



the platelet

MAR 2016

JOURNAL OF THE ITP SUPPORT ASSOCIATION



ITP NEWS & EVENTS .

**CONVENTION
DATE FOR YOUR
DIARY . . .**



AND PLENTY MORE INSIDE

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Charity Registration No:1064480

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In this issue ...



If we 'start at the very beginning' (to quote a song in Mary Poppins) you may have noticed that on the opposite page our list of medical advisors is growing. In recent issues we introduced Drs Cataland and Dr Neunert from America, and now we are delighted to welcome Dr Nichola Cooper to our UK advisory team. It is worth reminding everyone that our ten medical advisors assist us in a purely voluntary capacity, and we are most grateful to them all for their advice and support.

In this issue Prof. George looks at an analysis of platelet counts during pregnancy, Dr Grainger reports on the Childhood ITP Registry, and the PPTA issue a statement on Zika virus.

Included are updates from Anthony reviewing hot topics on the social networks, from Derek reporting on the international scene and from Shirley evaluating the work of the ITP Clinical Centres. Rhonda discusses nutrition and hydration in hospital while Howard tackles the press and web ambiguity in reporting medical matters.

In addition to the report on this quarter's wonderful ITP fundraisers, a patient recounts his ITP experiences, there are some interesting topics in Letterbox and in News & Views. Our full page advert on pg 16 gives details of the Patient Convention to be held in September, for which we are offering a members only 'early bird' booking using the back page of The Platelet.

Contents

4	Shirley Writes...
6	American Perspective
7	Zika virus statement
8	UK ITP Paediatric Registry
10	Taking a Rare Leap!
12	My ITP Experience
14	Fantastic Fundraising!
16	ITP Patient Convention details
17	News and Views
18	Letterbox
20	Nutrition & Hydration in Hospital
22	International update
25	More News and Views
26	Webwatch

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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...

How time flies! The establishment of ITP Centres still feels like quite a new initiative, but on looking back to find when we held that first meeting that set the ball rolling I was surprised to see it will be exactly five years ago in September. So an update is long overdue.

The main idea behind 'ITP Centres of Excellence' from the Association's point of view was to give patients access to a small number of hospitals around the UK with recognised expertise in ITP. What has happened in reality is beyond my wildest dreams! We hoped for six to ten hospitals but with Guys and St Thomas's Hospital recently coming on board both for adult and paediatric ITP we now have the grand total of thirty! Of these, nine hold clinics for both adults and children, thirteen focus on adult ITP services and eight are children's hospitals with a dedicated ITP clinic. Some of these separate adult and children's clinics are at different locations within the same hospital trust.

You will see from the list opposite that these Centres are indeed spread around the UK, hopefully giving everyone the opportunity to be referred to a specialist if they wish. This does not imply that the haematologist in a small general hospital is not well equipped to manage ITP patients

but they may lack experience with the most difficult cases because ITP is a rare disease which can present very differently from one patient to another. The expert centres, particularly the bigger ones, have the advantage of seeing many more ITP patients in their clinics so they are more familiar with troublesome ITP or in tackling the problems which arise when ITP exists with another chronic condition..



The thirty ITP centres which have become known as ITP Clinical Centres are all working towards an agreed criteria which despite the very tight NHS budget, offers high quality care and improved outcomes for ITP patients.

The Centre Directors have formed a very active group called The ITP Forum which holds regular teleconferences and email communication to share best practice, raise issues and look at how patient care can be improved. They offer advice to other doctors including how to obtain new drugs that were initially refused by the patient's hospital trust.

Additionally the ITP Clinical Centres are well equipped to carry out clinical trials for ITP research. Pharmaceutical companies seeking UK trial centres for new drugs find it most helpful that recognised ITP centres are easily identifiable.

Adult ITP Clinical Centres

- Barts & the Royal London NHS Trust
- Manchester Royal Infirmary
- Queen Elizabeth Hospital Birmingham
- Glasgow Royal Infirmary
- E. Kent Hospital
- University Hospital of Wales, Cardiff
- Belfast City Hospital
- University Hospital of Coventry and Warwick
- University Hospital of Leicester
- University Hospitals Southampton
- Aberdeen Royal Infirmary
- Bristol Royal Infirmary
- St George's Hospital, Tooting

Adult and Childhood ITP Clinical Centres

- Oxford University Hospital
- Royal Victoria Infirmary, Newcastle
- University College of London, Hospital
- Guys and St Thomas Hospital
- Addenbrookes Hospital, Cambridge
- St James University Hospital, Leeds
- Norfolk & Norwich Hospital
- Hammersmith Hospital
- Derriford Hospital

Childhood ITP Clinical Centres

- Royal Manchester Children's Hospital
- Birmingham Children's Hospital
- Edinburgh Children's Hospital
- Children's Hospital for Wales
- Sheffield Children's Hospital
- Belfast Children's Hospital
- Royal Aberdeen Children's Hospital
- Great Ormond Street Hospital



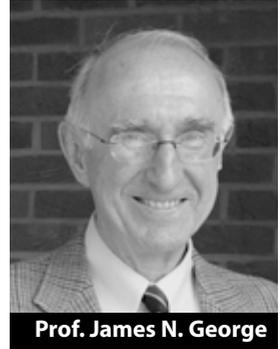
American Perspective



Prof. James N George MD

University of Oklahoma Health Sciences Center

Platelet Counts During Pregnancy



Prof. James N. George

Platelet counts became routine with the use of automated blood cell counters about 40 years ago. It was only then that the Full Blood Count (FBC) became the standard test when any blood count was requested. Often doctors had no suspicion that the platelet count may be low and would never have known unless the laboratory reported the platelet count with the FBC. This was when mildly decreased platelet counts were first noticed in pregnant women at the time of delivery. About 5-10% of women have lower than normal platelet counts at the time of delivery, when a routine FBC is done. The platelet count decreases only a little bit. Typically it is 100-150. There are no symptoms of bruising or excessive bleeding in either the mother or her baby. When these low platelet counts were first noticed in pregnant women, they were assumed to be caused by mild ITP. This is also what I thought for many years. The assumption of ITP seemed appropriate since other autoimmune disorders, such as lupus, can become worse during pregnancy and then resolve after delivery. Therefore I thought that these women with unexpected low platelet counts had very mild ITP and their platelet counts were low only because of the effect of pregnancy.

Several years later, in 1988, it was suggested that the platelet counts of all

women shifted to a slightly lower level during pregnancy, and therefore the lowest 5-10% were less than the lower limit of normal (which is usually 140-150). Therefore lower platelet counts seemed to be a normal, physiologic change with pregnancy, not an abnormal condition.

During the past year we have analyzed the platelet counts throughout pregnancy in women with uncomplicated pregnancies. Using the electronic medical records, we were able to analyze the platelet counts of 4000 women with uncomplicated pregnancies who delivered at our hospital, 2011-2014. We compared them to normal non-pregnant US women of the same age and race. This was important because there are small but significant differences in platelet counts among people of different races. The platelet counts of black women are slightly higher than white women who are slightly higher than Hispanic women. Among these 4000 pregnant women, platelet counts were slightly but significantly lower than normal even in the first trimester, and they continued to get lower throughout pregnancy, with the lowest values at delivery. At delivery,

10% of women had platelet counts less than 150. The lowest counts were 63. The average platelet count among women with low counts was 130. And, importantly, the racial differences were the same as among non-pregnant women: black higher than white who were higher than Hispanic women. At 4-8 weeks after delivery, platelet counts were again normal. This supports the interpretation that lower platelet counts during pregnancy are a normal response to pregnancy. Why does this happen? One reason is that women's plasma volume increases during pregnancy, and this dilutes the platelet count. Another reason may be that women's spleen size increases during pregnancy, and this can increase the number of platelets that normally accumulate, or "pool" in the spleen. A third potential cause that we are investigating is that platelets

may also accumulate in the placenta, since blood circulation in the placenta is similar to blood circulation in the spleen.

Why is this important for members of the ITP Support Association? The importance is that some obstetricians may still tell their patients that a low platelet count during pregnancy means ITP. This happened last summer to a woman (who is an obstetrician) we worked with on our study. She was 12 weeks pregnant and had a platelet count of 120. Her obstetrician told her, "I think you have ITP". She told her obstetrician, "No. We have studied platelet counts in women with uncomplicated pregnancies. This may be unusual in the first trimester, but it's a normal occurrence during pregnancy." She was right. She now has a healthy baby girl and a normal platelet count.

Zika virus statement

Although Zika virus was first identified in 1947 the recent outbreaks spreading across South and Central America have caused the World Health Organisation (WHO) to declare it a public health emergency of international concern. If any ITP patients are concerned about the transmission of Zika virus via immunoglobulin treatment the Plasma Protein Therapeutic Association (PPTA) offered reassurance in a statement on 4th February stating that the Zika virus "relatively large size and lipid envelope makes it highly susceptible to steps with virus inactivation and removal capacity used during the manufacturing processes, such as solvent-detergent (S/D), low pH incubation, caprylate, pasteurization or dryheat treatments, nanofiltration or fractionation processes. The effectiveness of these processes has been demonstrated on other lipid-enveloped model viruses which are quite similar to Zika virus, e.g. Bovine viral diarrhea virus or Tick-borne encephalitis virus, and most importantly the West Nile Virus, another Flavivirus which is even more closely related to the Zika virus". "Based on these data, PPTA is assured that existing manufacturing methods will also be effective against the Zika virus"

UK ITP Paediatric Registry

ITP Registry Announcements

by Dr John Grainger

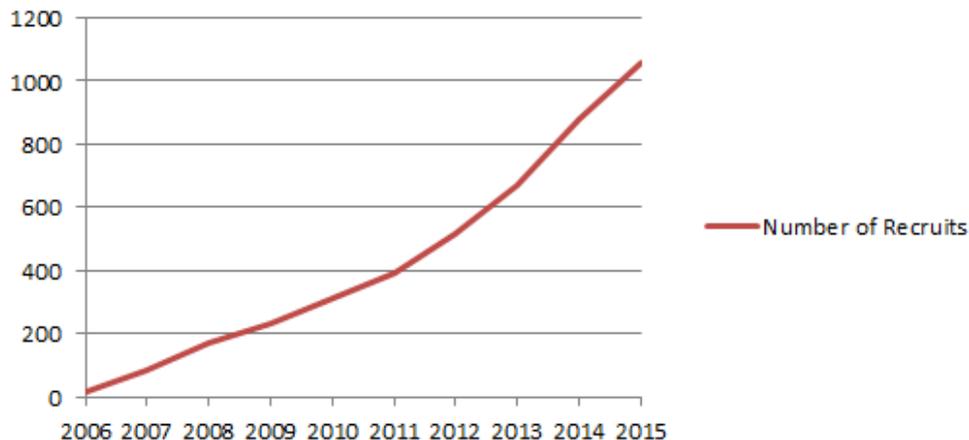
Major Amendment to the Protocol

We have recently received ethics approval for a major amendment to The Registry protocol. The main change is to the inclusion criteria. Previously any child added to the ITP registry must have been diagnosed within the last 12 months but now children with chronic ITP (i.e. those patients who were diagnosed over 12 months ago) can also be included. Additionally, paediatricians can now enrol patients who are between the ages of 2 months and 18 years whereas before the maximum age was 16.

Research update:

The ITP studies with Eltrombopag which have been running over the last 5 years have now been published. In brief, these studies have demonstrated that Eltrombopag is an effective treatment for children with persistent or chronic ITP. It offers families and physicians an alternative to Rituximab, splenectomy or long term steroids. On the back of these studies Eltrombopag was licensed by the FDA (Food & Drug Administration, the US government agency responsible for the control and safety of food and drugs) for use in children over 6 years

Total number of patients recruited to the ITP registry



of age. Licensing is currently in progress with the equivalent European agency, the EMA (European Medicines Agency).

We are currently working up future studies with Eltrombopag. In the meantime the Romiplostim paediatric ITP study is open for children with persistent ITP (i.e. ITP for over 6 months).

Recruitment Figures

As of the end of November 2015 there have been 1062 patients recruited to the ITP paediatric registry!

Thank you for your continued support of this study.

Two Changes to the Marketing Authorisation of Revolade for ITP

In December 2015, the European Medicines Agency's Committee for Medicinal Products for Human Use (known as CHMP) adopted a change to the terms of the marketing authorisation for the thrombopoietin drug, eltrombopag (known as Revolade in Europe) which was originally developed by GlaxoSmithKline, but is now marketed by Novartis.

References for Revolade to be used in splenectomised patients and use as a second line treatment in non splenectomised patients where surgery is contraindicated, have been removed. The authorisation now reads:

'Revolade is indicated for adult chronic immune (idiopathic) thrombocytopenic purpura (ITP) patients who are refractory to other treatments (e.g. corticosteroids, or immunoglobulins).'

In January 2016 the CHMP recommended a variation in marketing authorisation for the use of eltrombopag (Revolade) for the treatment of children aged 1 year and above who have had an insufficient response to corticosteroids or immunoglobulins for chronic ITP. A new oral suspension formulation of eltrombopag is now available for younger children who may not be able to swallow tablets. Known as Promacta in the US, eltrombopag was approved by the Food and Drug Agency (the US equivalent of the EMA) as a tablet formulation in June 2015 for children 6 years of age and older.

This amendment to the licence was implemented following randomised, multicentre, placebo-controlled studies focusing on efficacy and safety in children, as mentioned in Dr Grainger's article above.

Taking a Rare Leap!

by Anthony Heard

Unbelievably, not only is 2016 another Olympic Year (was it really nearly 4 years ago that London hosted the Olympic Games ?) but of course with 29 days in February, we literally take a LEAP YEAR.

So in the following article we reflect on RARE DISEASE DAY held as usual on the last day of February (in itself a RARE day, especially in this Leap Year). We also look at some of the most talked about topics from our social network platforms, including ITP and feeling cold, Papaya Leaf Extract and travel insurance for ITP sufferers.

The theme for Rare Disease Day 2016 was ... MAKING THE VOICE OF RARE DISEASES HEARD. Full details of the campaign are available from www.rarediseaseday.org.

ITP is of course just one of over 6000 officially recognised Rare Diseases, albeit new conditions are literally being discovered every day. The ITP Support Association is a member of Rare Disease UK and we have played a fully active part in promoting Rare Disease Day on our social network forums.

During February we published a daily Rare Disease fact on our Facebook forum to raise awareness for ITP and Rare Diseases as a whole. We have also attended (for the last 4 years) the annual Rare Disease Day

House of Commons Reception hosted by Liz Kendall MP. This has been a really useful forum for us to spread awareness about ITP and the Association itself in addition to gaining many valuable contacts. (For anyone who wishes to join Rare Disease UK you can do so completely free of charge via www.raredisease.org.uk)

We now turn to some issues which have been the cause of much chatter on the social media platforms.....

ITP and FEELING THE COLD.

Numerous comments and questions have come in about constantly feeling the cold, and ITP sufferers commonly saying that they believe they always feel colder than other members of their family, friends, colleagues. It does seem that quite a lot of ITP sufferers believe that they feel colder than most non ITP sufferers. So is there any truth in this or is it just complete coincidence ?

(See comment on pg 11)

PAPAYA LEAF EXTRACT

Lots of people have asked whether taking Papaya Leaf Extract can raise the platelet count. It is a product widely advertised and sadly it raises expectations in ITP sufferers that perhaps Papaya Leaf Extract is the miracle cure we all crave and have been looking for.

BUT sadly there is ABSOLUTELY NO EVIDENCE to show that taking Papaya Leaf Extract raises the Platelet count. In fact, further to this we can also say that because things like Papaya Leaf Extract, other herbal remedies and alternative medicines have no official register to record side effects, we have no idea at all what potential damage they could cause.

So we absolutely advise ITP sufferers to make sure that they refrain from taking anything like Papaya Leaf Extract or other herbal/alternative remedies. Our advice is also to make sure that you always have a full discussion with your doctor/ITP specialist before taking anything. You could end up

doing yourself more harm than good by taking substances/remedies which are not properly tracked for side effects or outcomes.

ITP and TRAVEL INSURANCE

Especially at this time of year, as people start booking holidays, we get lots of questions about arranging travel insurance. So this is a timely opportunity to remind everyone that we have some excellent information available about travel and ITP. There is our booklet entitled HOLIDAY INSURANCE AND TRAVEL GUIDE, plus our PATIENT HOLIDAY FACTSHEET. Both are free to members and can be ordered from ITP Support Association HQ or via <http://www.itpsupport.org.uk/leaflets.htm>

Feeling the cold . . .

We were surprised to hear that followers of our ITP social network believe that they feel the cold more than others, as this is not something our members have ever reported to us in surveys or in general feedback to us at HQ. Many factors can affect the wellbeing of ITP patients – severity of ITP, age, symptoms, treatments and side effects, and we don't know if these have a bearing on the people who commented on their susceptibility to feel cold. At the time Anthony sent his article we were hearing of severe weather in New York, so it seemed timely to ask our American advisors if they were aware of this phenomenon. Professor George replied "I've never heard this before, but then my careers have been in [the warmer climates of] San Antonio and Oklahoma".

Dr Spero Cataland stated "I've had some cold weather ITP action in both Chicago and Columbus, OH, but I have not heard this before either." and Dr Cindy Neunert added "Until recently I was in the sunny south, but I can say that it did not seem to be a common concern during this last snow storm that we just had."

Interestingly a Google search on the topic shows that included in the top reasons to suffer the cold are insufficient sleep (which could be associated with fatigue in ITP) and hypothyroidism (which can be caused by steroids). Also listed (without any particular relevance to ITP) are being too thin, being dehydrated, having too little iron or Vitamin B12, poor circulation, diabetes, and being a woman(!).

Shirley Watson

My ITP Experience

by Ian Salter

At the time I first was diagnosed with ITP I was a sixty four year old male, newly retired and enjoying living part time in Cyprus and part time in the UK.

I was in Cyprus when I noticed bruises on my arms and legs. I thought it was due to over enthusiastic DIY but the bruising persisted and on my return to the UK I rang up my GP. She suggested a blood test. I offered to ring the health centre on the following day to arrange an appointment with the nurse. Instead the Doctor wanted to know how quickly I could get to the surgery as she wanted the test done straight away. This started alarm bells ringing. Our health centre doesn't do immediate appointments.

As the nurse was taking the blood the inside of my arm from elbow to palm turned black. "How long have you had that" she asked, "only since you put that needle in" I replied. She rushed off to get the Doctor.

I was sent home to await the results of the blood test and two hours later received a phone call from the Doctor. "Your platelet count is quite low and we want another test to confirm it. We would like you to go to the hospital straight away for another test". By this time I was becoming very suspicious, should I take an overnight bag I asked, "Yes just in case" was the reply. Doctors are the masters of understatement.

On arrival at hospital they showed me to a bed, I wondered why I needed a bed for a simple blood test, but all became clear. They took the blood and shortly after that a doctor arrived, He explained that in a normal person the platelet count is between

a hundred and fifty and four hundred and fifty, mine was three. I was to stay in bed and not go anywhere as a fall could cause a haemorrhage. Luckily I did not need the loo.

A nurse arrived and connected me to a drip that gave me intravenous platelets and I began to resign myself to a long stay.

I spent the following week in a medical assessment unit undergoing numerous tests which happily ruled out things like leukaemia and prostate cancer. Finally the doctors told me that I had ITP. "IT-what" I responded, I had never heard of it. Nearest thing I had suffered from was PMT and that was second hand!

They gave me sixty milligrams of prednisolone per day with no mention of the side effects, but a promise that when my count reached twenty I could go home.

I started to learn some of the side effects of steroids.

When some friends visited me they kindly left an enormous bar of chocolate, one of those Cadbury Dairy milk things that are about a foot long. The following day when they called, it had all gone. Lesson 1: Steroids affect your appetite.

We were due to move house in two weeks and between hospital visits, my wife heroically organised removal men, packing and contacted numerous utilities whilst I was unrealistically relaxed in hospital, feeling quite high. Lesson 2: Steroids affect your mood.

After a week my count had reach fifteen and the doctors decided I could go home, on the strict understanding that I did not lift or do anything that could risk injury. Not easy when you are moving house.

The family rallied round and came over to do the final packing and get us moved. For a laugh my grandchildren made me a suit of bubble wrap to protect me during the house moving. I began to suffer from cramp in my legs and my hands would go into spasm causing me to drop whatever I was holding. Lesson 3: Steroids cause muscle cramps.

I was treated as an outpatient in the care of the haematologist at our local hospital and over the following three months my count rose to one hundred and fifty, whilst the steroid dose was reduced. After a year the steroid dose was down to one five milligram tablet every other day but within a month my count had fallen to fifteen.

Over the next five years I was given numerous treatments.

Cyclosporin had a marginal effect on my count and my kidneys began to suffer so that treatment was stopped.

Rituximab (low dose) combined with steroids maintained my count at about fifty for several months until the steroid dose was reduced to five milligrams per day at which time the count fell.

Micophenolate had little effect on my count which remained in the twenties.

Intravenous immunoglobulin caused a bad reaction with flu symptoms and high blood pressure.

In Aug 2010 I was given a larger dose of Rituximab combined with steroids. This raised my count to one hundred and fifty. The steroids were gradually reduced and

in June 2011 were stopped altogether, by August my count had fallen to twenty nine.

Splenectomy was suggested, I was told there was a seventy percent chance of success. I agreed and the operation took place in October 2011.

Initially my count rose to over four hundred but once I stopped taking steroids it fell and by January 2012 it was at thirty and the haematologist concluded that the operation had not worked, so back on the steroids.



I was referred to the specialist at Manchester where I was subjected to numerous tests.

Dapsone was prescribed for two months, whilst reducing the steroid dose, however once the steroids stopped my count fell rapidly.

In October 2012 my count was sixteen and I was taking steroids when I started injections of Romiplostim. Within nine days my count had risen to six hundred and thirty two and the steroids were stopped. Over the next twelve days my count fell to four and the steroids were restarted.

This up and down pattern continued for the next three months with my count reaching over six hundred following each injection but then falling to single figures.

This finally stopped in March 2013 when the rate at which my count fell eased and it levelled off at about two hundred and fifty where it has remained ever since, without the need for steroids or Romiplostim.

Hopefully, (it is not easy to type with your fingers crossed) this remission will continue.

So if doctors tell you that there is no cure for ITP they may just be wrong.

Fantastic Fundraising!

Lynn and her son Kevin McVittie inspired their family and friends to join with them in raising money for our cause. Lynn, whose son Lee Darren McVittie tragically died from acute ITP while in the army, collected £75 from her fabulous knitted poppies, and she and Kevin ran a concert night which raised £620. **David and Dawn Howe** collected £310 in sponsorship by competing in the Great North Run, and Lynn's local Keep Fit Class raised £430 from raffles, domino cards and coffee mornings. **Hazel Watson** collected £320 in ITP charity boxes displayed in her shop Plain N Purl, and **Alice Foster** added another £45 from knitting toys. Thanks to these wonderful efforts their combined grand total reached a tremendous £1,800.



Andy Allen, triumphant!

Andy Allen whose father has ITP ran the MBNA Chester marathon in October and raised an amazing £1,541 by participating in the Chester marathon on the 4th October. We are most grateful to Andy for his efforts in training, competing and collecting such a fantastic amount in sponsorship. Photo

Yet again the **Charity Shop** in Gt Yarmouth, Norfolk, came up trumps sending a contribution of £2,000 in December. Celina, Gloria and the team continue to put huge amount of energy and time in to their shop which does such an excellent job in supporting the ITP Support Association and The Fisherman's Hospital in Great Yarmouth.

Charlie Tompkins as Treasurer of the Lodge of Hospitality No. 7927 kindly sent in donation of £500 raised from their Soul Reunion Disco.

Shirley Watson has held a number of events in Bolnhurst in recent months in support of the Association, starting with a coffee morning at the new ITP headquarters in early December which raised £85. Her Pupils' Christmas Concert plus music sale raised £97, a Carol Singing Session in her local, The Plough Inn, raised £75 and a New Year's Eve Supper raised a further £89. In February Shirley held a Fun Quiz Night with questions supplied by ITP webmaster, Howard Anderson. Shirley said "Several people commented that they enjoyed the questions, and choice of rounds which were not 'run of the mill'. The most difficult round seemed to be Motorways as the highest team mark was 4 out of 10! The Quiz made £186 bringing Shirley's fundraising total to £532.





Anne faces fire . . .

Anne Dingwall bravely decided to take part in the Spartan Trifecta which involves three extremely tough endurance events. Anne explained 'The Spartan Super was a difficult race being in Scotland as it was a very hilly course and even the elite competitors found it a challenge. I did complete the race though and received my fair share of bruises (as expected!)but no other serious problems. Overall it was a fun, albeit hard, challenge and the weather was on



. . . water,

our side as well! We congratulate Anne on her commendable achievement in completing such a gruelling event, and for raising a super £602 for ITP.



. . . mud and obstacles

Katherine Cummings and the staff at Redwood Publishing kindly nominated our charity to receive half of their annual pub quiz donations, and sent us a cheque for £75 in memory of Steven Sims.

Michelle Floyd and staff at Aldworth School in Basingstoke raised £53 from a staff Christmas

raffle and Michelle used this as an opportunity to spread a little awareness of ITP throughout the school as her 8 year old daughter Millie has ITP. Michelle told us 'Millie's platelet count is always around 10 or below so buying a bike for her 8th birthday last July was quite a big deal, and hence the pads!! ITP hasn't held Millie back in that many ways, she is very lucky!

Finally we send our thanks to everyone who has sent donations – whether one off contributions, amounts added to membership or orders, donated from a winter fuel allowance, or a regular payments sent by standing order or set up through Paypal, we are extremely grateful for them all.



Millie on her new bike

CONDOLENCES

We are extremely grateful for donations totalling £500 in memory of

Robert White

We send our very deepest sympathy to Robert's sister Linda and to all his family and friends.

We thank them for their kindness in supporting of our charity in lieu of flowers.

ITP PATIENT CONVENTION



Saturday 17th September 2016

at

Cumberwell Park Golf Club

Great Cumberwell, Bradford-on-Avon BA15 2PQ (UK)

with

Prof Bertrand Godeau (Paris, France)

Dr Drew Provan (London, UK)

Dr Will Lester (Birmingham, UK)

Dr Charlotte Bradbury (Bristol, UK)

Booking forms will be sent out with the June Platelet

On-line booking will also be available from June

Members £25 Non-members £35

**Members only 'Early bird' reservations can be
made using the form on the back page**

News and Views

ITP Charity Lunch

Our celebrity supporter Neil Dudgeon (star of TV's Midsomer Murders) is to be guest of honour at a charity lunch and afternoon in aid of ITP. The location will probably be Fulham Football Club, but at the time of going to print the venue and the date have yet to be confirmed. Tickets will be around £60 and the event will include:

- Welcome drinks,
- Introduction to the event by DJ David Hamilton, followed by a hearty lunch
- A free draw with prizes that include sought after Fulham FC and 'Midsomer Murders' items.
- Q&A session with Neil compered by David. Ask Neil about any topic – including the secrets behind the scenes at Midsomer.
- Close at the end of an enjoyable afternoon when guests will be provided with a souvenir photo and autographs.
- If you would be interested in attending the lunch or sponsoring the event please contact us at HQ and we will send you details once they are finalised.

Insurance success

We are grateful to Caroline Metzger who recently asked us for our list of ITP friendly insurance companies. She has since informed us that the More Than website have ITP as one of their accepted conditions on a drop down box and have actually insured her son, who has ITP, to go ski-ing!

Gut Bacteria Study

Professor Hunter's Gut Bacteria Study which was running at Addenbrookes and Hammersmith Hospitals has now closed. Unfortunately the study reached its time limit very soon after our call for more participants went out in the December Platelet, and as the NIHR would allow no extension some of you who completed enrolment forms were not given appointments. Our apologies if this has caused any disappointment, but once the results have been fully analysed we will report back in The Platelet.

Payments from Inland Revenue!

Thanks to our vigilant treasurer Michael Levy, the ITP Support Association has received a rebate from HMRC of £2,700 in respect of VAT that had been charged for our new HQ.

The VAT system with regard to charities and new builds is very complex and we are most grateful to Michael, who manages our ITP accounts in a voluntary capacity, for his time and efforts in making this claim.

Michael also submitted a Gift Aid claim around the same time which resulted in another payment from HMRC for over £2,000. If you are a UK tax payer and haven't sent us a Gift Aid form for your subscription and/or donations do please ask us for one or download it from www.itpsupport.org.uk/docs/giftaiddeclaration.pdf It really does make a difference.

Letterbox



I was particularly interested in the article on Page 6 of the latest 'Platelet' magazine on the use of immunosuppressives. Having had ITP since September 1993 with relapses every two years approximately, I always was put on prednisolone 70mg which acted swiftly but took months to wear off each time.

In April 2008 I was given 40mg instead, plus Azathioprine 100mg, and in two weeks my platelets rose from 25 to 248. I stopped the steroids but stayed on Azathioprine, gradually dropping the dose until I was off them completely in April 2014. During all this time my platelets have been stable at 250.

I am now 90 years old, reasonably fit and quite mobile, despite having bladder cancer in 2011 and am still all clear. My treatment at the time was complicated by the fact that I was on an immunosuppressive which just meant that I had to have chemotherapy – mitamycin – instead of the usual BCG treatment.

I always look forward to 'The Platelet' each quarter so am renewing my membership even though I have been discharged from the Haematology service.

Joan Hards

Ed: Thank you for your lovely letter, Joan. I'm sure that many Platelet readers will find it encouraging that you have made an excellent recovery from both ITP and bladder cancer. It is not unusual for us to hear from patients that their ITP was manageable

until they developed a second (unrelated) illness, and found that treatment for one condition was contraindicated with the other. It was wonderful to hear you have reached your 90th year and are still fit and active despite your earlier health problems.

How do people with ITP stand regarding donating organs? I would love to be a registered donor, but would worry if my "contaminated" platelets within any transplanted organ caused a problem.

John Papworth

An official from the NHS Organ Donor Register administration department responded:

With regards to your enquiry regarding people with ITP, having an existing medical condition/taking medication does not necessarily prevent a person from becoming an organ or tissue donor. In the event of their death, a decision about whether some or all organs or tissue a person has chosen to donate are suitable for transplant or not will be made by specialist healthcare professionals, taking account medical history. Usually, but not always, it is possible for some organs or tissues to be donated.

With this in mind there is no reason why a person should not be on the NHS Organ Donor Register if this is their wish.

I had a surprising visit to haematology here at Nottingham before Christmas. I attended for my bi-monthly consultation and further prescription for Romiplostim which I have been 'taking' for around 4 years now, (500mg weekly by sub-cutaneous injection) and the blood test showed my platelet count to have risen to 192! I started reducing the dose after Christmas. I had only just read the article in The Platelet where this type of result was reported. I am told there are two other patients at Nottingham who have responded; one has been off drugs for two years, the other relapsed. My own count started to rise from its 'normal' 30 - 40 at the beginning of the year, with fairly steady rises to circa 60, then circa 90, then 130 and now 192. Exciting times!

Thank you for all your hard work on our behalf.

Paul Selby

Major changes have occurred in the recent years regarding the information patients have on their treatments, and the role patients have when making their own treatment decisions.

Therefore, EURORDIS is conducting an internet-based survey in an effort to better understand how well patients are engaged in medical care, including the relationship with health care providers, the understanding of the therapy (its efficacy, possible difficulties, benefits as they see them), reasons why they agreed to take this therapy, as well as if they are satisfied

with the information they were given.

Responses will contribute to the consultation on the off-label use of medicines launched by the European Commission.

This study is being conducted by EURORDIS in seven languages, English, French, German, Spanish, Italian, Portuguese and Russian under the guidance of the DITA Task Force (Drug Information, Transparency and Access) and can be accessed at <https://www.surveymonkey.com/r/YVY9PX8>

The survey is for patients aged from 15 years and over. Responses will be confidential to Eurordis and only identified by a code number. The survey will take about 30 minutes to complete and the final questions are about the Patient Information leaflet that comes with your treatment.

EURORDIS thanks you in advance.

Sincerely,

François Houÿez

Treatment Information and Access
Director / Health Policy Advisor
EURORDIS Paris' Headquarters-
Plateforme Maladies Rares,
96 rue Didot, 75014 Paris - France
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Ed: The European Organisation for Rare Diseases (EURORDIS) is a non-governmental patient-driven alliance of patient organisations representing 705 rare disease patient organisations in 63 countries covering over 4000 diseases, and is the voice of 30 million people affected by rare diseases throughout Europe.

Nutrition & Hydration in Hospital



by Rhonda Anderson

We all know food is fundamental to health. Unfortunately it is a fact that many people are overweight or obese. In the hospital context, the opposite is often true, the effects of lack of adequate nutrition and the danger of malnutrition are seen in one third of hospital admissions. A stay in hospital can make this state much worse due to the effects of treatment and sadly due to the lack of adequate nutrition whilst a patient is in hospital. Under nutrition increases the patient's risk of complications, delays recovery and increases length of hospital stay. All these things cost the NHS a lot of money and could be helped by simply feeding patients well.

Patients should have three meals a day, two snacks and seven drinks. Hydration is as important as food. Ask any patient who has recently been in hospital if they were offered 7 drinks every day, and I doubt that even one will say they were.

Apart from the fact that a lot of patients do not enjoy, or look forward to hospital food, it is a necessary and essential part of the daily routine of a ward to deliver a food service. No one would expect to have a top class meal in hospital, (although I don't see why not), but an adequate menu should be available and enjoyed by all patients. This includes people who have special dietary

requirements such as gluten free, true allergy diets, low sodium diets, low fibre diets etc.

There are those who need special feeds, and processes need to be in place to deliver this. As I am not qualified in this area, I shall concentrate on normal diets and special diets.

Cultural and religious preferences are also catered for such as Halal and Kosher. Vegetarians and vegans also have meals provided according to their preferences and needs.

I have been asked to comment on the draft Food and Drink Strategy for Barts Health. For about 15 years I have been a member of Whipps Cross Hospital Patients' Panel. As my daughter and I have allergies, I have a special interest in food and nutrition. I am on the Nutrition Action Team, (NAT), which meets once a month. Another member of the Panel is also now a member. This group includes Dietitians, Speech and Language Therapists, Customer Services Manager, Catering Manager and various staff from the wards. There is one of these groups at each of the 5 hospitals in Barts Health and they then feed into the Nutrition and Hydration Committee.

An education package is being developed, called The Link Nurse Training Programme. The link nurses are supposed to concentrate on nutrition on their wards and champion

good food service practice and help to encourage and train other staff so that all aspects of nutrition are a high priority.

So far there have been 2 training days. It is interesting to see how the staff react to this approach. After the first day they asked for more information on special diets and this was delivered in the second session. I would like to see a test done after these training days, with the staff who have been trained and those who have not, to see the difference on responses and to gauge the effectiveness of the learning.

The first time it was clear that staff were not familiar enough with the forms they needed to fill out using the Malnutrition Universal Screening Tool (MUST) assessment that every patient has to have on admission. Role play needs to be done over and over again, so that staff are fully confident and competent to carry out these vital assessments. The hospital policy for feeding the patient for the duration of their stay in hospital will be based on this initial assessment.

In spite of dedicated work by many senior staff in the hospital to improve nutrition, there has not been enough improvement. The reasons for this are many: turnover of staff which leaves gaps in continuity of care and knowledge and the employment of large numbers of agency staff; lack of confidence to ask senior staff for help or information; lack of visibility of senior staff doing hands on work at meal times; lack of

knowing what to do and how to do it, which comes from lack of leadership and training.

There is a protected mealtime policy on the wards. This means that at the designated meal time nothing else should be going on in the ward except the food service. In this way all staff are engaged in the one activity, delivering the meal to the patients. If this is done regularly, at every meal time, all staff are available to feed those who need assistance and no one gets left out. Also the meal can

be delivered speedily so that it is the correct temperature and therefore the correct texture and consistency. Of course this will only happen if it is organised. Everyone should know exactly what they have to do, be ready to do it, and deliver their part in the

food service seamlessly. It needs team effort and team attitude and initiative to be able to do this. The

food service needs to be masterminded like a military operation. Unfortunately too often consultants are doing their rounds during the meal service and nurses have to attend to them instead of feeding vulnerable patients. This should never happen.

As we have heard so many times, cleaning is everyone's business, so to, nutrition is everyone's business. Until it gets top priority there will be gaps that need filling and hospital nutrition will continue to be a hot potato that so many people cannot handle.



Rhonda Anderson

International update

by Derek Elston

Since my last report, there has been a tremendous amount happening in Europe, all of which augers well for the benefit of patients both here in the UK and also throughout the EU.

GRIP - Global Research in Paediatrics

Thanks to our good friend Davy Charlottenfeld from ITP Denmark, I was invited to represent the ITP Support Association at a GRIP Patient Road Show in Helsinki, Finland on Thursday the 22nd October 2015.

GRIP, based in Holland, had organised a one day workshop to consider the broad use of medication in paediatric patients. The attendees were by invitation only and as such was very select. I was of course delighted to meet with Davy Charlottenfeld again and also on this occasion with Heli Lastikka of ITP Suomi, Finland. The other invitees included the Danish Haemophille Association; The Norwegian Asthma and Allergy Association; Cancer Organisation Soumi, Finland and the Brain Tumor Association of Norway. An extremely select group of 15 patient advocates and medics, who were put through a very interesting and testing work shop.

The whole day was conducted by Professor Kalle Hopppu, Associate Professor of Paediatric Clinical Pharmacology, at the Hospital for Children and Adolescents, University of Helsinki. He raised questions on how you should treat young persons with medication designed for adults

where there were no guidelines for their use with paediatrics. He considered the ethical problems, the reaction of parents and ultimately the goal to be achieved of a reduction in the use of drugs 'off label'

He then considered the understanding of drug development in children; the regulatory and legislative environment of paediatric medicine development and the drug safety in children.

To conclude, he then set forward proposals for setting up young persons advisory groups in each country and how these can be achieved with the objectives envisaged. Within the UK, NICE has already a paediatric investigation procedure and GRIP has a partner in Liverpool University.

This road show is to be repeated in other member states and eventually, formal representation will be made to the EU Minister for health on the future of the use of medicines in paediatric treatment following the analysis of the workshop evidence obtained.

European Patients Academy – EUPATI

On the 27th January 2016, the EUPATI project into R&D reached a major and most important milestone. An announcement was released on the launch of the EUPATI Toolbox on Medicines R&D. and we received our notification from Jan Geissler, a director of EUPATI, early the following morning.

The toolbox is designed to assist patient advocates and patients alike with

understanding and participating in the research and development of drugs. It is available in six languages and has over 3,000 content items with more than 1 million words in 100 thematic areas. It contains fact sheets, graphs, presentation slides, videos and recorded webinars. There is print ready material and much more for public use and re-use by patient advocates, patients and support associations.

This announcement is the culmination of much concentrated effort by patient organisations from any fields and their advocates, and will be invaluable for patients to discover how research and development takes place.

It also provides a pathway and advice on how to set up a 'mini-EUPATI' within each member state. This is something which we will as an association, be pleased to collaborate with other patient organisations within the UK.

There is an excellent video on the toolbox which I recommend to you. It can be found at :- <https://vimeo.com/152251690> and the full press release is available at :- www.patientsacademy.eu/index.php/en/news/press-area/press-release/589

You can also access the 'EUPATI Toolbox on Medicines R&D' at www.eupati.eu.

European Reference Networks – ERNS

The term ERN is not widely known and certainly not understood by many in the medical profession let alone patients for whose benefit it is directed. The background to ERNs is as follows.

ERNs are concerned with Rare Disease (of which ITP is one of many haematological conditions) which would be the subject of this EU directive. The history starts with the

EU Directive (2011/24/ EU) on the application of patients rights in cross border healthcare and acknowledged the unique potential of European Reference Networks for the rare disease field. In this document the European Commission pledged to support the development of ERNs between healthcare providers and Centres of Expertise in Member States,

in particular in the area of rare diseases.

Much happened between this directive and the eventual recommendation of 2013. In this document it was recognised that there were between 6,000 and 8,000 separate rare diseases that would need to be accommodated into manageable groups. The recommendation in 2012 was "to help focus on the specificities of rare diseases and the criteria for the establishment and evaluation of ERNs in the field of rare diseases".

ITP 'Friends'

a listening ear

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Eventually it was agreed that broad, thematic ERNs for rare diseases are established for the purpose of grouping rare diseases thematically into 21 groups. We will logically be located in the haematological group.

It was also noted that patients and patient groups should play an integral role in the decision and opinion making process of RD ERNs and be involved in structural and clinical network activities.

At the present time, there are approximately 30 advocates from different haematological conditions who make up the membership of the EHA Advocacy Group. As all readers may be aware, we are an official member of the patients advocates group on the European Haematology Association, an organisation with over 9,000 members concerned with blood. As a group of advocates, we have, and are, extremely active in the development of the haematological group within EHA and have grown in contribution to their meetings and conferences apart from being consulted on many points relative to patients requirements. During December 2015 and into the New Year, there have been several discussions, international telephone conference calls and proposals for submission to the European Commission for the establishment of an European Reference Network for haematological rare diseases. Initially these

discussions were purely within the advocacy group of EHA, but I am pleased to say, the board of the EHA have decided to join with us and we are hopeful this will support our endeavours, possibly with a joint proposal.

This is still very much work in progress with much to be discussed and agreed between all the advocates and the board of EHA in a short time span. The advocates are

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being led by a well known haematologist from Cyprus and several advocates from various member states who represent both malignant and non-malignant conditions. EHA are represented by two board members both of whom are very eminent and pro patient involvement haematologists from Holland and Austria. It is hoped, at the time of writing this report in February 2016, we will shortly be submitting a joint letter

from EHA and the patients advocates, to the Ministers involved in the EHA process at each member state, to each individual Secretary of State for Health and each member state haematological society. In addition, each member of EHA will be emailed.

Suffice to say, this is an exciting and extremely involved process which is taking time to assimilate, debate and prepare. Ultimately, it should be extremely beneficial to ALL patients within the EU. Should anyone like more information, this is available at :-http://ec.europa.eu/health/ern/policy/index_en.htm

More News and Views

Innovative Treatments Bill

The Access to Medical Treatments (Innovation) Bill (an amended version of The Medical Innovation Bill) seeks to promote access in two key ways; firstly by giving power to the Secretary of State for Health to create a database of innovative treatments, and secondly to allow doctors to depart from the existing range of accepted medical treatments without fear of negligence claims providing the doctor's decision is taken responsibly. The Bill's supporters argue that doctors should be able to try untested drugs and treatments on patients without the fear of medical negligence claims, as the fear of litigation stifles innovation.

The Bill's critics believe this moves medicine into dangerous territory. Doctors are concerned that the meaning of the proposed legislation is not clear enough, and they fear coming under pressure from patients suffering difficult or terminal conditions who are prepared to try anything. In December before the Bill was about to be debated at the committee stage The Patients' Association joined with The Royal Colleges of Pathologists, Paediatrics &

Childhood Health, Psychiatrists, Physicians, The Academy of Medical Royal Colleges, The British Medical Association, and The Medical Protection Society to express concerns. Their letter stated '*Between our various organisations we represent patients, researchers, doctors and medico-legal experts. Whilst we wholeheartedly support greater medical innovation we fundamentally disagree that this Bill is a sensible way of achieving this aim. On the contrary we think that if enacted this Bill will actually harm good innovation by weakening patient protection, adding unnecessary bureaucracy and undermining good scientific practice*'. This was followed by a full explanation of their objections.

At the end of January as the Bill went to the report stage The Patients' Association gave a press release reiterating their concern about the impact on patient safety and medical innovation. The Bill has since started its journey through the House of Lords with its first reading on 1st February and its second reading on 26th February. To follow its progress go to <http://services.parliament.uk/bills/2015-16/accesstomedicaltreatmentsinnovation.html>

The ITP Support Association is now on Instagram!

We launched just in time for ITP Awareness Month in September, and we now have over 200 followers!

If you would like to join us on Instagram you can find us at @itpsupportassoc where you can see pictures of ideas, projects, people and the odd uplifting quote from the Association plus from people around the world. You can also tag us in your pictures, showing us your ITP related stories, days and fundraising activities.

We look forward to seeing you there.....

Hayley Keefe (Instagram Forum Manager.)

Webwatch



by Howard Anderson

Getting a good grip of medical matters can be difficult; it is hard enough for doctors, much harder for us patients. It is not helped that news media such as the Daily Mail or Mail Online routinely mis-report statistics to make the headlines. A typical report will say "X doubles the risk of getting Lurgy". (It does not matter what X is here, nor does it matter what illness Lurgy is, it is the idea that is important.) People see the headline and buy the paper to read all about it. Some are fooled and give up on X. Had the report been complete, the stats may have been something like this: Without X the risk of getting Lurgy is 1 in 100,000, with X the risk increases to 2 in 100,000. Yes, it has doubled, but that does not make for a good headline "X makes a tiny increase in the risk of getting Lurgy".

Such papers have been at the vanguard of mis-representing the news for a long time, that is why the Daily Mail is given rude names like the Daily Wail, but it is interesting to see their reports explained on an NHS website. On www.nhs.uk/news/Pages/NewsIndex.aspx headed *NHS Choices*, there are various reports of health matters, some of them sourced from the media. One report from the Daily Mail states "*Stop blaming SAD for your bad mood – it doesn't exist! Seasonal changes have 'NO effect on depression'.*" That looks quite clear and unambiguous but the NHS response takes a more measured approach to the evidence. It points out the source of the media report, its

limitations and likely conclusions. It takes the position of all good science, not attempting to proclaim the "truth", instead stating what is likely given the current evidence and how to come to a balanced conclusion, not a headline grabbing but misleading sound bite. In contrast, on the same website are reports from the BBC on the Zika virus. They state the facts as reported and do not seek to make attention grabbing headlines, despite the very grave nature of the news item.

The link *Miracle cure or scam?* gives timely advice not only on supposed miracle cures but also the risk of buying drugs on the internet. The Association always takes the view that the best evidence must be used to arrive at a conclusion, if we do not have that evidence then we are always glad to be told of new work, but we remain very sceptical of supposed miracle cures, anecdotal "evidence" and reassuringly expensive treatments, especially for a difficult condition like ITP. In the financial world, we are told "if it sounds too good to be true, it probably is", the same applies here. If a miracle cure is discovered that is supported by the evidence, we will be amongst the first to tell everyone, but life is sadly rarely that simple. Six years ago we were told that "ITP will be curable in three years". Really?

Happy surfing!

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