



the platelet

MAR 2018

JOURNAL OF THE ITP SUPPORT ASSOCIATION

**LAST CHANCE
TO COMPLETE
AN ITP CENTRE
SURVEY!**



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

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Charity Registration No:1064480

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

Shirley writes . . .



On June 9th I will celebrate my 70th birthday and although I still feel 35, I have for some years been making preparations to retire from my leadership role. Towards this end first we built an independent headquarters, then Mervyn replaced me as CEO, and last year three new trustees were invited to join the board. With an increasing amount of my time devoted to two older members of my family with Alzheimer's I decided to relinquish the burden of responsibility on 31st January by retiring from the trustee board. However, I will continue my roles as editor /designer of ITP Publications and The Platelet, as Association representative on the ITP , and as one of the team providing telephone /email patient and parent support.

In October Michael Levy, our esteemed treasurer and trustee was 80, and not surprisingly he too has decided that it is time to call it a day after 8 years dedicated service. He has kindly agreed to continue keeping the books until a replacement is found, so you will see an advert for a new treasurer on page 10. If you have the necessary attributes, do please apply! It would be wonderful to have a treasurer with a personal interest in ITP join our team.

To ensure a smooth transition in this time of change Professor Newland has taken the reins as acting Chair of the Trustees (I include his article on pg 20 with some embarrassment!) The governing team are full of enthusiasm and ideas, and Michael and I are confident that the charity will have a very successful future.

*Front cover: Dr Nichola Cooper receives BMA award (pg 19)
We are grateful to the BMA for permission to use this photo
Lexy Monks & team complete the Rough Runner (pg 12)*

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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.

Round up from ITP HQ

by Mervyn Morgan, CEO

News from the ITP Office

Even after the Christmas rush the office has remained extremely busy during the early months of 2018.

No sooner had Big Ben welcomed in the New Year there was then an announcement from the Charities Founder Shirley Watson MBE, announcing her intention to retire and stand down as a Trustee.

There is a wonderful tribute to Shirley from ITP Trustee Professor Adrian Newland CBE in this edition of the Platelet, but it would be remiss of me not to say a few words of my own. I know from my own experience that building a Charity, from scratch is a huge undertaking, an endeavour which seems to take over every waking hour. Shirley started the Association in 1995 and achieved charitable status in 1997. She has worked tirelessly over three decades building the Association. The charity that 'Shirley and Frank built' has grown into one of the most respected patient groups in the country, that is a legacy that would make anyone proud. Although we use the word retirement, this is said in the loosest of terms, Shirley will be acting as one of the Associations advisors and we are also pleased that she will be

continuing as the publications editor (which includes the Platelet). In addition, Shirley has accepted the position of Honorary President of the ITP Support Association, the charity 'Shirley and Frank built'.

Convention 2018

After the success of the 2017 Patient Convention, held in London, initial planning work is now underway for next ITP Convention (all very exciting), we are hoping to be able to publish some initial information about the venue and speakers in the next edition of the Platelet. As with the 2017 Convention, once the venue and date are confirmed you will



be able to book tickets via our website.

I-WISH Survey

Just prior to the Christmas period the Worldwide Survey of ITP patients (I-WISH Survey) was launched in the United Kingdom and we are pleased to announce that the take up by UK members has been fantastic, thank you to everyone who took the time to complete the survey. Please be aware that you can still take part in the survey, if you wish to do so please email me at mervyn@itpsupport.org.uk and I will send you the link. The results of the I-WISH survey will be available later in the year.

Your questions answered...

Dr Will Lester responds to questions on ITP in adults

Consultant Haematologist, University Hospitals Birmingham NHS Foundation Trust

Q After having my spleen removed, my ITP has gone. I'm being signed off at hospital, does this mean my ITP has gone away for good?

A *Hopefully your ITP is cured however there is a small chance of relapse and this can even happen after several decades. In one study of long term follow up after splenectomy, about a third of patients relapsed after an initial response¹. It's not unreasonable to stop regular monitoring of the platelet count if it's been stable for a while, considering that relapse is unlikely to coincide with a check up, so my advice would be to look out for symptoms and get a medical review if you have any concerns eg. excessive bruising, petechiae (tiny pinpoint blood spots on the skin) or blood blisters in the mouth.*

One bit of 'small print' worth mentioning relates to pregnancy. If a women with a history of ITP and previous successful splenectomy has a pregnancy, there is a chance that the baby can have a temporary ITP at birth, even if the mother has a normal platelet count. This reflects the presence of persisting platelet antibodies in the mother that can pass through the placenta to the baby. ITP in the newborn is uncommon however and most babies born to mothers with ITP have a normal platelet count.

¹Vianelli et al *Haematologica* 2013; 98(6):875

Q I have been on romiplostim for the last 10 months with increasing doses. I have the injection every week. I feel well on it and my platelets are not too bad, although sometimes they do fluctuate. My question to you is how long can I stay on this injection, as I do not want to go on steroid therapy ever again.

A *There is no official limit on the duration of treatment with this type of drug known as a TPO-RA (Romiplostim and Eltrombopag). Some people will spontaneously go into remission on treatment in which case it can be stopped. No drug therapy is completely free of potential risk and as doctors, we have to be vigilant about looking for any side effects, both expected and unexpected. There are some rare complications, one being fibrosis (scarring) in the bone marrow but this seems to be reversible on stopping the drug.*

Q I was diagnosed with ITP 6 years ago and have been successfully treated with a low weekly sub cutaneous injection of Romiplostim but 2 years ago I suffered a clotting stroke (POC) and afterwards was prescribed Clopidogrel as well. My haematologist has never had

an ITP patient with clotting stroke, more usual would be a haemorrhage. I wondered if any other subscriber to your magazine has had similar . Fortunately I have recovered well from the stroke and with NHS help managing my ITP. I am 76 years old and lead a fairly active life. My platelet count is between 50-150 and blood taken every other week.

A Sorry to hear about your stroke but it sounds like you've made a good recovery. Unfortunately, ITP is not protective against thrombosis in either the

veins (deep vein thrombosis, pulmonary embolism) or arteries (strokes and heart attacks) although it's less likely to occur when the platelet count is very low (<10) where bleeding is the main risk. Perhaps surprisingly, patients with ITP are actually at slightly higher risk of thrombosis than the general population. There may be a number of reasons relating to both the ITP itself and its treatments. Once a thrombosis has occurred, we try to keep the platelets at safe levels (ideally over 50) so that we can give the appropriate treatments eg. clopidogrel as in your case.

Dr John Grainger responds to questions on childhood in adults

Consultant Paediatric Haematologist, Royal Manchester Children's Hospital

Q My 4 year old daughter has chronic ITP, and has been on eltrombopag for approximately 10 months.

Her counts fluctuate, so what are the recommendations for play and activities? Can she participate in activities such as gymnastics with a count that is below 20? Are there any specific guidelines that I or school should follow or be provided with?

A It is very common for counts to fluctuate on Eltrombopag. We generally advocate not over responding to count fluctuations and would avoid excess counts or dose changes. When the count is below 20 this is likely to be apparent to parents due to increased bruising and presence of fresh skin petechiae (pin prick blood spots).

I would also ensure that the dietary timings around eltrombopag are reviewed as high calcium foods do interfere with Eltrombopag. For a four year old most gymnastics will be floor based and completely safe. I would discourage unsupervised use of high apparatus, rings or horse in an older child. Specific guidance is tricky to make a one statement fits all. With any sport there may be increased bruising but this is not dangerous if the child is keen to participate. What we worry about is heavy head trauma. I would forbid contact rugby and boxing but most other sports can be done with some moderation following discussion with medical team and coaches.

{Ed: You may find the Association's two booklets, *ITP & Sport*, and *Guidelines for Schools, Clubs & Playgroups* useful}

Q My daughter had cows' milk protein intolerance until she was approximately 16 months old. Could this be linked to her ITP ?

A Severe inflammatory bowel disease is definitely linked with ITP and any history of chronic tummy pain or diarrhoea

needs to be investigated by a gastroenterologist. With regard to food intolerance there has been numerous reports of associations and this prompted an ITP Support Assoc sponsored study that was published in November 2017. The study concluded that dietary modification had no effect on platelet counts.

Vacancy for ITP Treasurer

The ITP Support Association is seeking an Honorary Treasurer whose duties will be to:

- monitor the financial administration of the charity and report to the board of trustees
- oversee the charity's financial risk-management process;
- act as a counter signatory on cheques and on-line banking;
- prepare annual financial statements to the board of trustees and annual accounts for the external auditor;
- ensure that proper accounting records are kept, financial resources are properly invested and economically spent;
- liaise with relevant members of staff and volunteers;
- monitor and advise on the financial viability of the charity;
- oversee the implementation of and monitoring financial systems;
- advise on the financial implications of the charity's strategic plan;
- assist and advise the CEO in any financial matters;
- claim back tax from Gift Aid donations;
- undertake or oversee various bookkeeping duties and banking of cheques;

This voluntary post would suit an experienced treasurer or retired accountant. Although much work can be done from home an occasional visit to the charity's HQ in rural North Bedfordshire would be desirable. We would be delighted to hear from you if you think you could fill this vital role and become a key volunteer of the ITP Support Association.

To apply: Please contact Mervyn Morgan by email (mervyn@itpsupport.org.uk) outlining your qualities and experience (please entitle the email 'ITP treasurer') Applications should be sent before 5pm on 31st March 2018.



American Perspective

Professor Spero Cataland MD
Columbia University Medical Center

"I have ITP. Should I be taking this blood thinner?"



The question of whether or not a patient with immune thrombocytopenic purpura or ITP could take a blood thinner (called "anticoagulants") is one that is asked of hematologists commonly by both physicians and patients alike. While on the surface it might seem strange to think that a patient with ITP might develop a blood clot of the legs or lungs, patients with ITP appear to be at slightly greater risk for both venous and arterial thrombotic events than the general population. Therefore the more important question that has to be asked is not whether or not an ITP patient can take a blood thinner. More specifically, what level of platelets would be considered safe to take a blood thinner?

The risk of bleeding is the most common side effect that can be seen with all blood thinners. While the risk of bleeding may be decreased with some of the newer oral anticoagulants (apixaban, rivaroxaban, dabigatran) compared to warfarin (which has been the common anticoagulant for 50 years), the risk of bleeding with all anticoagulants will be increased when patients also have a platelet count that is

lower than normal.

Similarly, patients who take a baby aspirin (i.e. low-dose aspirin) daily to prevent heart disease or stroke can also have an increased risk for bleeding with a lower than normal platelet count. Physicians prefer to rely on clinical trials to more accurately understand the risks and benefits of any particular treatment, but in many situations there just are just no such studies or data to rely on. One example is the question: At what level of platelet count can a patient safely take a blood thinner or aspirin? Is there a specific platelet count above which there is no increased risk of bleeding on a blood thinner or aspirin?

Physicians as much as patients ask and seek an exact number for which they can be confident that it is "safe" to be on a blood thinner. There is a belief held by many hematologists that patient with ITP may have a level of platelet function that is greater than what is measured by the platelet count, based upon the hypothesis that younger platelets are larger and may

have increased function. It is also thought that an ITP patient's platelets may still retain some function even after they are coated by anti-platelet antibodies prior to being cleared by their immune system. A platelet count of 50 is presumed to be safe by most hematologists and surgeons for the majority of surgical procedures, so physicians have typically worked from this starting point and presumed that at a platelet count of 50 it is "safe" to be on a blood thinner. Is there, however, an exact number that can be used for this decision?

The best (and most honest) answer that can be given is that there is no absolute number that can be used. The lower the platelet count, the greater the risk for bleeding complications with a blood thinner. The reason for needing anticoagulation is also a very important factor in this decision.

In situations such as an acute blood clot to the lungs or atrial fibrillation with an increased risk for stroke, anticoagulation can be life-saving. Then () physicians would tolerate a lower platelet count for treating with anticoagulation. Therefore the decision is really a balance of the risks and benefits that should be discussed with the patient. In some cases where the platelet count is much lower (less than 30, for example) and there is an urgent need for a blood thinner, patients may begin anticoagulation but also require treatment for their ITP, to increase their platelet count. So there really is no exact platelet count that can be relied upon to determine when it is safe to be on an anticoagulant. Rather, there should be an ongoing discussion regarding the risks and benefits of being on an anticoagulant or aspirin (or not) in the context of their ITP and their typical platelet count.

You can raise money for ITP with the following schemes...

Give a Car

1. Contact Give a Car on 020 0011 1664 or '<http://www.giveacar.co.uk/how-it-works>' and say you wish to donate your scrap car in aid of ITP. It takes a couple of minutes to get your details and answer questions. Once they have your approval, a collection agent will call you in order to arrange a convenient pick-up time.

2. Your car is picked up. A tow truck usually arrives within 1 to 3 days to pick up your car, though in a few rare cases it may take up to 10 days.

3. Your car is sent to scrap or auction. Give a Car then donate all the proceeds, after administrative costs, to the ITP Support Association. Within 6 weeks you will receive a receipt for your donation, and so will we.

[easyfundraising.org.uk](http://www.easyfundraising.org.uk)

Shop on-line and raise money for ITP! You shop directly with the retailer but by signing up to '<http://www.easyfundraising.org.uk/causes/itpsupportassociation>' for free and using the links on the easyfundraising site to take you to the retailer, a percentage of whatever you spend comes directly to ITP at no extra cost to yourself. You'll get access to hundreds of exclusive discounts and voucher codes.

Hammersmith ITP Patient Day

by **Camelia Vladescu**

'ITP is an autoimmune condition which results in the destruction of a patient's platelets.' This is probably one of the first definitions of ITP that you heard. But there are a lot of questions that this definition leaves unanswered. Why is the immune system destroying the platelets? How does it do it? Can we stop that from happening and how do we do that? Are there any environmental or dietary factors that contribute to this condition? If you or a loved one has suffered from ITP for a while, you will know that we don't currently know the answer to a lot of these questions. This makes ITP an 'annoying' condition, as it has been described by both patients and doctors.

But every cloud has a silver lining. As you might already know, if you read this magazine regularly, there are multiple teams around the world who are carrying out research to find answers to the above mentioned questions. Teams of doctors, nurses, scientists and many more are involved in research but none of it would be possible without you, the patient!

With that in mind, our team of ITP researchers led by Dr Nichola Cooper, organised an 'ITP patient day' in September 2017. The aim of the day was first of all to thank all the patients who have participated in research by donating blood and other tissue samples, who have allowed us access to their data and who have been happy to try out new drugs in phase I trials.

The day started with an introduction to ITP including information about diagnosis, pathogenesis (which simply means what causes ITP), and different types of treatments available. The second part focused on research and included an introduction to the different types of research and touched on the various projects that we have running at the moment. A new app called 'ITP Pocket log' was also introduced. The app is now live and you can download it for free from your app store. The event finished with Shirley, who kindly agreed to speak on behalf of the ITP Support Association followed by a patient who presented her journey since being diagnosed with ITP. Attendees had the opportunity to ask questions throughout the event and also meet other patients and share their stories.

We have received great feedback from the audience and would like to thank everyone who made the day possible, including all the speakers and of course, the ITP Support Association. A lot of patients and family members said they left with a better understanding not only of the condition but also of the current research. And most importantly, they liked being in a room where they were not the only ones with this weird, rare condition that sometimes people around them find hard to understand and relate to. So for all these reasons, we decided we will be hosting another ITP Patient day this summer. The date will be announced closer to the time so watch this space.

But enough of blowing our own trumpet! Before I finish, I would like to say that the event was a massive learning curve for us as well and we are looking forward to the next one! In the meantime, if you have any questions about the patient day, the research that we do or any suggestions please feel free to contact me (camelia.vladescu@nhs.net).



Photo: Nichola celebrates her birthday with her team – From left to right, Elisa Lucchini (Clinical Fellow from Italy, doing ITP Research in the lab for one year), Dr Nichola Cooper, Senior Lecturer in Haematology, Camelia Vladescu – Clinical Research Coordinator, Imperial College NHS Trust Deena Paul – Clinical Nurse Specialist in ITP

Bristol & Wales ITP Patient Day

on Friday 27th April from 1.30 - 5pm

The ITP Support Association and ITP expert teams from hospitals in Bristol and Wales invite ITP patients and parents of ITP children to attend a Patient Day at

The University Hospital of Wales

This informal free event will provide an excellent opportunity to share experiences and develop friendships and to talk to the medical teams.

The event will include a discussion session in which you can put your questions to the expert clinicians:

- Dr Charlotte Bradbury** (Bristol University Hospital)
- Dr Rachel Rayment** (University Hospital of Wales)
- Dr Emma Phillips** (Bristol Children's Hospital)
- Dr Philip Connor** (Children's Hospital of Wales)

Tickets are available from ITP HQ
 Email: info@itpsupport.org.uk Telephone 01234 376559

Fantastic Fundraisers!



Made it! Running Rough for ITP

Lexy Monks, her fiancé **Jonathan Oliver** and three close friends **Alice Gregory**, **Emily Eastern** and **Caroline Martin** took part in the Manchester 10km Rough Runner in October. Lexy wrote " We are pleased to tell you that despite race day coinciding with Storm Brian, we completed the course in one piece and smashed our fundraising target of £150. . . in the end we raised £485.20! I think people felt sorry for us when they saw how cold and muddy we were when we crossed the finishing line!! I hope that it helps lots of people with ITP such as my lovely mum". We very much appreciate their efforts to

raise money for ITP in what made a difficult challenge even tougher by the awful weather!

The charity was delighted to receive a cheque for £275 from **Hope Baptist Church** following a Christmas concert. **Jack McIntyre** is the grandson of one of the church members and suffers with ITP. He bravely stood up in front of the entire congregation explaining what ITP is and his experience of it. Mrs Kelso the treasurer said 'Jack spoke so clearly and knowledgeably it resulted in a heartfelt round of applause. We as a church, and his family were extremely proud of him and he is an excellent ambassador for The ITP Support Association.' Our warm thanks goes to the Hope Baptist Congregation once again, and a big 'well done' to Jack for his awareness raising.

We are most grateful to **Neil Dudgeon**, star of Midsomer Murders, who appeared as a contestant on TV's Pointless Celebrities and very kindly nominated The ITP Support Association to receive a donation of £250.



Neil Dudgeon

A street dance group based in Lancashire called **Jennifer's Dancers** raised an excellent £236 for ITP Support Association. Catherine Wright, whose daughter Lexi is in remission from ITP explained 'Every year Jennifer Sims, who runs the dance group, holds a Christmas party for all the children and the proceeds go towards charities nominated by the parents. This year the proceeds were split between 3 different charities, ITP being one. The children had a great time and on the day Lexi won first prize in a competition for her age group.' Our hearty thanks go to Jennifer, also to Catherine



Jennifer Sims & Lexi Wright

for the nomination, and congratulations to Lexi on winning first prize!

Another dance class, Denise MoneyPENNY's **Ironhorse Linedancers**, also supported our cause, raising £75 as Denise's grandson Charlie has ITP.



Ironhorse Linedancers

Gillian Horner also has a grandchild with ITP, and sent in £35 being proceeds from the sales of her handmade hobby items. Gillian told us "My granddaughter Lyla, aged 7, is a real trooper. She suffers a lot with exhaustion but she tries so hard not to show it and always has a big smile when I see her." (See Gillian's ITP bracelet, left)



Gillian's ITP bracelet

Our thanks to regular supporters **Atlas Trading Ltd** of Ashton-under-Lyne who raised a further £60 up to the end of December 2017 from their ITP collection tin. (If anyone else has space at work or can find a safe and appropriate place to put an ITP collection tin, do let us know!)

Bolnhurst Carol Singers were once again invited to sing and take a collection in their village pub and restaurant, The Plough. While the carollers performed the audience tucked into complimentary mince pies and mulled wine. The collection raised £66 for ITP.

We received £30 as a donation in lieu of presents to celebrate **Elizabeth McKeown's** 70th birthday. We hope Elizabeth, who has ITP, had a wonderful day.

Lisa Parkes, the team treasurer of **Market Bosworth Netball Club** in Leicestershire sent in £22 donations raised from the team as one of the players has ITP.

Finally, our delight was tinged with sadness when we recently received the final ever donation of £2,400 from The Charity Shop. Since they opened their doors in Great Yarmouth on November 18th 2008 they have raised £29,550 for The ITP Support Association and they sent an equal amount to the other charity they supported, The Fisherman's Hospital. Unfortunately they did not find a buyer willing to carry on the business, and the shop has simply closed. We owe a tremendous debt of gratitude to **Celina Wyatt** and her mother **Gloria Doyle** for their marvellous support. Over the 9 years they raised a remarkable sum for charity, £5000 of which went towards the building of our ITP headquarters.



Lyla Oxford

Long Service Award?

27 years of living with ITP

by Jill Straw

I was diagnosed with ITP in January 1991. I went to see my GP with an irregular heartbeat following a viral illness that had lasted for weeks. I had been having nosebleeds for some months but never mentioned these to my GP as I had attached no great importance to them. I had several blood tests which showed my platelets to be in the region of 50 – 60. (There was no obvious cause for the irregular heartbeat at that time and it eventually settled down.) I was referred to a Consultant Haematologist who was very interested in the nose bleeds. He took a bone marrow sample from my sternum which confirmed that I had ITP and so my story began.

At that time a platelet count of 50 or below was felt to need treatment and the great anxiety seemed to be the risk of a cerebral haemorrhage. In the next 15 months I had 3 courses of prednisolone each of which produced an immediate beneficial effect which faded after the course was completed. The amounts of

steroid seemed massive. Each course started at 60 mg a day for two weeks, followed by a further two weeks on 40 mgs and so on until the drug was tapered off completely. Each course lasted 8 - 10 weeks. I felt dreadful, experiencing weight gain, gastric irritation, sleeplessness and most of the other side effects that steroid takers will be all too

familiar with. When in 1992 it was suggested that I should have a splenectomy, with an 80% chance (as it was then thought) of overcoming the ITP completely, I jumped at the idea without any hesitation! I had a course of immunoglobulin therapy immediately before being admitted for surgery.



For two years after surgery I was well and my encounter with ITP seemed to have ended. I felt none the worse for being without my spleen except for the need to take 1000mg of Penicillin VK every day! Then, in April 1994, I had a heavy nosebleed and a blood test the next day showed that I had a

platelet count of 20. Steroid therapy, still the treatment of choice followed. Once again the steroids only worked while I was taking them. Once I had been off them for a few weeks the platelet count soon began to fall. This situation dragged on for two of three years until it was decided to try azathioprine as a treatment. To my delight it did work and taking 100mg a day seemed to be doing the trick without any recourse to the hated prednisolone. Of course, the effects of prednisolone had taken their toll and in 2001 I was diagnosed with type 2 diabetes. The Endocrinologist urged me to lose the weight I had gained while taking steroids so I took the bull by the horns, not only following the excellent diet recommended by the hospital Dietitian but also joining a gym. I lost two and half stone and happily brought the diabetes under control needing only metformin – which is still the case.

Azathioprine seemed to have enabled me to forget all about the ITP and I maintained a reasonable platelet count of 50 – 100. When I needed surgery for the removal of my gall bladder in 2002 I again had a course of immunoglobulin therapy before being admitted and all went well. I had no noticeable side effects from azathioprine and didn't seem to catch infections any more readily than anyone else. That all changed in 2013.

I haven't mentioned my family in this story but should do so now. I have been married to my husband, John, for 50 years

and we have one daughter, Bryony, who is a GP. In 2012 our grandson William was born, to everyone's great delight! Like most grandparents we were, and are, over the moon and went to see our grandson and his parents as often as we could. All was well until William started going to nursery and shared his newly acquired viruses with me! I had one particularly nasty flu-like illness and in the midst of it began a nose bleed so heavy that I ended up being admitted to hospital. My platelet count was 1! A course of immunoglobulin therapy produced a good response and got me discharged but all of a sudden I was a regular attendee at the haematology out patient clinic again. Clearly the azathioprine had failed and steroid treatments were ineffective but thankfully new treatments were now available.

Unfortunately my chronic ITP is now described as relapsing and to some extent refractory as several of the newer treatments have failed to produce any really long term improvements. I have tried romiplostin – which was good for a year or so but then ceased to be effective (platelet count of 8) and I have also tried mycophenolate which had some unpleasant side effects without producing a long lasting benefit. I have been given a pulse dose of dexamethasone (20 mg a day for 4 days which was the most unpleasant experience I have had in terms of side effects) to no avail. I am currently taking eltrombopag and azathioprine - again. In a crisis a 4 day course of 4mg daily of

dexamethasone has proved effective together with tranexamic acid. I have a treatment plan which I keep with me, especially if we are away from home, in case I am admitted to hospital. I also have a rescue course of augmentin as any flu like infections invariably result in a sharp drop in my platelet count.

I have a wonderful, patient, and good humoured haematologist who has been seeing me every week for the last two or three months and I do feel we are on my ITP pathway together. In general terms I am well and try to remember that ITP is a condition, not an illness - drug side effects

notwithstanding! We still see our family on a regular basis and William often comes to stay with us in the school holidays. Ironically my husband has Parkinson's Disease and I am his registered carer. Of course, the truth of the matter is that we prop each other up and we have never lost our sense of humour!

If there are any newly diagnosed ITP patients who want the advice of an 'old timer' I would say remain optimistic, there are plenty of different treatments to try, and don't spend too long reading about the possible side effects of those treatments – everyone responds to things in different ways.

A tribute to Shirley Watson MBE

by Professor Adrian Newland, CBE

In the mid-nineties Professor John Lilleyman and I, who between us looked after the children and adults with ITP at the Royal London Hospital, agreed to meet a force of nature. Shirley Watson through her experience of a child with ITP had come to realise that there was little good quality information available for patients and equally importantly few people were even aware of the disease. It was also clear that many doctors (including haematologists) had no detailed knowledge of ITP or the subtleties of its management.

She decided that what was needed was a patient organisation. It would be easy to say that we now have the ITP Support Association

and the rest is history, but that would be to seriously underplay the work that Shirley has put into getting us this far. The Association received its trust deed as a charity in 1997 and now has over 800 members and it has been through her leadership, dynamism and effort that we have reached this far. Her ability to persuade friends, acquaintances and volunteers (and her long-suffering husband Frank) to engage has been instrumental in the development of the Association. Through the Newsletter and the large collection of high quality literature it has become an important patient support group, that acts as a source of independent advice and support for patients and their relatives.

The annual conference with a mix of international speakers and breakout sessions has allowed members to meet other patients (often for the first time) and to hear of the latest developments in the disease. As the first major national support group for ITP the association has also been a leader in supporting the development of organisations world-wide and the interchange between these groups has been vital in spreading good practice and patient involvement on an international scale.

Fundraising has been a major goal of the Association and it has been important in supporting both the Adult and Paediatric Registries which have played a significant part in helping improve patient access to newer treatments and in studying the medical background in large cohorts of patients, which is crucial in planning management.

In its earlier years the Association also held a number of meetings for clinicians to educate them about newer thinking in patient care and was delighted to support the development of the ITP Clinical Forum in 2011, a group that has over 60 interested clinicians. Shirley has represented the Association on the Forum and has funded and run its website and is supporting the first audit of UK ITP clinical centres. This initiative will help provide local specialised clinical expertise for patients who are not able to travel to a major centre.

The Forum is now supporting original research and this will be to the positive

benefit for patients and the Association has actively encouraged and enabled patient participation in the development of these research projects and now the first non-pharma clinical trial in ITP in the UK. The patient surveys have been important in understanding how the care they receive is delivered.

Over the years the Association has become much less of a one person (woman) band as the size and complexity of the organisation has increased, although Shirley's enthusiasm and energy have remained behind much that is done. However, the infrastructure that Shirley has developed is well placed to carry on her work and see the Association thrive.

We were all delighted when, in the 2010 New Year's honours list, she was awarded the MBE for her major charitable input. This was a great boost to the Association and a fitting recognition of the many hours she put in to developing the charity.

We understand why, after many years, she is unable to continue at her current level. We have however asked her to take on the role of Honorary President which will allow her to continue her links with the group but relieve her of the administrative burden that she has carried for so long. We all thank her for getting us to the place where we are and know how much patients have benefited from her efforts over the last two decades. Because of her ITP care is in a much better place.

The I-WISH Survey

Your views on living with ITP

The ITP World Impact Survey (I-WISH) is a collaborative project developed by global ITP experts, patient groups (including the ITP Support Association) and Novartis. This global survey is designed to improve understanding of the impact of ITP on daily life, and patients' perceptions towards treatment and management of their condition. Ultimately, the results of the survey could be used to help patients and physicians improve how to live with and manage ITP. Approximately 120 of you, our membership, have already taken part in the I-WISH Survey – thank you!

UK leads global survey

The UK was the first country to launch the I-WISH Survey when we shared the link to the online questionnaire with our network in late December 2017. The survey is now being launched in 14 other countries where ITP patients will be asked to complete a local language version of the same questions about their views and experiences.

Quality of life measurement

The I-WISH Survey includes a set of 10 questions which have been specifically developed as part of the I-WISH project and

are designed to assess the impact of ITP on a patient's quality of life. Collectively these questions form a measurement tool that has been named the 'ITP Life Quality Index' (ILQI). One of the purposes of the I-WISH Survey is to pilot the ILQI to see if it could have a place in the clinical management of ITP. If so, it could become a standard measurement tool which supports ITP management decisions.

Sharing the results

To make sure the results of the survey are given the status and attention they deserve, the hope is to present them at medical conferences and publish the final results in a medical journal. Because the survey is being conducted around the world, some of the results may be available sooner than others.

Take part in I-WISH

If you would like to contribute to this valuable project, you can obtain the

survey's login details from Mervyn Morgan (mervyn@itpsupport.org.uk). Once you are logged into the I-WISH Survey site, just click the 'Register Now' tab to proceed.

Patient Mentors

a listening ear.....

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News from ITP Clinical Centres

The British Medical Association (BMA) Foundation for Medical Research have been awarding funds and prizes to encourage and further medical research since 1839. How exciting that in December 2017 ITP found its way into the list of awards with the John Moulton grant of £50,000 to assist research into immune thrombocytopenia! Our congratulations to three directors of ITP Clinical Centres who shared this award for their work: Dr Nichola Cooper of Hammersmith Hospital is looking to understand clonality in T cells in ITP, Dr Charlotte Bradbury of Bristol is working on the development of a blood test to predict responses to steroid treatments in ITP patients and Dr Quentin Hill is researching the impact of Fc gamma receptor polymorphisms on treatment response in adult patients with primary ITP. (More about the BMA research awards and photos of the award ceremony that took place on December 5th can be found at www.bmafoundationmr.org.uk)

Also putting ITP on the map, Dr Drew Provan and Dr Nichola Cooper were invited to give a talk on ITP in an 'Advances in Haematology' meeting arranged by Novartis, which is usually dominated by malignant blood conditions.

Led by Dr Jecko Thachil of Manchester Royal Infirmary, fourteen Directors of Adult ITP Clinical Centres completed a survey in

2016 about their individual approaches to using the TPO drugs, Revolade and Nplate. The conclusions of these leading ITP specialists was first available on-line but has now been published in the Feb 18 issue of the British Journal of Haematology and can be found on-line at <http://onlinelibrary.wiley.com/doi/10.1111/bjh.14395/abstract>.

Many ITP Clinical Centres are participating in the Flight Study, which is comparing the use of standard steroid treatment in newly diagnosed ITP with combined steroid and mycophenolate (MMF). It is hoped that the results will lead to improved patient care. This is the first independently funded UK multicentre clinical trial for ITP, and is supported by the ITP Support Association. More information can be found at www.cardiff.ac.uk/centre-for-trials-research/research/studies-and-trials/view/flight

The ITP Clinical Centres Survey closing date was extended as Centres were still collecting these in. The final closing date is now 31st March after which the anonymised survey results will be sent to the Centres who meanwhile are conducting an electronic audit to assess how well they are meeting their agreed ITP Centre criteria.

The UK ITP forum, the national group of expert ITP clinicians, will next meet at the British Society of Haematology Annual Meeting in April.

Letterbox



I got ITP after having too many vaccinations after chemotherapy for leukaemia. Having a stem cell transplant apparently clears all the vaccinations that you have been given. So your immune system is very vulnerable for a year after the transplant.

One year on I was given eight vaccinations in one sitting, which was supposed to happen once a month for three months. After the first injections I went for my usual weekly blood test and they found that my platelets had fallen to 10. Panic set in and they immediately did a test on my bone marrow to see if the leukaemia had returned. But after a few tests they realised it was ITP, the incurable one.

After more tests I received immunoglobulin which brought the platelets to above 150 but did not last for very long. They then tried me on the following medication, Danazol, Steroids and Aciclovir. None worked so as a last resort they put me on Eltrombopag, at 25 mg daily. This got my platelets up to around a 100 but the count keeps going up and down from 100 to 50, which is good.

I still keep having blood tests every three months and have recently had the Eltrombopag lowered to 25 mg every three days. My last count two months ago was 81.

So if you know anyone who goes through chemotherapy and then has to have their vaccinations again after one year then tell them to ask to have them over a longer period of time. You obviously need to have all your vaccinations up to date but mine were done too quickly. Better to have two every week or even further apart if possible. It is a known fact that vaccinations can cause ITP.

Ray Arman

Dr Will Lester commented:

Thank you for your observations. We know that risk of getting ITP after vaccination in the general population is very low and the consequences of infections like measles can be severe (including a much higher risk of ITP than from the vaccination itself). I'm not aware of any study looking at whether multiple vaccinations at the same time can be more of a risk, which is understandably your concern based on personal experience. Our advice as Haematologists would be to follow the 'recommended' vaccination regime after stem cell transplant which as you note it usually staggered over time. Unfortunately stem cell transplants, and other solid organ transplants do appear to increase the risk of 'auto-immune' conditions like ITP, even without vaccination and it can be tricky to treat; although drugs like eltrombopag and romiplostim alone or in combination with other therapies seem to be a little more effective than traditional treatments.

Informal Regional Patient Meetings

by Prof. Adrian Newland and Xenia Norman

The Association holds an annual convention that has always been well attended and appreciated, and has recently started to hold smaller 'ITP on the Road' meetings based in hospitals and hosted by members of the Clinical ITP Forum. These are excellent ways of conveying information but some patients find them rather scientific and the numbers a little intimidating for active involvement.

The Association therefore decided to try a slightly different approach in interacting with its members in addition to our usual meetings. We felt that a more informal get together, in the home of a patient or volunteer with one of the local doctors, would be an opportunity for a small number to get together and chat, without formal presentations, and discuss any issues that came up that were causing worry. In such a small group more interaction would be possible and problems could be aired that could seem trivial in a larger forum – but were not for the patient.

The first meeting was held in Woking, hosted by Xenia Norman (a Trustee and patient) and attended by Professor Newland. Eight attended in all and aided by tea and cake the evening flew by. Two hours of chat and plenty of interaction. It was very well received and a few of the comments sent afterwards are added below.

Overall our strongest impression was how patients and their relatives welcomed the opportunity in a small, informal setting to discuss anything and everything on their mind relating to their experience of ITP. It was interesting how the patients fed off each other in raising issues and often explain their own way of coping. Although the numbers were small this seemed ideal for the type of meeting we had in mind.

The first meeting was clearly a success but where we take it from here depends on you, the members. We will plan through the Association but ideally if anyone is prepared to hold a meeting the Association can support it by asking a local doctor from one of the ITP Clinical Forum hospitals to attend and also advertising it to local members. If you would like to discuss it please get in touch with the Association through our email info@itpsupport.org.uk and we will get back to you.

Quotes . . .

"It was particularly useful to have the opportunity to ask questions of an expert in an informal environment. The information imparted about the background to treatment of ITP (especially in light of the current thinking on splenectomy) over the years and the new studies that were being done was very interesting as well as listening to some of his old cases and patients' stories too."

"I personally found the evening so helpful. As a newly diagnosed patient I hadn't met anyone else with the condition. Over the past months I had thought I had really come to terms with living with ITP. However meeting others and discussing experiences, both the ups and downs, has really helped me get through this. It's hard to put into words how much I came out of that evening with a smile on my face and feeling somewhat more 'normal!'"

"It is the first time that we have actually met anyone else with ITP, and I was especially nice to hear that they are faced with some of the same experiences and challenges as my son."

"For me one of the main benefits of getting together is to meet other people who have this condition and to hear about their particular stories, as whilst we all have, or have had,

similar issues everyone's story is different it seems. My partner also found it beneficial to hear other people's perspective of treatments and the condition which was helpful in the light of our own experiences, especially in relation to the effect of steroids on the patient."

"I would strongly recommend anyone with ITP go along to a support group meeting should they have the opportunity. I was a bit apprehensive beforehand, but I needn't have been - it was a very relaxed environment with a small group of nice people (as well as some excellent cakes!). It was interesting and reassuring to hear about others' experiences and share what we'd all picked up on our various ITP journeys."

"Overall, the meeting was a brilliant idea, and if other areas can do something similar, they certainly should!"

Vaccinations for asplenic

Have you been adequately vaccinated?

by Rhonda Anderson

When I saw the Practice Nurse for my influenza injection last year, I asked if there was anything else I should have, as I am Asplenic. Nurse Liz was new to me, and in fact really excellent. She gave me the very best service I have ever had from my GP practice on this issue. Sadly she only fills in. She went the extra mile to find out all about the needs of patients like me, printed off things to give me, and made sure it all went well.

Liz said I needed extra cover, so after checking my record, prescribed the meningitis vaccines. I needed to have Meningitis ACWY (a single injection) and Meningitis B. I hadn't heard of some of these strains.

For the Meningococcal B vaccine, I had the co-operation and knowledge of my local pharmacist. He was obviously up to date, and contacted the surgery to double check

I was getting the correct type of vaccine. As the 2 doses had to be prescribed and kept at a constant low temperature, they kept them in their fridge for me, and I collected them just prior to my appointments for the injections, about 6 weeks apart.

So what does the Department of Health say for asplenic patients? You can look up the detail online, but in summary it is this:

Annual influenza vaccination, with additional vaccination against *hæmophilus influenzae* type b (Hib), also pneumococcal polysaccharide vaccine (PPV23), every 5 years, and meningococcal groups A, C, W, Y and B.

The schedule of these vaccinations will depend on many things, such as your age, child or adult, when you had your splenectomy, and what vaccinations you had at the time. As always, the advice is to consult your own medical team and discuss it with them. If they are reluctant to engage, then refer them to the Green Book which lists all the necessary information, which can be found online. You can even print it out and take it with you to your consultation. Some doctors and nurses love this patient proactivity and some don't!

You can ask your GP surgery to print off all your vaccination record, and mine offered, from 1996, (when we both had

a raft of jabs for a trip to Egypt), to the present day. This is useful to file and refer to, if you have any worries about what you have had, and when. I now feel better protected due to the added injections.

Of course there are also limitations to vaccinations, of which we must always be aware. Even if you have had the influenza vaccination, you can still get 'flu as it does

not cover absolutely every strain. Most people seem to be aware of this these days. In fact the effectiveness of the 'flu vaccine this season seems to have been disappointing and many cases of 'flu have caused severe winter pressures in A&E departments across the country. One strain dubbed

'The Australian 'Flu' or 'Aussie 'Flu' has been blamed for much illness misery this year.

In the end when I thanked her, Nurse Liz she said it was her job which she loved, and it was good and interesting learning for her to know all these things, and she was only too pleased to be of help. This is the NHS at its best, and wonderful to know there are people like Liz, and there are many of them. However, if there were even more of them, then the NHS would be even better. Thank you to all those fabulous NHS people who give patients like me such a satisfying service with the correct information and clear communication.





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