



the platelet

DEC 2016

JOURNAL OF THE ITP SUPPORT ASSOCIATION



**MAY 2017 ITP CONVENTION AT
THE ROYAL SOCIETY OF MEDICINE
(DETAILS INSIDE)**

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Charity Registration No:1064480

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ITP 'Friends'

Rhonda Anderson

Dave Farrow

OFFICE STAFF (part-time)

Senior Administrator

Mervyn Morgan

Fundraising Co-ordinator

Liz Gooch

Office Services Clerk

Natalie Baylis

The ITP Support Association

The Platelet Mission

Kimbolton Road,

Bolnhurst, Beds.

MK44 2EL (UK)

Tel: 01234 376559 (manned most mornings)

Web: www.itpsupport.org.uk

E-mail: info@itpsupport.org.uk

Medical Advisor (Adult ITP)

Prof. Adrian C. Newland CBE

MA FRCP FRCPATH



Medical Advisor (Adult ITP)

Prof. James N. George

MD FACP(USA)



Medical Advisor (Adult ITP)

Prof. Spero R. Cataland

MD FAAP(USA)



Medical Advisor (Adult ITP)

Dr. Drew Provan

MD FRCP PRCPATH



Medical Advisor (Adult ITP)

Dr. Jecko Thachil

MRCP FRCPATH.



Medical Advisor (Adult ITP)

Dr. Will Lester

MBChB(hons), BSc, MRCP, FRCPATH, PhD



Medical Advisor (Adult ITP)

Dr. Nichola Cooper

MA, MBBS, MD, FRCP, FRCPATH



Medical Advisor (Childhood ITP)

Dr. John Grainger

MBChB MD MRCP FRCPATH



Medical Advisor (Childhood ITP)

Dr. Mike Richards

MA BM BCh DM MRCP FRCPATH



Medical Advisor (Childhood ITP)

Dr. Cindy Neunert

MD MSCS



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In this issue . . .



As you may have noticed this edition of The Platelet is rather late so we accommodate news of the Charity Lunch, Global ITP Meeting and our Patient Convention which all happened in the third week of September. In fact we had so much to cram in this issue that two items have been carried over for the December edition.

Included within these pages, Shirley welcomes a new member to the team, Mervyn Morgan, and looks back at the first year in the new headquarters. The American Perspective essay considers spinal anesthesia for childbirth growing in size year by year, and we welcome our ITP veterinary advisor.

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

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

Shirley Writes...

Convention 2017

Thank you to everyone who completed the on-line Convention Survey, your responses certainly helped us to plan events for the forthcoming year.

Having celebrated the ITP Support Association's 20th birthday in 2015 we will be marking our 20th patient convention in 2017. We held our 10th Convention at the Royal College of Pathologists, and return to London for our 20th, this time at the prestigious Royal Society of Medicine in Wimpole Street. You may know this address for its medical associations and as the street where Elizabeth Barrett Browning lived, but did you know John Lennon & Paul McCartney wrote 'I Want to Hold Your Hand', and Paul penned the tune of 'Yesterday' while staying in Wimpole Street?

Our Convention will take place in the Max Rayne Auditorium & Atrium (see photo, front cover) on Sat 13th May from 10am to 5.15pm with what can only be described as an ITP star cast! Your surveys left no doubt that expert speakers are by far the most important requirement at conventions, and as you will see from the list on the opposite page, it reads like a 'Who's Who of ITP'!

Your convention survey answers showed that some people find their ITP to frightening to attend. The feedback we receive at the end of conventions is that patients feel more able to cope, both through what they have heard, and from meeting others with ITP. Our speakers' presentations explain about ITP and related issues with the intention of increasing patient confidence

and easing the fear and worry that so often accompanies the condition. Their presentations are not depressing or scary and they often give patients ideas to take back and discuss with their own doctor. Do give it a try if you haven't been before!

London venues have the advantage of being more accessible by public transport but they are considerably more expensive. We could not have contemplated holding our convention at the RSM had we not been promised some very generous pharma sponsorship enabling us to charge £25 per ticket to our membership (£40 non-members) instead of the actual delegate cost of £79 plus VAT at the RSM.

The ITP Convention will be held in the Max Rayne Auditorium which holds 150 people. We will be sending out the full booking form with the March Platelet, but if you wish to ensure your place you can make an 'early bird' booking using the form on the back cover of this Platelet.

Membership renewal due for 2017

To keep office work and costs to the minimum our membership subscription runs for a calendar year (January to December) so subs are due now please. We do hope you will continue your membership, and even if you no longer have need of our services, your continued support of £10 a year would be really appreciated.

If you pay your ITP sub by Direct Debit it will appear on your bank statement as an £8 payment to Go Cardless, 12 months from the date of your first payment.

ITP CONVENTION 2017

The ITP Support Association's 20th Patient Convention

on

13th May 2017

at

**The Royal Society of Medicine
1, Wimpole Street, London, W1G 0LZ**



Featuring:

Prof. James George
Prof. Adrian Newland
Prof. Victor Blanchette
Prof. John Hunter

Dr Drew Provan
Dr Jecko Thachil
Dr Marie Scully
Dr Paula Bolton-Maggs

The day will include:

Presentations from the experts on various aspects of ITP and ITP treatment
Updates on ITP research
Keypad sessions seeking audience opinion on ITP scenarios
Question and answer session
Head to head discussion on "Splenectomy: Is it an outdated treatment for ITP?"

More details on the opposite page



American Perspective

Prof. James N George MD

University of Oklahoma Health Sciences Center

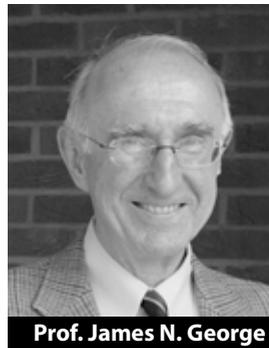
ITP and Depression

Depression is one of the world's most common and most disabling disorders. It is the leading cause of disability among adults in high-income countries. Depression is not just being sad. We all are very sad some of the time – that's normal. Depression is a disease. Doctors should routinely screen their adult patients for depression. Diagnosis of depression is important because treatment is very effective.

Why do you need to know about depression? For the answer, we go back several years to our survey about symptoms of fatigue. Many of you participated in this survey. It was a project led by Dr. Julia Newton (Newcastle University). We thought this survey would be important because we had heard from our ITP patients that they commonly had symptoms of fatigue. Our survey confirmed that symptoms of fatigue were significantly more common in ITP patients than in the UK population. Our ITP patients in Oklahoma also participated in this survey, and the results were the same: symptoms of fatigue were significantly more common in ITP patients than in the US population. But we did not know why fatigue was a common symptom among ITP patients.

Fatigue is important because it is a symptom of depression. One of the 8 questions in the standard diagnostic

depression screening questionnaire is: "Have you been bothered by feeling tired or having little energy?" This connection between fatigue and depression was why we did a survey of members of the ITP Support Association and Oklahoma ITP patients last year. We used the standard 8 question diagnostic depression screening questionnaire. The questionnaire asks if you have been bothered by symptoms of depression within the past 2 weeks. The answers can be not at all, several days, more than half the days, or nearly every day. The results of this questionnaire sent to UK and Oklahoma ITP patients were clear. Depression is a common problem among ITP patients. The Table shows the results for the 110 UK patients who completed the survey.



Prof. James N. George

Depression severity	110 UK patients
None-minimal	57 (51%)
Mild	26 (24%)
Moderate	17 (15%)
Moderately severe	10 (9%)
Severe	1 (1%)

These 110 patients were only 11% of the 1039 ITP Support Association members who had received the survey with the June 2015 issue of The Platelet, and we assume that patients who were more concerned about depression were more likely to complete and return the survey. But still, these results are very important. 28 (25%) of the 110 patients had moderate, moderately severe, or severe depression. When the same survey had been previously given to many people who were representative of the entire UK population, only 3% of people had symptoms of moderate, moderately severe, or severe depression. The results were the same for our Oklahoma patients. 68 (66%) of the 103 Oklahoma patients completed and returned their surveys. 11 (16%) of the 68 patients had moderate, moderately severe, or severe depression compared to the expected US frequency of 2%. The reason why the frequency of depression was not as high among Oklahoma patients may be that we repeatedly contacted our patients and urged them to return their surveys, and 66% did.

These results make us worry about our ITP patients. Depression can be a dangerous disease. It can disrupt lives and families. It is easy to ignore. Many people are reluctant to admit that they feel depressed. Many people who are depressed are told that they just need "to get over it". There is a stigma about mental illness. These are real and serious problems. In addition, talking about these symptoms with your doctor may help with avoiding medications that can have depression as a side effect, such as corticosteroids.

Our conclusion is that ITP patients need to be aware that depression happens, it can be accurately diagnosed by your doctor, and if you are depressed, there are very effective medicines. If you have little interest or pleasure in doing things, if you feel tired and have little energy most of the time, or you feel bad about yourself, that you have let yourself or your family down, you need to see your doctor and your doctor needs to evaluate you for depression. The medicines are simple, safe, and very effective.

The importance of ITP surveys

There may not be a 100% cure for ITP yet, but there is certainly a lot more interest in the condition in recent years, with both clinicians and pharma companies seeking patient opinion on a variety of issues related to living with ITP.

After our 2008 membership survey showed a high proportion of ITP patients struggled with fatigue we enlisted the services of Professor Julia Newton, an expert in autoimmune disease and fatigue. Her landmark publication of data from her 2009 survey of our members resulted in fatigue finally being recognised by the medical profession as a real symptom of ITP.

We do appreciate that the survey enclosed with this edition of The Platelet is very long, but all data collated from surveys increase the chances of finding a cure, or help improve the management of ITP.

Do please complete and return the enclosed survey – Thank you!

ITP today

by Professor Adrian Newland

Prof Newland provides a summary of ITP in 2016

I would estimate between 800 and 900 adults are diagnosed with ITP in the UK yearly (slightly over 1 per haematologist!). The number of children is probably slightly lower but only 15-20% of those become chronic and most of the rest may not require any treatment.

In the under-60s it remains a more predominant disease in women, as with many other autoimmune diseases. We don't know the reason why – although it is assumed to be related to the hormonal balance. In the over-60s men become more predominant and this is the age group with the highest incidence.

Treatment always starts with one of the forms of steroids unless they are contraindicated as it is cheap (although not so cheerful!) and the majority of people respond albeit temporarily. There is a lot of current discussion both in the UK and abroad as to whether adding something else in at an early stage can enhance the quality and length of the response and be steroid sparing. A UK study adding in Mycophenolate is being led by Dr Charlotte Bradbury from Bristol University Hospital, and I have also had discussions with Amgen regarding looking at TPOs as a more up front option.

This really merges into the discussion on 2nd line therapy which remains unclear. I published about the decline in splenectomy in the The Platelet last year and there are

many discussions on the best 'next-line' treatment depending on the patient's age-group and underlying problems.

We know that the use of splenectomy has dropped off significantly from studying Registry data, as there are now more acknowledged alternatives that are splenectomy sparing. This is being mirrored elsewhere as well. It has, in part, been driven by patient-power as patients realise that while doctors may discuss a 60% success rate, this is really a 40% failure rate and it is this latter group that have most problems. The ITP Support Association has been crucial in highlighting the problems and options.

Because ITP is such a relatively rare disease and no one clinician sees enough to understand outcomes the Registry has been very important in collecting large numbers of patients so we can look at presentation, associated conditions, treatment effects and clinical outcomes. The many publications that have come out of the data is a testament to the importance of such a resource. We now have over 2,000 patients registered.

The enthusiasm that many clinicians have shown in supporting the Registry allowed us to identify those keen individuals who have become the backbone of the ITP Forum. This has allowed us to develop the network of centres in the UK where there is a clinician with an interest in ITP

who can help and support their local hospitals. This means more local experience and expertise and should improve the overall standard and quality of care.

The presence of the network means there is a ready body of hospitals available to join in clinical studies so that we can more rapidly look at newer treatments and offer them, where appropriate, to treat difficult cases.

This is an important resource for clinical research looking at genuine areas of need in treatment. Also, by enrolling patients on the Registry and obtaining samples, it allows us to look at some of the basic underlying questions in ITP, related to cause and the underlying immunological defects, in numbers that provide meaningful results.

At the moment treatment is aimed at treating the effects of the disease and stopping platelets being destroyed or increasing their production, but not at the underlying reasons as to why the disease happened in the first place. There are many units and companies around the world looking at just those questions (or different aspects of them) and a number of agents coming through that may affect the immune imbalance that need studying. The ITP Forum is in an ideal position to take part in those

studies and our lab at Barts is one looking at some of the underlying questions.

The ITP Support Association has had a very central role since its inception in providing patient support and education, and stimulating research. Apart from our unit and the work of some individuals there was very little interest in ITP and consequently patients were getting a poor deal. Patients

were being treated according to the whims of the local clinician who may not have been up to date and had little access to new treatments and developments. Obviously the internet has changed access but that has only given access to a mass of poorly policed data. The Association has acted as a fulcrum for patient information and education and as a vehicle for putting patients in touch with each other and interested

doctors. By supporting both the Registry and the development of the ITP Forum it has helped spread good practice so any patient, wherever they live, can have access to an interested clinician and modern treatment thinking. The post-code lottery of treatment has not disappeared but has been reduced considerably. The stimulation of, and funding for, research has also been a driver in getting patients involved in their disease and the questions they consider important.

ITP 'Friends'

a listening ear

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

Derek Elston
0151 625 8213
derek.elston@btconnect.com

Dave Farrow
01664 852218
davidfarrow40@yahoo.co.uk

My ITP experience

by Christine Boynton

Through reading articles in the ITP magazine, I'm aware that ITP can have a dramatic and profound impact on people's lives. However, ITP comes in many guises and I thought it might be helpful to describe the impact it's had on my life over the last 30 years. Please can I stress that this is my ITP experience and I'm very conscious that not everyone with ITP is as unaffected as I have been.

My first suspicion something might be wrong was shortly after the birth of my third child nearly 30 years ago when I noticed I'd developed a number of petechiae on my body. My GP dismissed me with a wave and explained it was down to the ageing process – I was 34 at the time so that was a little depressing! Roll on a decade and a plastic surgeon who's removing some moles asks if I'm taking blood thinning tablets. My family knew that I'd always had the ability to bruise spectacularly but around this time, I felt that even I was bruising more than usual. We had a smallholding and managing that as well as working and raising a family was leaving me with more than a peppering of bruises on legs and arms. I went to my new GP, gave blood and was initially alarmed when the surgery phoned me at work the next day to ask me to come in for further tests urgently. I'm sure most of you have had the same tests as myself (and you've probably had more) but I fairly quickly received a formal diagnosis of ITP and all tests of my platelets

have been around the 50 – 65 count in the 25 years since. With hindsight, the lower count which resulted in more bruising was possibly due to my use of Nurofen at the time.

I initially attended annual outpatient appointments but it seemed daft to have a blood test once a year when my platelet count could do something weird on any of the remaining 364 days. When I shared my thoughts with the consultant, he explained what to look out for in terms of a significant platelet count change and we agreed I'd phone the hospital if any of these changes occurred (which hasn't happened in 25 years) and I no longer needed to attend appointments.

After I got over the surprise / alarm of the diagnosis, I decided that ITP would not define my life and that whilst I would take reasonable precautions, I would carry on as normal and live with the inevitable bruises.

The bruises are the biggest challenge. People noting them at social gatherings (or holidays when I decided to give windsurfing a go!) can be wearisome and I will sometimes catch myself sitting at a dining room table with my arms folded so my hands are able to cover a visible bruise. If I'm attending an event where I want to wear a dress, I'll avoid activities that I know will result in leg bruises over the preceding week. I always wear a cycle helmet. I never take Aspirin and check ingredients before taking other

pain relief medication. I take responsibility for questioning doctors, who are prescribing medication, on the consequences for my ITP and my husband knows he has to take on this responsibility if I'm in an accident etc.

Some health professionals don't always know the consequences of ITP. Once in hospital awaiting surgery, the nurse explained that everyone had to have anti-clotting injections. I told her I didn't think that would apply to me but she overrode my protests and the injection was given anyway. I felt like a 'clype' telling the Haematologist who was making sure my platelet count was OK for surgery but he had more authority than I did in ensuring no more injections were given.

Cuts and grazes do bleed for longer but they will stop. As I get older, intermittent and short term nosebleeds can be a nuisance. But if you asked me to score how I feel healthwise on a day to day basis, I would give myself an 8.5 out of 10. Because I feel so well I do forget about the ITP – to the extent that when questioned by a consultant about a temporary eye problem, I assured her that I was in excellent health (but corrected myself when I heard my husband uttering 'ITP' in a loud whisper).

I read the ITP magazine to see if treatments or cures are on the horizon but wonder if I would want to recover a normal platelet count. I suspect my body and I have got used to what we've got after all these years, and long may it continue!

News & Views

Compare your GP

Having a good GP is important to everyone, particularly to those who have a chronic condition like ITP. The GP Patient Survey is an independent survey sent out to over a million people across the UK. The results let people see how their practice scored and how they might fare if they need to move to a new practice. To see how your practice is doing go to <https://gp-patient.co.uk/>

Platelet readers might be interested to know that Great Staughton surgery, from where Dr Roberts wrote many Prescription Pads for The Platelet, scored very highly with 100% of respondents finding it easy to get

through to this surgery by phone. This seems very unusual, the national average is 73%.

TPO drug licences and NICE

Patient should be aware that the wording of EMA licences for Eltrombopag (Revolade) and Romiplostim (Nplate) differs from the guidance given by NICE. The EMA (European Medicines Agency) no longer states that these TPO drugs should only be available for patients who have failed splenectomy. NICE guidance continues to suggest that the drugs can only be used in patients who have failed splenectomy or have a contraindication to having their spleen removed.

ITP Research Update

Dr Nichola Cooper reports on research projects being carried out at Hammersmith Hospital, some of which have been funded by The ITP Support Association. Our thanks to Platelet Readers for your donations and fundraising efforts, which enables us to fund important research like this.

At the Hammersmith Hospital/Imperial College, we have developed a strong research team to help us understand immune thrombocytopenia (ITP). Our aims are to identify factors that predispose patients to ITP, biomarkers to help us to direct treatment, and identify novel pathways that can be used to better target treatment.

Over the last year we have appointed Deena Paul as our research nurse and Alice Glaser and Nicola Window as our research coordinators. Our new team has allowed us to collect data for entry to the UK ITP registry; a very important resource which will enable us to understand much more about the different patterns of ITP. We have also entered patients on to a UK-wide genomic study, and are also driving forward our own metabolomics, phenomics, and functional cellular studies.

On the laboratory side, Anwar Syed is currently in the second year of his PhD examining the role of T cells in ITP. Ahmed Khoder is a Postdoctoral Clinical Fellow establishing methods to understand the pathophysiology of B cells in ITP. We also have a number of great students in the lab (funded in part by the ITP Support Association) including Luis Gonzales, Thomas Mayo, Lenni Graebner and Daniel Ang evaluating different aspects of bone marrow biology and cytokine changes in patients with ITP. Past students include Adrienn Teraz-Orosz, supervised

by Jim Crawley and funded by both the ITP Support Association and NORD, who studied anti-platelet antibodies. All have contributed greatly to our understanding of ITP.

I will now briefly describe some of our recent findings:

1. We are studying the genetics of ITP using exome sequencing to identify gene variants that might predispose to autoimmunity. We are also looking at the genetics of T cells to see whether there are specific changes that cause them to attack platelets or megakaryocytes. This is part of a larger study of genetic causes of immune dysregulation, where we have identified some very exciting novel gene variants in patients with more complex autoimmunity.

2. We have analyzed the bone marrow in patients with ITP. This has been a complex project, which involves processing the bone marrow and staining it so that the megakaryocytes can be visualized with a fluorescent (confocal) microscope. Our aim is to understand the relationship between megakaryocytes (MK) and other cells in the bone marrow that might affect their function. This project was pump-primed with a pilot grant from the ITP Support Association and has yielded very exciting preliminary results: we have found a high frequency of intimate MK: T cell contacts

(see figure below), probably representing immune synapses, which may indicate that there is T cell-mediated attack of MK. In addition to providing novel insights into the pathophysiology of ITP, these results point to the potential for new therapeutic strategies. We are now developing a way to grow megakaryocytes in vitro to be able to explore this novel biology in more detail.

3. In a separate project (also funded by the ITP Support Association), we have developed a robust method to strip anti-platelet antibodies off platelets from individuals with ITP. We are now beginning to examine what these antibodies bind to and what effect do they have on platelet function.

4. We have also been tracking longitudinal cytokine and T cell changes in ITP and have identified a distinct inflammatory signature which changes over time. We are now working out where these cytokines come from and whether specific treatments alter these cytokines.

Overall, our research suggests that ITP is not just one disease but rather a group of pathophysiologically distinct

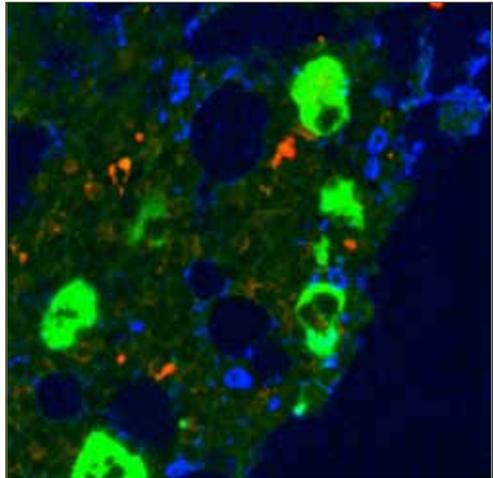


Figure 1. Example of confocal fluorescence microscopy of a bone marrow sample from an individual with ITP, showing CD4+ (red) and CD8+ (blue) T cells tightly associated with megakaryocytes (green).

processes ending up in immune mediated thrombocytopenia. If we can understand these processes better, we can work out which treatments are most appropriate for individual patients and also hopefully design new therapies for refractory individuals.

We are indebted to the ITP Support Association for pump priming our research programme and to our patients who have contributed and informed our studies.



The Charity Shop

in aid of The ITP Support Association & The Fishermen's Hospital

73 St Nicholas Road, Great Yarmouth, Norfolk,

NR30 1NN (opposite Sainsbury's car park)

Tel: 01493 855614

Open: Mon-Fri 10am – 5pm: Sat 10am – 4pm

books – clothes – pictures – toys – bric-a-brac – accessories – jewellery & more

COME AND VISIT US FOR A FRIENDLY WELCOME OR DONATE YOUR ITEMS BY POST

Pupils and staff of Tonbridge School, a leading boys' boarding school in Kent, organised a hugely successful 'Dancing with the Praes' charity event which raised an amazing £3,457.79 for ITP funds! Ten very brave sixth form boys put in plenty of rehearsing and training time. The photos shows some very polished looking performances – the one to the right shows Richard Monham dancing with Esther Saurel who is



head of French at the school and who kindly nominated our charity as beneficiary from this event. Esther's daughter Lucie was diagnosed with ITP last year.

The school told us '10 school Praes took to the floor to perform four dances each in Strictly Come Dancing type event. For the previous few months, the boys and their partners had been learning the

Waltz, Quickstep, Cha Cha and Jive, each of which they performed to the audience and to a panel of judges.

The evening started with a champagne reception at 6.30 pm in Old Big School moving at 7.30 pm to the

dance hall in the Big School. In addition to the couples performing their dances there were demonstrations during the evening by a former pupil and his partner who are the current University-level National Champions.

A silent auction and entertainment took place during the interval.

The astounding proceeds from this spectacular evening were shared between The ITP Support

Association and the Down Syndrome Research Foundation.

We are enormously grateful to everyone at Tonbridge

School who assisted with the organisation, or contributed to the event, but most of all we send a HUGE thank you to the wonderful dancers!



Fantastic Fundraising!

We reported in the September Platelet that Debbie Lloyd had raised a brilliant £2641 from the Charity Lunch she ran in aid of ITP, which featured guests Neil Dudgeon, and Dr



Mike Smith. We were absolutely thrilled when All3Media, who had already been generous sponsors and attendees of the event, gave a matching gift bringing the grand total an absolutely superb £5282. Debbie put much hard work into this event, and it was wonderful news to hear that she hopes to plan another ITP Charity Lunch 2017.

Our gratitude goes to the children and teaching staff at Abbey Lane

Primary School, Sheffield who held a Charity Day at the end of last term and sent us a cheque for the excellent amount raised of £522. We pass on a hearty thanks to all those involved in the day.



Jackie & Janice - hats ready!

Janice Caryl and her daughter Jackie Lawson (whose 9 year old son has ITP) completed the 'Pure Challenge' sponsored 45k walk along the Lancaster canal from Bolton Le Sands to Glasson Dock. They raised a fantastic combined total of £528 while enjoying the outstanding beauty of this lovely area. Janice told us 'Jackie did really well and managed to walk the whole 28.5 miles but I am afraid I only managed half way. However, between us we managed to raise plenty of money so well worth the effort (and pain)!!' We are most grateful to Janice and Jackie for

their endeavour and hope their feet soon recovered!



Jackie & Janice well on the way

Sally Hiscock very kindly organised another Saddleback Farm Shop Open Day and Ploughing Match in memory of her mum Mrs Sue Hiscock. We are extremely grateful for the £441 which was raised by visitors to the farm, and hope they all enjoyed this fun event. We would have loved some photos!

Leith Academy, a Comprehensive High School in Edinburgh, and one of the oldest schools in Scotland, raised a super £341 for the Association by running a non-uniform day, which from their photos looks great fun and very extremely organised! We are grateful to Leith Academy Charities



Committee and the pupils at Leith Academy for thinking of The ITP Support Association, and for sending us these lovely photos. recording the event.



Betsy Bates organised a ladies product party from which she raised a total of £138. We are most grateful to Betsy for organising this get-together with her friends and thank them for their kind support.

Beacon Church New Buildings Congregation raised £120 for ITP at their recent Harvest Festival Auction for which we send our gratitude, particularly to whoever in the congregation suggested support for our charity.

Our thanks go to Jill Kemp who held a raffle at her dance centre and raised £40, and also to Shirley and Frank Watson ran a coffee morning and raffle in the Platelet Mission in early November and raised £141.

Just before this issue was due to go to print we received a cheque and photo from Pensilva School in Liskeard, Cornwall, and just had to squeeze them in! Their pre-school and reception class took part in a sponsored walk along with

If you are considering holding an event in aid of ITP and would like a fundraising pack please contact the office info@itpsupport.org.uk Don't forget to take photos of your event for The Platelet!

their parents and teachers to the local farm shop and back - two miles in total raising an impressive £340. The staff used the opportunity to speak with the children about the importance of helping others and said "This was quite a distance for such little legs and



they did marvellously!" Hollie (Deputy Manager of Pensilva Pre-School) added that it was her little boy who suffered an acute attack of ITP after a minor vomiting virus. He has had no recurrence but it made them appreciate the difficulties of living with ITP.

We are most grateful to everyone who has supported our charity throughout the year, whether it be through a fundraising event or personal donation(s). The ITP Charity Shop is regularly featured on these pages, so we are delighted to include a photo taken when delivering goods to them a couple of months ago.



Your questions answered

Q My ITP has been raising it's ugly head again and as a result of the platelet count dropping into single digits my hematologist is suggesting that my auxiliary spleen should be removed.

Prior to having this major surgery (the splenectomy was originally done 7/2014 laparoscopically) I am trying to determine the percentage of cases in which the Indium test has been shown to be useful in predicting whether removal of the spleen would be helpful.

Professor Adrian Newland replies:

A *We never looked specifically at the influence of the splenunculus [Ed: small nodules of splenic tissue] on Indium results and future response to treatment. Indium labelling is very poor at identifying a splenunculus and any results, if it were present with a spleen, would be part of the overall scan. When we attempted to identify a splenunculus in patients post splenectomy the results were poor and the only way of identifying whether one was there is by using a technique known as 'heat-damaged red cells'. This gives no indication as to whether further surgery would be effective.*

In general the impact on the platelets of removing a splenunculus in someone who has failed splenectomy are very poor in the literature. Whether it is effective in someone

who has previously responded is not known with any certainty. A reasonable rule of thumb if the peripheral blood appearances show typical post-splenectomy features then there is no significant splenic activity and further surgery is probably pointless (not to say risky).

Q I had a burst appendix and had to have an emergency operation, for which they made platelets available in case and I was given antibiotics. I am on 25mg + 50mg on alternative days of Eltrombopag. When I had my blood tested about 2 weeks after the op. they discovered my blood count had gone up and had to take me off medication. After a week or two I had to go back on some medication but as I did not need a transfusion for the operation why did my platelets rise because I must have lost blood? Was it the antibiotics? Was it the infection?

Dr Jecko Thachil replies:

A *You are right that patients SOMETIMES get a raised platelet count after antibiotics. However, it is difficult to confirm whether this is due to antibiotics or the infection which required the antibiotics. In the present case, sometimes platelet count can go up after an operation so that can also be an explanation.*

Vaccinations & ITP

We have recently added a new Vaccinations section to our website which includes specific information on the MMR vaccination (already available as a factsheet) and Dr Cindy Neunert's American Perspective article published in the June 2016 issue of The Platelet which ended with the following advice: "In the majority of patients with either a history of ITP or active ITP, vaccinations should be given on schedule. An exception

should be made for patients who are receiving medications that may weaken the immune system. The most important thing is to discuss vaccinations with your doctor at the time they are regularly scheduled and before starting any new treatment.'

Two of our medical advisors have now provided advice for ITP patients about the seasonal influenza and shingles vaccinations (see opposite).

Who's eligible for the 2016/17

SHINGLES VACCINE?



AGE: The age you will be on 1 September 2016

<p>X NO!</p> <p style="font-size: 2em;">69</p> <p>or under</p> <p><small>i.e. born on or after 2 September 1946</small></p>	<p>✓ YES!</p> <p style="font-size: 2em;">70</p> <p><small>i.e. born between 2 September 1942 and 1 September 1946*</small></p>	<p>✓ YES!</p> <p style="font-size: 2em;">71</p> <p><small>i.e. born between 2 September 1944 and 1 September 1945*</small></p>
<p>✓ YES!</p> <p style="font-size: 2em;">72</p> <p><small>i.e. born between 2 September 1943 and 1 September 1944*</small></p>	<p>✓ YES!</p> <p style="font-size: 2em;">73</p> <p><small>i.e. born between 2 September 1942 and 1 September 1943*</small></p>	<p>X NO!</p> <p style="font-size: 2em;">74 to 77</p> <p><small>i.e. born between 2 September 1938 and 1 September 1942*</small></p>
<p>✓ YES!</p> <p style="font-size: 2em;">78</p> <p><small>i.e. born between 2 September 1937 and 1 September 1938*</small></p>	<p>✓ YES!</p> <p style="font-size: 2em;">79</p> <p><small>i.e. born between 2 September 1936 and 1 September 1937*</small></p>	<p>X NO!</p> <p style="font-size: 2em;">80 or over</p> <p><small>i.e. born on or before 1 September 1936*</small></p>

* inclusive

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The safest way to protect children and adults

SHINGLES VACCINE AND ITP

by Prof Adrian Newland

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

Who can have the shingles vaccine?

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

Can the vaccine trigger ITP?

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

INFLUENZA VACCINE AND ITP

by Dr John Grainger

The influenza vaccine has been linked to the development of ITP in a small number of adults and may cause a dip in platelet counts in children or adults receiving the vaccine. However the risks are higher for children or adults who are unvaccinated and develop influenza.

Newly diagnosed ITP

(within 3 months of ITP diagnosis)

My preference is to avoid the 'flu vaccine unless there are other co-existing medical conditions, such as cardiac disease or asthma.

Persistent or chronic ITP

(over 3 months from diagnosis)

The 'flu vaccine can be administered. Patients should be aware that there is a small risk of a platelet drop in the 4 weeks following vaccination so may wish to consider timing if there are any planned operations, dental procedures or overseas holidays.

Live vaccine (nasal) or inactivated vaccine (intramuscular)?

Patients who have been on steroids in the last 28 days or rituximab in the past 12 months should not receive the live vaccine. For patients receiving the inactivated vaccine by intramuscular injection there is a need for firm pressure to be applied over the site of injection for at least 10 minutes.

Please note that this general information kindly supplied by Prof Newland and Dr Grainger should not replace any advice given to you by your consultant or GP who knows you and your ITP.

Have you heard

by Anthony Heard

It's not all in the mind, but some of it is!

One of the many common phrases that people respond to me with, when I tell them about my ITP is....."But you don't look ill". My first thoughts are often something along the lines of..." How ill do you want me to look ?" or something similar. But what I often explain to them with some difficulty is that with ITP the symptoms are often not immediately visible. Then it is even more bothersome to describe the sometimes horrible side effects of some of the treatments.

Trickier still is getting across to non ITP sufferers, the mental fatigue that the illness inflicts upon us purple folk. It's the uncertainty, the realisation that ITP can return even after a period of remission. The reality that we have to be on the lookout all the time for the tell tale signs of mystery bruising, nose bleeds, gum bleeds or worse. It's part of our routine.

Going for regular check ups is another part of our routine. It is also often fraught with hassle, not least because it takes time, money, and is always a matter of juggling other commitments to fit it in. So here's the latest account of my recent ITP check up. I didn't look ill, I didn't feel ill but like most of us purple people, so much of the energy, even agony goes on unseen in the mind.

The date is Monday November 7th 2016, it is 9am and I am standing in a long queue of people at the reception desk of South Block Clinic at The Royal Berkshire Hospital, Reading. I am waiting to check in for my 11am appointment with my specialist. I have become a regular at this clinic since I was diagnosed with ITP in July 2006 and I've slipped into a well rehearsed routine.

My cunning plan is to arrive at least an hour and a half before my appointment as this ensures that I get a parking space in the always overcrowded hospital car park. This morning I get a good space and this must surely be a good omen. I proceed to check in at the clinic reception to make sure that I can get all the pre appointment formalities done in good time. The first thing is to advise the reception desk that I've arrived. This allows them to get my file ready for my appointment. They also check that since I last visited the clinic I have not changed my address, telephone number(s), email, family doctor, sex or emergency contacts. The various boxes are all ticked off.

The reception team recognise me now and comforting smiles pass between us as they wish me luck for my appointment today. I proceed to the holding area where the duty nurse is stationed to weigh all

patients attending clinic. Again we recognise each other, and exchange greetings as I am taken to the unforgiving scales. The nurse notes down my current kolograms and adds them to my file notes which my specialist will see later. I vow to start cutting down my calorie intake and do more exercise just as I always do. My file notes are growing almost as quickly as my girth.

Amazingly I have actually lost a couple of kilograms since my last check up, so that is perhaps another good omen that all other vital numbers might go in the right direction later. After dozens of visits I am amazed that I still insist on clinging to things like good omens. Even things like a small weight loss convince me that today my platelet reading will be safe. Because, you see, it's a positive sign and obviously a good omen.

Following my weigh in, the duty nurse asks me as usual when I had my last blood test. She knows that my answer is always the same but automatically asks the question each time. I always have a blood test straight after my weigh in, so I advise her that I am just going to the blood test clinic now. It is part of my routine and superstition suggests that if I change my routine it might bring bad luck and a low platelet count. I just cannot take that risk.

I have a blood test form which I was given at my last check up in June. In fact I have a valuable currency in my possession in the blood test clinic world. You see, my blood test form has a priceless GREEN SPOT attached to the top right hand corner. Without the magical GREEN SPOT, indicating that I am an urgent case needing priority, I would probably face a wait of at least an

hour. I wave my blood test form, my rare currency, at the senior nurse and I am called straight in for my test. I sense the piercing stares of the 40 pairs of eyes of those sitting in the queue which I have now jumped. The magic of a green spot has sent them all green with envy and I feel quite guilty but at the same time somewhat relieved. I feel almost special although as we know, ITP is anything but special, even if it is rare.

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.

The blood test nurse recognises me from my regular visits and I remember her because she always manages to draw my blood with minimal fuss and leave my arm bruiseless. This is another sign that today might go well. I am told that I have veins which are difficult to locate. It had never crossed my mind but it is yet another thing I have learned from my ITP adventure. She routinely takes the required samples and we laugh about how she takes more blood than Dracula. But it is difficult to escape the serious nature of

her daily work. The nurse wishes me well and we conclude by saying that we hope we do not see each other again for ages.

I have become a familiar face in an unfamiliar place as I saunter through my well rehearsed routine. I recognise most of the other patients waiting to be seen by the specialists today as I walk back to the waiting area of the clinic itself. I am grateful that so far my routine has played out exactly according to plan. One of the only things I cannot now control is how long the specialist will take to see the other patients booked in ahead of me. I am told that they are on time so far this morning. This is another one of those good omens that I cling to. But of course the reality is that I cannot control that crucial platelet count, that arbitrary number which will determine the course my life takes from today.

I acknowledge the nervous signs from all the patients waiting to be seen by their respective specialists. I probably display those very same nervous signs too. We all try to read a newspaper, book or magazine. We all read the same line twenty three times. We all make sure at least a dozen times that our mobile phones are switched off. We all check the time every thirty seconds. We all comment on the weather as all British people do when nervous or just don't know what else to talk about. We all hold back on any meaningful conversation because we cannot really discuss anything of any substance until after our appointments.

Hopefully then the pressure valve will be released if the results are good. Sadly they will not be good for all of us and we all realise this as we await our respective fates.

It is now two minutes past eleven and I am looking at the examination room doors intently to see when my specialist will come out of his room. His door is number seven (my lucky number and surely another good sign). He is obviously running a bit late but that is not unusual, so I convince myself that there is nothing to worry about even though my palms are not buying into that argument as they get ever stickier. I have cleaned them 37 times already with the antiseptic gel provided by the hospital to prevent the rampant spread of germs. But still I think I will need at least one more sanitising moment before seeing my specialist.

At last the door to examination room seven squeaks open and my specialist comes down the corridor to greet me. He shakes my hand and ushers me into his room. I wonder if he has used the antiseptic hand gel 37 times as I have? He turns his computer screen towards me to show me the results of my blood test and the words he next uses confirm the good omens that my routine had suggested. I decide that I really must buy a lottery ticket this afternoon.

My specialist explained that indeed it was really good news this morning as my platelet count was 154. The

Mycophenolate treatment I have been on since April is obviously doing the trick. Whilst I understand my count can lapse again at any time my specialist confirms that for now I only need to see him three monthly for a check up, unless any symptoms re-appear. I am to continue taking Mycophenolate at 750 grams twice per day until my next check up when we can review matters again.

Those words confirmed that the omens had been good after all. For the time being at least, my platelet count was 150 higher than when I started out on this journey in July 2006. I know that remission is not redemption and it may only be a temporary reprieve. I understand that

ITP will always be a part of me, I am stuck with it and it is stuck with me. We are each other's guilty secret. But for now the omens had indeed been good.

I can forget all about blood tests, hospital visits and waiting in corridors with familiar strangers for another 3 months. Until then I can put my ITP to the back of my mind even though I can never really put my Purple Jack, back in the box.

Best wishes ...

Anthony

You can check out my weekly ITP blog at <http://anthonyheard.simplesite.com>

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

Give a Car

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

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

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

easyfundraising.org.uk

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

Spend £100 with M&S online or Amazon and you raise £2.50 for us. £100 with WH Smith puts £2.00 in our pocket and so on. There are over 2,000 retailers on their site, and some of the donations to ITP can be as much as 15% of your purchase.

My ITP journey

by Ronald Sait

In 2003 at 53 years of age I was getting bruising for no apparent reason. I asked a nurse I knew what might be happening and she said I probably have leukaemia. I saw a doctor and had a blood test that indicated I had a reduced level of platelets. In October 2003 I had a bone marrow biopsy which confirmed I had ITP. The haematologist suggested it could have been caused by the shingles I had in 2000. She added that I had just been unlucky and I would now have low platelets until I die – that is, there is no cure. My platelets varied between about 45 and 55 so the haematologist did not put me on any medication but instead just monitored my platelet level.

I read up on ITP on the internet and to help with my low platelets I started taking a multi-vitamin pill and tried to eat a healthy diet as possible. I found certain foods and drinks that caused more bruising. These included blackcurrants, blueberries, garlic, ginger and aloe vera juice (anything that is thought to stimulate the immune system). I also tried alternative therapies including using a chiropractor and herbalist. My platelets have been relatively stable at about 50 for the last 13 years.

In 2015 I needed to have a haemorrhoidectomy. The haematologist said it was okay to have the operation

without needing to boost my platelets. I had the operation and the specialist told me later that I started to bleed out on the operating theatre and they needed to pump steroids into me to stem the flow.

Also in 2015 I plotted my platelet levels since 2003 then extrapolated them back to 2000 and it intersected the normal platelet level of 150 at the time I got shingles (November 2000). Apparently a virus such

as shingles can result in ITP and this appears to be the case with my ITP.

At 66 I have many health issues but by far the worst is ITP. The fatigue I have had for 13 years prevents me and/or reduces the time I can spend doing such things as bush walking (rambling), working in the garden,

maintenance on my house and volunteering. I also have aching muscles just about all the time. I am quite stoic about my situation!

Ron Sait
(Retired)

Canberra, Australia

**If you would like to
share your ITP story with
other Platelet readers
please email it to
info@itpsupport.org.uk
or post it to
The Platelet Editor at
ITP HQ (address on pg 2)**

Ed: We are delighted to hear from one of our members in Australia! Ron's story provides a useful reminder that people with ITP (or any autoimmune disease) should avoid all products in health food shops or on-line that are advertised as 'boosting the immune system', which include echinacea and ginseng.



Letterbox

I wish to bring to your attention that for the third time in four years, the yearly 'flu injection has affected my chronic ITP.

Throughout most of 2016 my ITP has been steady with 50mg of Revolade/ Eltrombopag on alternative days, and 750mg morning and 500mg evenings of MMF [*Ed: mycophenolate mofetil*] daily.

My platelets had been steady-ish of around 120, but within 3 weeks of the 'flu injection my platelets had dropped to 5 which entailed another trip to my local Accident and Emergency dept. (Yet another story!).

The only reason I keep having a flu injection is under the advice of my Haematology team at the Royal Berkshire Hospital. As I have no spleen, I would make myself in even more danger without the 'flu injection.

I have had chronic ITP now for 10 years and winter is the trigger point. The Haematology team at the R.B.H. will now monitor me closely from late summer 2017 with more regular blood tests and increased ITP medication when required. However, I would not like other ITP patients to suffer how I do at the start of each winter.

K.J. Porter

Ed: We are grateful to Mr Porter for sharing his experiences of the 'flu vaccine. It would seem that he is one of the few (as mentioned on pg 19) who do notice a drop in platelet count after the vaccination. We would be interested to hear from other Platelet reader whether you r count has been affected or not by the 'flu vaccine.



I send this email is by way of a cautionary tale for ITP sufferers!

I was very poorly in May and large gallstones were diagnosed. I was hospitalised in June with biliary colic and when stabilised was discharged with medication and a very low fat diet to await a date for keyhole surgery which I was told would be 12 weeks. As the symptoms were still painful I decided to have a private operation. I saw the surgeon who said he was happy

to perform the operation within a matter of days but first I needed to see their haematologist because of my ITP.

Because I would need IVIg (immunoglobulin) beforehand they told me the cost to supply and administer this would be a minimum of £10,000 and furthermore, if it didn't work the money would be lost and I would have to pay for more treatment! This cost was in addition to the cost of the operation.

As we were self funding we decided I couldn't go ahead and would remain on NHS waiting list. The haematologist said not to worry about his fee as it would be nominal if a charge was made at all.

Some 3 months later I received an invoice and had to pay almost £500 in total, so I would not advise anyone with ITP to go down this route.

I remained on the NHS list and coped as best I can with symptoms and I now have a date of 16th December for surgery. This totals a wait of 24 weeks and I am booked in for IVIg a few days before to raise my platelets above 80, which I can't achieve normally even with Romiplostim!

Linda Willis

Ed: Our sympathies go to Linda, as a 24 week wait with such a very painful condition as gall stones must have been very hard to cope with. We asked Prof George if Linda

could have been offered a cheaper treatment to raise her platelet count, and he replied:-

The main problem is what you identify, the cost of IVIg. Is there an alternative? I'm not sure. I'm guessing that since she's already on romiplostim, she has received multiple previous treatments and that she may not respond well to steroids. But in a hypothetical patient, in whom we don't know a history of previous treatments, I think high-dose steroids, such as dexamethasone, 40 mg/d for 4 days, may be equivalent to IVIg. This regimen of dexamethasone is becoming the standard initial treatment for ITP in the US (and I assume also in Europe). I think that it's very inexpensive. (like prednisone would be) and may cost 2 pounds, not 10,000. It's her statement that she can't achieve a platelet count of 80 with romiplostim that is a concern. I wonder if she's on the maximum dose (10 ug/kg/week).

ITP Survey Panel needed!

The ITP Support Association is being approached from time to time by clinicians, researchers, and pharmaceutical companies who wish to learn more about ITP patient experiences and opinions. In order to truly represent the ITP patient voice we needed to find a cost effective way of getting responses with the minimum of office administration, and without annoying members who don't want to be bothered

with surveys. Thus we invite readers who would be willing to answer any emailed questions or surveys relating to ITP to join a volunteer ITP Patient Survey Panel .

If you are interested and have, or have had ITP, please email the office (info@itpsupport.org.uk). We would also like to hear from teenagers and parents of children with ITP. (The Association will continue to run occasional surveys of the full membership.)

Webwatch



by Howard Anderson

In the past few years there has been much in the media about the safety of drugs, but as patients, how are we to know what to make of these reports? How are we expected to make a decision about whether to take drugs slated by anti-Pharma campaigners as "dangerous"? Should we rely instead on "safe, natural" alternatives so vigorously marketed by a wide range of people? The first line of course is to trust your doctor, the second line is to research the efficacy and effectiveness of drugs and their alternatives, including side effects, thereby becoming an informed patient rather than a meek recipient. The trouble is, that research is difficult and fraught with danger, one must test the source of such information taking care of who funds it and what they have to gain by publishing it.

As Ben Goldacre and others (www.testingtreatments.org) have been at pains to point out, the drug companies tell less than the whole truth about their products. We hear about the drug trials that are successful but less often about those that are not. The most famous case here is that of Oseltamivir, marketed under the trade name Tamiflu. It simply does not work as well as was claimed. As the Guardian newspaper reported (www.theguardian.com/business/2014/apr/10/tamiflu-saga-drug-trials-big-pharma) "*That is a scandal because the UK government spent £0.5bn stockpiling this drug in the hope that it would help prevent serious side-effects*

from flu infection. But the bigger scandal is that Roche broke no law by withholding vital information on how well its drug works. In fact, the methods and results of clinical trials on the drugs we use today are still routinely and legally being withheld from doctors, researchers and patients." As a Cochrane report stated*, "*Oseltamivir and zanamivir have small, non-specific effects on reducing the time to alleviation of influenza symptoms in adults, but not in asthmatic children*". So how do we trust companies like Roche and similar?

Cases such as this lead people to distrust big Pharma but this distrust leads some to an unsupportable conclusion, *big Pharma is bad, therefore the alternatives are good*. This kind of logic error is sadly very common; we see it in the political sphere, criticise a policy promoted by party X and people automatically think you support their opponents in party Y. That is simply stupid, the world is more complex than that.

So how about those safe, harmless alternatives? A nice dose of say Echinacea, claimed to prevent the common cold. After an apparently well designed trial using 775 people**, various sources claimed that Echinacea did indeed prevent colds, so that it ok then. Well no, this and other similar trials suffer from the same UK flaws as the Roche trials for Tamiflu, the lack of completeness, the lack of a comprehensive statement of all

the results and the obfuscation of important information such as who funded the trial.

This is the very problem that Ben Goldacre describes for big Pharma in evidence

presented to Parliament and which forms the basis of the information on www.alltrials.net. So even if

Echinacea is not effective at preventing the common cold, surely as a natural product it is safe? Oh no,

as advised by www.drugs.com, Echinacea is contraindicated for *"any condition in which immune stimulation or suppression would be considered disadvantageous."*

Was that in the trial? Were the participants screened for that? Echinacea is not advised for people with an auto-immune disease such as ITP. It is instructive to look up other "natural" alternatives in www.drugs.com, noting especially the contraindications. It is also a good idea to look at who funds www.drugs.com; they do not sell drugs or alternatives, they get their information mainly from four companies whose business is selling information. Probably more reliable or at least less biased than companies selling drugs or the alternatives.

I admit I have trouble with the notion of "natural" products. Products marketed under the banner of "natural" are sold as safe, a product of the benign Mother Nature, used by kind people for centuries to treat a range of illnesses. What utter tosh, being eaten by a natural crocodile is pretty brutal,

so is dying from a natural snake bite, dying from eating natural amanita mushrooms or being struck by natural lightning. No, nature is at best brutal and uncaring, almost never

benign, but the word has been hi-jacked by marketing people to sell ineffective and often dangerous products to unsuspecting yet fearful people. The medical profession exists to counteract the action

of nature. For me, if it says "natural" on the bottle, I assume the makers are trying to hoodwink me into thinking it is safe. Take care and have a look at this: – www.ncbi.nlm.nih.gov/pmc/articles/PMC2700706.

Happy surfing,



*Cochrane Database of Systematic Reviews 2014:- onlinelibrary.wiley.com/doi/10.1002/14651858.CD008965.pub4/abstract

** www.nhs.uk/news/2012/10October/Pages/Herbal-remedy-echinacea-does-protect-against-colds.aspx

We can accept any of the following...

Any Stamps, old Envelopes, First Day Covers, Postcards** (including Pre-1940s Birthday Cards and World War 1 silk cards**) - used or unused.**

Please leave a 5 to 8mm border around stamps.

**If foreign stamps (of any date) or UK stamps postmarked BEFORE 1970 are on envelopes or postcards - DO NOT REMOVE THEM! They may be worth more as a collectible item complete.

Coins and Bank Notes - any and all, old and new, from ANYWHERE in the world, obsolete or otherwise.

Precious Metals - including broken jewellery, old trophies, gold, silver etc.

Medals and Badges - any, and not limited to military items, other medals and badges accepted.

Costume Jewellery - is accepted.

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Metal Cutlery - any Metal Toys, Ornaments & Cutlery - any age, type or condition.

Watches - Quartz or wind-up, working or not.



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Help raise funds by saving your stamps and send them to the ITP office. Send other items direct to Stamps N All quoting The ITP Support Association

To arrange collections (over 10kg), please telephone 0845 257 0813, Monday to Friday, 9am to 5pm.

Small lots / donations can be mailed, direct (please ensure correct postage is paid) to:

***Stamps N All, Dept ITP, PO Box 245, Plymouth, PL5 2WX**

*NOTE: Please include sender's name & address (details for internal use only & will NOT be passed to third parties).

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If you feel that your organisation might benefit from the Stamps N All zero cost** fund raising solution, please call David on 0845 257 0813 to discuss how Stamps N All can help you. **Terms & Conditions apply. Stamps n All (Sole Trader), which means that all goods donated to Charities are paid for, but the sole trader profits from goods purchased



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- JOIN THE ITP SUPPORT ASSOCIATION
- DISCONTINUE RECEIVING THE PLATELET

Please tick the 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 for membership 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 PR on the back of your cheque if you wish your donation to support the ITP in Pregnancy Registry)*



**The ITP Support
Association App.**

Please complete:

Name _____

Address _____

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

Signed _____ **An SAE for info packs, or for donation receipts, is much appreciated!*

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