



Welcome back to The World of PBC

Where we try to share as much as possible from what is going on around the world in PBC.

Robert J. Mitchell-Thain - CEO

Welcome back to the World of PBC: a most interesting place to be, for sure.

You will have read in the other pages of this Bear Facts, and seen from the front page, that the Summit was a huge success. So many people have shared with us their feedback, we had one person from industry who said, "In 29 years in the business, this was the best conference she had ever attended". Both clinicians and patient advocates wrote to us telling us it engaged both their hearts and minds, that it inspired both quality thoughts and immense feelings.

It truly was an incredible four days for the Foundation.

It made history in that there had never been such a collection of industry partners, clinicians, patients and patient advocates together. That, in itself, is enormously important but not that important. The absolutely key part of the Summit is the "So what?".

There are so many "So what?"s that have come from this Summit, all of which will have an enormous impact on PBC care, treatments, trials and the quality of life in PBC patients and their families.

First of all, the community is starting to work together to speak with one voice. It is no longer just clinicians saying one thing then industry saying something similar but kind of different then the patient voice saying something close to that but with a different emphasis again.

We agree on many points that need to be addressed.

And so we shall be working on a joint document which we are hoping to have published in an international academic journal highlighting, as a community, what we see are the issues, the data behind that and how we propose to provide solutions. That document will not only be co-authored throughout all three communities, but will also be

signed by the entire breadth and depth of those working in the PBC field.

One of the other main outcomes is that we will be publishing a white paper document, as the PBC Foundation, from both the Patient Services Team and the clinicians of the Medical Advisory Board, many of whom were in attendance at the Summit. We will be using this to highlight the unmet need of the PBC patient in 2023.

There are too many still unanswered questions when it comes to PBC care. Many patients are asymptomatic and are responding to first-line therapy which is great. There are patients who require a second-line therapy, also great, but only some of those patients are getting the treatment they need. That unmet need may be due to locale, systems or people, but we have to overcome all three obstacles.

There is also the question of Quality of Life, which is hugely important. If we are going to talk about normalisation, then it's not just about liver tests: it's about symptom burden and living as normal a life as possible. This is important and this drives the next big campaign: to look at the everyday burden of living with PBC.

Another important aspect of the Summit was to bring together the Patient Support and Advocacy groups. There were 18 patient organisations in attendance, and we have agreed to find ways to support each other, to work together and to work smarter. This will have implications for the Foundation as we work to internationalise the access to the website and App even more, and to address inequality of access issues around the world and this will take time, work, and finances: but we shall make this happen.

This also has implications for patients, albeit positive ones, as more services, more information and more support will be available to you, plus more campaigning and advocacy on your behalf will be carried out, year upon year. It will mean that more services will be available in more countries, and that even more patients than ever can access the information and support they need when they need it.

The work wasn't the Summit. The work started at the Summit and continues now. We need to use everything the Summit brought to us - knowledge, shared goals, partnerships, collaborations, determination - to serve the patient population as best as we can.

To achieve this, we still need to hear you: you need to tell us where the gaps are, be that in service type or in geography, or indeed anything that you need us to know.

We realised this month that the Foundation directly supports over 20,000 patients who are using our various services. That means we need to ensure we are making the most of our time to help as many of you as possible, as often as possible but in a way that best serves your needs. Now that we are back on the road again hosting face-to-face events, it will be important for us to take stock and to adapt our online services. Do keep an eye on the website as we announce these changes.

Do let us know what would be of benefit to you: more digital meetings; more face-to-face events; fundraisers; awareness events; clinical education; whatever you think we can do, let us know.

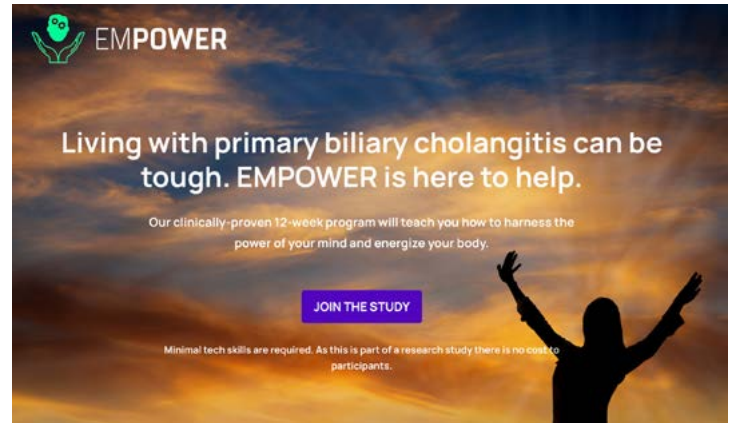
Or even come and be part of it! We are always looking for new people to join our team as a volunteer: to be a local contact and host meetings, to share your experience at various meetings where the patient experience can enhance the knowledge in the room and the journey of that particular project; to be involved in fundraising or to bring your particular skill set to our Board. All of these are just examples of the way your skills could take forward the cause of PBC patients around the world. Remember, we have a UK post code, but we are not just in the UK. We have members in over 80 countries now and we would love to work with you in your own country to help the bigger picture improve.

Could that be you?

On the subject of could that be you, we were at the Canadian PBC Society's conference early in June. Congratulations to Gail and the crew for an incredible event. I genuinely hope that anybody in Canada who uses our services is also registered with the Society because they do great work. One of the things they are doing, and this is open to anybody around the world, is a study to look at

the effects (read benefits!) of self-care upon quality of life. We have known for years, through our self-care modules, workshops, online seminars, etc., that it works, but this is purely anecdotal. The Society has put together a project where you can be involved, hopefully learn some self-care techniques in a supportive environment and that then will produce validated data to support that this all makes an impact. Another game-changing initiative that we'd love to support.

www.empower-program.com/pbc is where you need to go to learn more but we would also love for you to show the world what good self-care can do.



As you read this, we will be in the midst (or is that mist) of EASL's ILC: the International Liver Congress. Thousands and thousands of people working in liver all come together to learn to share, to do business, to inspire and be inspired and we will be there on your behalf. I think we are currently due to present 6 times over the piece on different topics, and very much hope to make an impact on not only PBC care, but on care of all liver diseases.

More and more work is being carried out now on quality of life as well as improved second-line care so we shall have lots to share with you in the next edition! (Not to mention PBC Day and the upcoming Patients' Conference.)



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<p>We are members of</p> 	<p>Corporate Partnerships: Sapphire level</p> 	<p>Corporate Partnerships: Bronze level</p> 	<p>Corporate Partnerships: Bronze level</p> 
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