel that my opinion is listened to and that gives me confidence in making choices about possible treatments.'

'I think the care is superb here and only wish it was available to all who have ITP!'

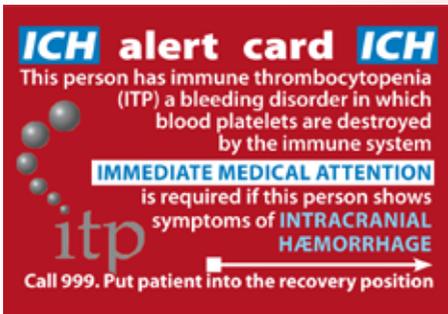
Order a free ICH alert card!

Having an ICH alert card is rather like taking out travel insurance. You hope you'll not have to ever use it but it is there to give you peace of mind in case the worst happens.

It is very rare for anyone with ITP to have a brain haemorrhage (ICH), but if it should happen to you, fast action by you or those around you, plus prompt scans and specific treatment by emergency doctors can help prevent a serious situation becoming a disaster.

The ITP Support Association's ICH alert card was developed in 2012 with assistance from Professor Adrian Newland, who said 'ICH is very rare in patients with counts over 10, and even in those under 10 is only usually seen if there are other complicating factors.' The card's purpose is to make patients aware of the early warning signs of ICH and to alert paramedics or A&E staff that these signs in ITP patients must be taken seriously. We have sent batches of ICH alert cards for distribution at ITP Clinical Centres and other interested hospitals.

Our medical advisors strongly suggest that ITP patients should carry one just as people on steroids carry steroid information cards, and people with epilepsy carry alert cards to help in the event of a seizure.



SYMPTOMS INCLUDE:

- Headache - often sudden and severe (with or without vomiting)
- Unconsciousness
- Altered mental state or confusion
- Seizure
- Paralysis or weakness on one side
- Slurred speech
- Loss of co-ordination
- Unable to count fingers held up

THE RECOVERY POSITION

With patient on their back, put left hand on right cheek and pull over by left knee

If you or your child have ITP and don't already have one of these folded red plastic alert cards, you can order yours now by sending your request with an SAE to:

The ITP Support Association, The Platelet Mission, Kimbolton Rd, Bolnhurst, Beds, MK44 2EL. The cards are free, but donations are appreciated.

Diagnosed by CT Scan

<p style="color: white;">Emergency treatments include: oxygen, platelet transfusions, high-dose IV steroids, IV immunoglobulin</p>	<p style="color: white;">In ITP these symptoms can have a slow onset like a dripping tap and are SERIOUS</p>
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©The ITP Support Association.
More information for clinicians can be found at: www.itpsupport.org.uk/ICH

Fantastic Fundraisers!

Congratulations to Pauline Woods who participated in the Simplyhealth 10k Great Women's Run in Glasgow on the 10th June and raised a super £413 in aid of the charity. The scenic route in Glasgow's West End has bands and pipers along the way to provide entertainment of runners and those cheering them on. Pauline, whose platelet count sits around 20 or lower can be especially proud of her achievement, as she says: On a good day I might not feel anything at all, other days I'm covered in bruises and feel like someone has poured all of the energy out of my body. I could literally sit down wherever I am (in the office, in the street), and sleep. I have



Pauline Woods, halfway there

also been asked, on more than one occasion, if I've been beaten up!

Julie Bell and nine other climbers took on the challenge to climb the three tallest peaks in Scotland, England and Wales, known as the Three Peaks Challenge. They successfully climbed Ben Nevis (1344m), Scafell Pike (978m) and Snowdon (1085m) all in 24 hours! Julie's sister Jacqueline has had ITP since she was 12 years old. The group collectively raised £3,674 to be split between 4 charities including The ITP Support Association.

Marilyn Coulter organised a charity night and raised a

fabulous £500. We very much appreciate all her hard work which made this event such a success.

Kevin O'Shea donated £200 as a retirement collection by his colleagues. We wish him a very happy retirement and are



Pauline's triumphant finish



Julie Bell and fellow climbers

most grateful to Kevin and his colleagues for their generous support.

Kayleigh Shaw decided to ask for donations in lieu of birthday presents this year raising £100 for ITP. We hope Kayleigh had a wonderful birthday and send a hearty thanks to her, and to her family and friends for their kindness.

Bolnhurst may be a tiny village with just 66 houses, a church and a gastropub, but it is also home to a national charity (The ITP Support Association) and since 1984 it has hosted the extremely popular Bolnhurst Vintage and Country Fayre. This began with a group of farmers showing their old vehicles and sending some money to a local charity, and it has now grown to a huge event that takes place over the second weekend in June. In recent years they have raised over £2000 annually which is divided between a number of local charities including The ITP Support Association. We were most grateful to receive £300 this year.



Two kind donations have been received from regular supporters of our charity: Hope Baptist congregation held a collection which raised £75 towards our work, and Atlas Trading sent £56 as yet another donation from their collection box. We are grateful to Simon Gledhill the Managing Director for having this collection tin at his premises.

CONDOLENCES

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

£700 in memory of **Barry John Bearman** sent by his wife Mrs D. A. Bearman

£200 in memory of **Eddie Mills** sent by her daughter Josephine Hickinbottom

£100 in memory of **Yvonne Mittens** sent by her son Perry Gaffney
Yvonne had been a supporter for many years.

£95 in memory of **Denise Ann Delderfield**

£50 in memory of **Jennifer Thomas**

ITP Patient Afternoon at ITP HQ

by Nev Watson



Shirley Watson, Liz Gooch and I were delighted to host a 'full house' at the Patient Afternoon held in the Platelet Mission at Bolnhurst in North Bedfordshire on Friday 13th July. With temperatures soaring into the 30s on this lovely sunny day we were extremely pleased that we had installed air conditioning

units in when we built our headquarters three years ago. Shirley had borrowed the village marquee and extra chairs to enable a logistically smooth afternoon with no time wasted moving furniture for discussion groups or refreshments.

Patients started arriving from 1pm for a sandwich lunch in the marquee and were soon chatting to each other about the trials and tribulations of ITP. At 2pm it was time to assemble in the Steven Sims meeting room where Shirley, the ITP Support Association founder, welcomed everyone and introduced the medical guest speakers who represented 3 different ITP Clinical Centres.

Dr Martin Besser, Consultant Haematologist at Addenbrooke's Hospital in Cambridge, gave a talk enthusiastically outlining innovations in managing outpatients at Cambridge University Hospitals. EPIC, a secure state-of-the-art electronic patient record (EPR) system has been implemented in both Addenbrookes and The Rosie Maternity Hospital in Cambridge. The system includes a patient portal, called MyChart, which is an integral part of the same EPR system, giving patients aged over 18 access to their medical information. Dr Besser explained that patients can now have a blood test in the afternoon and see their results on their phone or computer in the evening. The patient's medical history, including other conditions, allergies, medications, previous blood test results and appointments are all registered on the system, and patients are encouraged to report changes or redundant information so their record is completely accurate and up to date. In





a crisis on holiday or away from home this system enables the patient to show another doctor their full patient history on their phone. Patients are able to send messages to their doctor, for example if their symptoms worsen, although they are advised to phone if it is urgent. Although expensive, this system has greatly increased efficiency, reduces the number of

patients who previously had to be seen occasionally just to keep their case open, and has improved patient care. 81 of their patients are on the system, the oldest being 91. One of Dr Besser's patients in the audience summed up the benefits from a patient point of view and helpfully agreed to write about it for Platelet Readers [Ed: see pg 21]

Dr Nichola Cooper gave a presentation on her research work at Hammersmith Hospital & Imperial College, and her team's efforts to answer the many 'unknowns' in ITP: what causes it; why some patients bleed and others don't; what is a safe platelet count; why some people go into remission and others don't; what treatments should doctors use; how do patients know if they will respond to treatment. They are carrying out research to understand the risks of bleeding, and are running a study using MRI scans to investigate whether ITP patients have had microbleeds in the brain. Dr Cooper reported the encouraging news that no microbleeds were found in patients with a platelet count over 10 and only 50% of those with a count under 10 showed any evidence of a microbleed, none of which had suffered any cognitive problems. They have also discovered that only 70% of patients have antibodies which can be eluted from platelets while 30% do not, suggesting there are different types of ITP. Hammersmith Hospital is running various studies using new drugs, or using licensed drugs in a different way, and Dr Cooper explained that these have been tested for safety before they are given to patients in a Phase 1 study. Anyone interested in participating in clinical trials at Hammersmith should get in touch with their ITP research nurse Camelia Vladescu <Camelia.Vladescu@imperial.nhs.uk>



Joanne Read gave us a brief insight into her relatively new role as ITP Clinical Nurse Specialist at the Norfolk and Norwich Hospital. She accompanies the doctors on their ward



rounds every morning and sits in on outpatient appointments, seeing all the ITP patients and following up on their visits. After they have seen the consultant she takes patients to another room where she explains about treatments and possible side effects, answers any questions the patient might have about ITP or how their ITP is being managed, and gives the patients useful leaflets. Haematology patients at the N&N have access to a 24 hour telephone answering service which is

manned by the CNS nurses during the day and then goes through to a haematology night service. In summary, Joanne has a dual role giving support to both doctors and patients.

At 3pm the delegates split into 2 discussion groups, one chaired by Dr Emily Symington in the marquee and the other by Dr Besser in the meeting room. Various topics were discussed including symptoms (especially fatigue), treatments, and side effects. This session was followed by afternoon refreshments in the sunshine before we reassembled in the meeting room for a question forum with our three expert doctors answering patient queries.



Shirley brought the meeting to a close at 4.30, thanking the speakers and asking patients if they would like to attend another such event at HQ. A show of hands gave their answer as a resounding 'yes!' We are extremely grateful to everyone who left a donation in the collection box in the foyer, which totalled £104!

A big thank you to Shirley for organising the day, and to helper Liz Gooch (ITP Office Administrator, see photo left), to speakers Dr Martin Besser, Dr Emily Symington, Dr Nichola Cooper and Clinical Nurse Specialist Joanne Read, to 4 village volunteers for erecting the marquee and to John Douglas for collecting and returning extra furniture to the Old School Hall. They all contributed to the success of this informative and enjoyable day.



Ed: And thank you too, Nev, for your help throughout the day, especially when we needed an IT expert!

MyChart (patient portal)

(Anonymous by request)

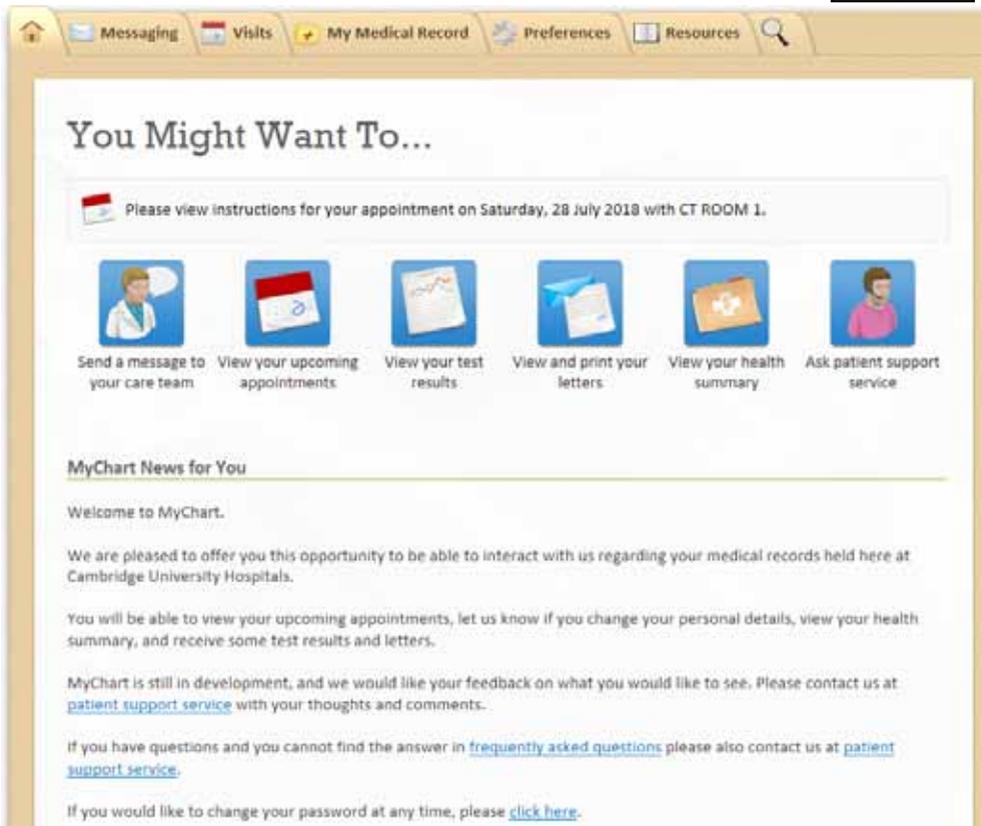
I am a patient under the care of Dr Martin Besser at Addenbrookes Hospital, Cambridge. Having been recently diagnosed with ITP, the condition is such that requires constant monitoring and follow up.

I was signed up to "MyChart", an application which is part of the hospital's eHospital digital strategy. The MyChart application links with the patients' hospital

records so that patients have access to their own information and the ability to communicate with their doctor/s and the team charged with their care.

Only the information which has been reviewed by the doctor or team in charge of the patient's care is released to the application for the patient's access.

Fig. 1



How does MyChart work?

The system can be accessed via your own PC and there is also an app for your smart phone, both Android and iOS. The system has many helpful features. The ones I find most helpful are:

1. Access to your test results as soon as they are available after being reviewed by your doctor.

The best turn around I have experienced is a FBC blood test taken in the morning, and having the results online before midnight the same day. The norm is the following day and subject to weekend timing and doctor's availability.

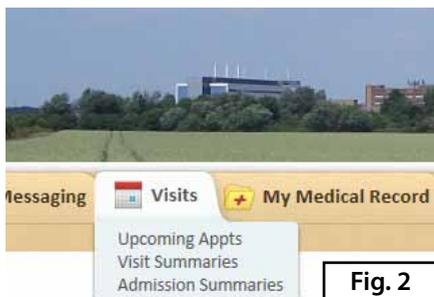


Fig. 2



Fig. 3

2. Being able to message the doctor and his team with any questions regarding the test results, the medical treatment being received and any changes in symptoms before the next scheduled appointment. This works very well with responses received within 48 hours and normally same day depending on time sent and doctor's workload.

This is not a live chat but a valuable tool to enable speedy direct communication between patient and care team, reducing

stress and anxiety about concerns that arise in the periods between hospital appointments.

3. Appointments are notified as soon as they are requested and made by the doctor. An email is sent to the patient to login to My Chart to view changes. The electronic appointment normally arrives 2-3 days before the paper notification by Royal Mail.

There are many more features as you can see from the screenshots of the application (Fig 1-4).

The Smartphone app is so convenient, allowing you to review your test results. I have been able to access these



Fig. 4

results and able to discuss them with my doctor in real time during a consultation.

The home screen in Fig. 1 (pg 19) shows the main options. The app lists all your appointments (Fig. 2) both future and past. It also lists details of your health conditions, allergies and medications being prescribed (Fig 3).

The messaging system (Fig. 4) in the application allows the patient to send and receive the equivalent of email messages.

Where there are changes on the system an email notification is sent informing the patient to login and review. Once the

patient accesses the system and reviews the change, be it a test result, message from the doctor or an appointment notification, this is marked as 'read' on the system and the doctor and his team are aware that the patient has seen the notification.

This system is being rolled out across all departments over time at Addenbrookes. If you are a patient at another hospital it is well worth enquiring if they are offering the same or something similar. I would recommend this as an efficiency enabling technology tool for doctors which will promote Health Care excellence.

News & Views

ITP Awareness article

Derek Elston, trustee of the ITP Support Association, was interviewed by *PharmaTimes* about his experiences of being diagnosed and living with ITP. You can read the article at http://www.pharmatimes.com/magazine/2018/september_2018/patient_files_immune_thrombocytopenic_purpura. Derek has made a great start to September Awareness month by explaining about his ITP in this publication – can you get your story published in a paper or magazine to bring ITP to public attention in September?

Gut bacteria research advances

Those of you that participated in the ITP and gut bacteria research study, may be interested to read an article in *New Atlas* which gives a round up knowledge gained by gut microbiome research. A number of conditions are now believed to have a link with gut bacteria, and a growing body of research is examining how gut bacteria influences diseases outside of our gut, particularly in relation to regulating immune system responses. You can read more at <https://newatlas.com/gut-bacteria-microbiome-revolutions-round-up/55786/>

Research Updates

UPDATES ON ITP RESEARCH PROJECTS FUNDED BY THE ITP SUPPORT ASSOCIATION

The development of a blood test to predict responses to steroid treatment in patients with immune thrombocytopenia

We are the grateful recipients of the John Moulton prize (from the British Medical Association), which, alongside a grant from the ITP Support Association, we are using to develop a blood test to predict responses to steroid treatment in patients with immune thrombocytopenia (ITP). International guidelines recommend steroids (such as prednisolone or dexamethasone) as the first line treatment for ITP, but side effects are very common and responses to treatment are variable with some patients not responding at all and the majority of others relapsing when steroids are reduced or stopped. Currently there is no way to predict whether an individual will successfully respond to steroids before treatment. If it was possible to predict this with a blood test, then only patients expected to get better would receive steroid treatment and for others a more effective treatment could be chosen sooner. Overall, this would reduce side effects and lead to earlier disease control of ITP.

Seventy patients in Bristol have been recruited to the "Low platelet blood study" and

given blood samples for research. The results have shown that lymphocytes (immune cells) in the blood from patients failing to get better with steroid treatment behave differently in the laboratory to steroid treatment compared to lymphocytes from patients who get better with steroid. This forms the basis of the hypothesis that it would be possible to predict which patients would get better with steroid by a blood test. This data has now been presented at the 2017 annual scientific meeting of the American Society of Haematology in Atlanta, USA, and the 2018 annual scientific meeting of the British Society of Haematology in Liverpool, UK.

However, we need to confirm this finding in a separate population of ITP patients whose blood samples are taken at the beginning of treatment (prospectively validate the assay). The FLIGHT trial is a clinical trial for early treatment in ITP. This trial opened for recruitment on 26th October 2017 and is now recruiting patients in 39 hospitals in the UK. We expect to recruit 120 patients in total and so far 64 patients have entered the study. All

patients recruited to this trial are offered the opportunity to contribute to the laboratory sub-study by giving extra blood samples. These blood samples are sent to the University of Bristol research laboratories where they are separated and tested for different markers of immune function as well as being stored for future batch analysis at the end of the trial. One of the tests being done on blood samples is the immune response to steroid assay. We have excellent results so far on >60 patient's blood samples, the results of which will be compared with patient outcomes at the end of the trial (the laboratory researchers are deliberately unaware of the patients response

to steroid to ensure the results are not biased). The results after 2 months treatment will be compared with those at the beginning of treatment and with healthy controls.

We are also collaborating with an expert group in France (Institut Pasteur) to develop a novel approach (Truculture) for testing immune cell responses to steroid. If successful, this would be an easy test to use in the NHS with only small amounts of blood needed and rapid results. Our current work is to optimise and adapt the conditions of the system for this purpose.

Dr Charlotte Bradbury,

Consultant Haematologist, UHB, Senior Lecturer, University of Bristol

The role of bone marrow mesenchymal stromal cells in chronic ITP

The project aims to analyse the potential role of bone marrow MSC in the pathogenesis of chronic ITP by studying their basic characteristics using various phenotypical and morphological assays and assessing their functional properties through proliferative, clonogenic and cross-over culture experiments.

The current work is focusing on growing MSC from ITP bone marrow in the laboratory and assessing the growth characteristics and stem cell properties of these cells. Cells from 13 ITP patient bone marrow samples have been isolated and cells from

8 samples formed MSC layers of spindle shaped cells with confluence ranging from 30-80% at passage 1 and 5-80% at passage 2. MSC from these samples have been frozen. One patient did not grow any MSC from isolated cells. Unfortunately, we were unable to grow cells from 4 patients due to inadequate BM sample preparation.

Patient recruitment has been rather slow. however, the aim is to recruit as many patients as possible in the next few months and continue with cell maintenance and analysis.

by Dr Edita Hamzic,

Department of Infection and Immunity, St George's University of London

RESEARCH updates continued . . .

Identification of novel pathogenic antiplatelet antibodies in ITP

The ITP Support Association funded a post doctorate researcher for 12 months to work in Jim Crawley's laboratory at the Hammersmith Hospital, to interrogate the role of anti-platelet antibodies in ITP. As you probably are aware, it is often difficult to identify these antibodies, and we don't usually use this as a test to diagnose ITP. However, there is plenty of evidence to suggest that these antibodies cause disease. We believe that if we can identify anti-platelet antibodies, then it will be easier for us to make a diagnosis of ITP and possibly help to decide how to treat people. One possible reason for not identifying anti-platelet antibodies is that the test we use at the moment misses some antibodies (most tests look specifically for antibodies to something on the platelet (an antigen) called GPIIb/IIIa).

In this study, we collected platelets from patients with ITP and then used a chemical to remove the antibody from the platelets. This way we can collect all of the antibodies, rather than specific antibodies. We then mixed these antibodies with healthy platelets and then used a system which can detect antibodies

on the platelet (another antibody which is fluorescently tagged). It sounds complicated, but this system allows us to detect small numbers of antibodies on small numbers of platelets. It allowed us to show that nearly 70% of patients had antibodies on their platelets (higher than the 50% usually detected). It also showed us that there were different types of antibodies, some that covered lots of the platelets (high density) and others which only covered a little bit of the platelet (low density). This difference between patients (called heterogeneity) could be why different people respond to one treatment (such as rituximab) whereas others do not.

We now need to understand better what part of the platelet the antibodies target and whether we can find the immune cell which produces this antibody so that we can target it for treatment. The whole article with more details of the study has been published in the British Journal of Haematology. We are very grateful to the ITP Support Association for their support.

Dr Nichola Cooper

Senior Lecturer and Honorary Consultant Haematologist at Hammersmith Hospital,
Imperial College, London

Can you help us fund vital ITP research projects like these?

Your donations and fundraising events will enable us to support valuable research to better understand ITP, improve treatments and hopefully find a cure

Prescription pad

Medical Advice for University Students

Whether you're a fresher or in your final year, we have a few basic health care tips for students.

1. **Get an ACWY vaccine**

It protects against four different strains of meningococcal bacteria that cause meningitis and blood poisoning (septicaemia): A, C, W and Y. Ask your GP! (For more info visit <https://www.nhs.uk/conditions/vaccinations/men-acwy-vaccine/>)

2. **Register with a GP at university**

You never know when you might need medical help. If you take regular medicines that are only available on prescription, for example the contraceptive pill, make sure you have enough to last the term or until you can register with a doctor close to the university.

3. **Take a first aid kit with you**

It might not be the most exciting thing to pack but a first aid kit with plasters, painkillers (ITP patients should avoid aspirin or ibuprofen medications) treatment for upset stomachs, thermometer, tweezers, insect bite cream or spray and antiseptic cream is a good start.

Our thanks to Gt Staughton Surgery, Hunts for this advice.

You can find the nearest GP surgery to your university and more info on getting medical care as a student at <https://www.nhs.uk/live-well/healthy-body/getting-medical-care-as-a-student/>



More questions answered...

by **Dr Jecko Thachil** (Consultant Haematologist, Manchester Royal Infirmary)

Q I was recently diagnosed with atrial fibrillation. My doctor prescribed, blood thinners and statins/beta blockers (not sure which one). The latter are because I have high blood pressure. I've been diagnosed with health anxiety, something I have endured for most of my adult life, and managed without taking medication for other disorders. I refused to take any medication, looking at life style changes, such as eating habits and exercise. Trying to scare me into taking tablets doesn't work. I am told not taking anything has made the chances of having a stroke fivefold. The scariest thing for me would be a serious bleed, particularly with my ITP. It's easy for people to say 'just take the medicine'. Counselling has helped identify the cause of my anxiety, however no one can help me (it seems) to find a way to overcome it.

A I presume the person with ITP here is worried about taking blood thinners (anticoagulants) for atrial fibrillation (AF). The decision to take anticoagulants for AF is based on a risk stratification score termed CHADS2VASC score. If this is more than 1, then there is benefit in taking anticoagulants to prevent blood clots in the brain (stroke) and clots elsewhere. Of course, in a person with

ITP, this can be a problem especially if the platelet counts runs less than 50, which is the threshold required for anticoagulants. So, if the risk score is high, ITP treatment may be required to co-administer blood thinners

Q At the moment my platelets are in good shape i.e. over 150 and therefore normal. How is it still possible to feel so very tired, as I do every day?

A Fatigue can be caused by a number of things including ITP. As you may be aware, ITP is an autoimmune condition. People with autoimmune disorders are likely to develop other autoimmune problems, which can be associated with fatigue. Some of these are vitamin B12 deficiency, underactive thyroid and gastrointestinal disorders. So, it would be useful to check for these conditions and also rule out iron deficiency from other causes like menstrual bleeding or altered diet. Poor sleep pattern and work schedules can also have an impact on fatigue.

Q I had my spleen out in 2010 and have since been on 500mg of clarithromycin. I now have bowel

problems which someone suggested could be long term use of this antibiotic. (I go several times a day sometimes loose, sometimes not) Do you have any advice for me or suggestions of what I should ask my doctor to improve my situation?

A Loose stools can be a side effect of antibiotics although usually this tends to start soon after commencing the tablets. One way to find out if the loose stools are indeed caused by clarithromycin is by stopping it and seeing if the symptoms improve. If they don't, then alternate causes should be investigated for the loose stools. While the clarithromycin has been withheld, different antibiotic should be substituted according to the local antibiotic policy available to the GPs.

Q My daughter had a kidney transplant and was later diagnosed with ITP. She gets pain during her monthly cycle so could you please advise about medications she can take to relieve her period pains?

A This would be best advised by a gynaecologist although medications like non-steroidals should be avoided if the platelet count is less than 50.

Q I would really like to get some more information on exercise and if and how it affects my ITP. I was diagnosed last autumn and previously

had been a regular runner. But for the last 9 months or so I have been much more sedentary. Do certain types of exercise impact more or less greatly on platelet levels?

A There is not much research on exercise having a negative impact on platelet counts although it would be more likely that it has a great positive influence due to the sun exposure and reduced risk of infections noted in regular runners. It would however be advisable that the types of exercise which may run the risk of bleeding like mountain climbing and weight-lifting are avoided unless the platelet count is running at a reasonable level. I wonder whether this person has fatigue secondary to ITP which is limiting their exercise schedules. If such is the case, it would be useful to discuss with their ITP specialist measures to increase the platelet count to help with the regular exercises.

If you would like to have a question answered by our ITP medical advisors please email it to: shirley@itpsupport.org.uk or post it to: The Platelet Editor, The ITP Support Association, The Platelet Mission, Kimbolton Rd, Bolnhurst, Beds, MK44 2EL

Round up from ITP HQ

by Mervyn Morgan, CEO

THE ITP CONVENTION 2018

Following last year's well-received ITP Convention in London, several members requested a future event to be held in the North West of England. We agreed. The 21st ITP Support Association Convention will take place at the world-famous Chester City Racecourse, known as the ROODEE, on Saturday 27th October 2018 from 10.00 am to 5.00 pm.

We are pleased to welcome for the first time this year, Dr Cindy Nuenert from New York, one of our medical advisors on childhood ITP together with Dr Paula Bolton-Maggs. The program has been designed to also introduce delegates to other elements relative to ITP.

We have therefore invited notable speakers to discuss and consider what happens behind the scenes which is for the benefit of patients and of which many are unaware.

The City of Chester is full of history, from its Roman ruins to its 1,000-year-

old Cathedral, coupled with an unusual shopping area all within the old Roman Walls. If you are thinking of attending the Convention, why not have a long weekend and explore this unique city and the surrounding areas. There are numerous hotels; guest houses and restaurants in and around the City including the Holiday Inn Express which is only yards from the

Convention venue at the Racecourse. We have negotiated special rates here, subject to room availability, of £85 per room including breakfast for delegates wishing to stay. The main line rail station is only five minutes by taxi from the Roodee and Chester is close to the motorway network.

If you are

travelling by car, please supply your car reg. number to obtain a security pass to the racecourse car park

Convention tickets can be purchased online, £25 per head for members and family. £40 for non-members. If you are a

Patient Mentors

a listening ear

Rhonda Anderson

0208 504 2688

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Derek Elston

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Dave Farrow

01664 852218

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non-member why not join the association for £10, you will then make a £5 saving on the non-members ticket price. If you do not have access to the internet you can purchase tickets for the convention by completion of the booking form enclosed with this issue of The Platelet indicating the number of tickets required. Please make your cheque payable to The ITP Support Association, and post to The Platelet Mission, Kimbolton Road, Bolnhurst, MK44 2EL.

We look forward to seeing as many of you as possible on the 27th in Chester.

We are grateful to pharmaceutical companies Novartis, Amgen and Rigel for their generous convention sponsorship.

TEXT GIVING

Don't forget that you can make a donation through **Justtextgiving** at your mobile operator's standard rate by texting the message ITPA22 and the amount (£1 – £5 or £10) to 70070.

The Association will receive 100% of your donation which can be increased by adding Gift Aid.

**ITP AWARENESS MONTH
SEPTEMBER 2018**

We all know that September is ITP Awareness Month and this year we would like to do something a bit different. We would like to hear YOUR stories.

What better way to raise awareness than hearing from ITP sufferers, and their daily struggles and triumphs. Get in touch and tell us all about your ITP story, how you are getting

on and the achievements that ITP has not held you back from. Not forgetting a lovely photograph of yourself, we can then post about your journey on facebook and therefore help others with theirs, as well as raising awareness. Get in touch by emailing: hayley.keefe@itpsupport.org.uk

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

Patient Participation Group

by Rhonda Anderson

Have you heard of the PPG at your General Practitioners' surgery? Another acronym with which the NHS world abounds. PPG stands for Patient Participation Group and every GP surgery is supposed to have one. Does your GP surgery have one? Do you know what it does? Do you get regular reports on progress? Perhaps you are already a member. If you are, do let me know how your PPG is organised and the successes you have had.

The following is from the Patients Association:

The role of the PPG includes:

- being a critical friend to the practice;
- advising the practice on the patient perspective and providing insight into the responsiveness and quality of services;
- encouraging patients to take greater responsibility for their own and their family's health;
- carrying out research into the views of those who use the practice;
- organising health promotion events and improving health literacy;
- regular communication with the patient population.

It took me a while to get onto my PPG. I was initially interested when I heard about it, which must have been around 2015. However, they were keen to have a diverse

group of people and the older, retired, white, female, was already well represented, so I did not get a place. It was only when I went to see a particular young doctor in the Practice and happened to get chatting about the NHS and my voluntary role on the Patients' Panel at Whipps Cross hospital, that he said, "You are just the kind of person we need on the PPG", and that is how I got a place through him. It is very difficult to get young students, young mothers, ethnic minorities and patients with mental health issues to become members. It doesn't take a genius to realise that the people who will be available and keen to engage, are the retired population. This is the same for all groups.

We meet about every three months, which I do not think is often enough. We have a Chair and a Secretary who do the paper work and our venue is the surgery premises. Other members would ideally work on some area of interest, and so far mine has been EPP, another acronym, standing for the Expert Patient Programme. I have written about in previously in this column. It is a self-help 6 week course, for people with long-term conditions, to self manage their condition. It has been slow going and very frustrating as nothing seems to happen quickly. Patients can self refer, but we were hoping that the GPs would be proactive in pointing suitable people in the direction of EPP. It is free

and should be beneficial to everyone. What not to like? One wonders, as there have been no referrals so far, in spite of delivering 100 leaflets to the practice.

Other members have taken up disabilities such as access for the partially sighted. The Diabetes Nurse and the Chair have been to the local school to facilitate discussions with young people, in the presence of a teacher, about their health concerns and the way they wish to access NHS services. Unsurprisingly they like to be contacted by text and interact with social media for peer support.

We have a Newsletter for patients that comes out irregularly, but we usually have something to report a few times a year. This is to keep people up to date on the technology that is being used to answer phones and book appointments, and the changes to the system for holding patient records. Also referrals, patient access to records, and clinical items such as ear micro suction availability through local GP surgeries. This is very much an ongoing issues that we are trying to resolve, as patients from our practice are being referred to pay for this service, which we think should be free for all patients regardless of the clinical state of their ears. Only some conditions are accepted for referral to the hospital where they



have the equipment. The CCG, Clinical Commissioning Group, hold the purse strings on this. However, it is possible for a clinician in the GP practice to be sent on a course and the GP practice to buy the equipment, but this seems to be unacceptable to our practice for some reason, indicated to be financial.

At times we have felt unsupported by the GPs and have had to ask for positive affirmation that they are keen to have us working with them and that they are prepared to listen to us. I feel that some members are somewhat in awe of the medical profession, and my experience on the Patients' Panel and the hospital inspections I have done, have given me confidence to challenge the GPs.

Indeed the experience I have had with the ITP Support Association has stood me in good stead to realise that our medical advisors have been so generous with their time and knowledge. I do expect all medical professionals to live up to this very high standard that we find with all our speakers and participants in Conventions and contact with them. Thank you all for being so professional in your contact with ITP patients and for setting such a high standard, to which we wish all medics would aspire.



USE THIS FORM TO:-

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- * 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