



American Perspective

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

Understanding medical disorders and choosing the right treatment (or, maybe, choosing no treatment) is difficult for patients. It may be impossible.

How can you cope with this?

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

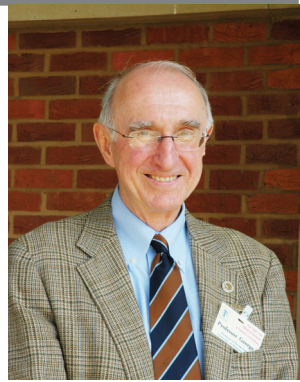
Patients, of course, can have serious problems affecting any body system. They can have anything. How can they learn about their illness and how to manage it? Patients can also go online, but they may be

overwhelmed by a tsunami of information, most of

it not relevant to their own questions, some of it misleading, some not true. Often the information is commercial, pushing whatever the company is selling. Often patients become confused, and they may become frightened.

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

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



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

How did the ITP Support Association begin? It began because 25 years ago Shirley Watson was frustrated. Her young son had severe ITP that had not responded to treatment. She talked with her doctors. But she had many more questions. Nothing seemed certain. She could have stopped there, but she recognized that her problem was a common problem because ITP is not a common disorder. Shirley is not only very intelligent and insightful, she is determined.

How she rounded up the best of England's ITP experts, I don't know. I do know that in 1996 she contacted me and asked for my help, for providing an American perspective for ITP. I remember that saying "No" didn't seem to be an option. I see adult patients; I asked George Buchanan, who sees children, to help. He couldn't say "No" either. And then we began the American Perspective in each issue of The Platelet, beginning in June 1997.

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

Research Funds Appeal

It is only through the generosity of your donations and fundraising events that we have been able to fund ITP research.

Please help replenish our ITP Research Fund for future projects!

You can donate by cheque (HQ address pg 2), on line at www.itpsupport.org.uk through facebook at www.facebook.com/ITPSuppAssoc or by texting ITPA22 and the amount (£1 – £5 or £10) to 70070.

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