Miranda Mihkelson

LBCA UK

I am proud to have been an advocate for UK Invasive Lobular Breast Cancer (ILC) patients at SABCS 2024. I owe a HUGE debt of gratitude to Lobular Breast Cancer Alliance Inc. for enabling me to attend this thoroughly inspiring symposium. Travelling to San Antonio from the UK would not have been financially possible for me without the generous travel grant I was kindly awarded.

It was hugely inspiring and humbling to witness the hard work of the huge number of dedicated researchers, clinicians and fellow patient advocates working to increase our understanding of this sneaky type of breast cancer…

As an active European ILC patient advocate, I already knew that ILC is the second most common subtype of BC yet is seriously understudied. ILC is particularly hard to detect, and complex to diagnose, both as a primary cancer and when it has spread (metastatic). By attending the SABCS symposium, I was able to develop a greater understanding of what is – and isn't - currently understood and consolidate my learning. Of particular interest to me were the differences between global healthcare systems and the differing expectations of US patients versus those in the UK, and their high degree of involvement in clinical decision making.

Once diagnosed, ILC patients may be relieved to learn that it's generally considered less aggressive than other breast cancers – as I was - BUT are often unaware than it tends to reappear later than other breast cancers (5-15yrs later) and once metastatic, can be very hard to diagnose in time for successful treatment due to vague and unspecific symptoms. It is sobering to hear these challenges reiterated by all the specialists present, and underlines how important it is for us to increase awareness, understanding, and funding for research into the unique characteristics of ILC.

Fortunately, thanks to the work of an army of dedicated patient advocates (it is amazing to see how well-established patient advocacy is in the US) shining a light on ILC, research and awareness is constantly expanding. From the use of AI to improve imaging analysis, to driving a risk-based approach to early screening, and gaining a better understanding of tumour genomics to design personalised treatment options, ILC specialists are striving to enable a brighter future for ILC patients.

I was particularly interested to learn about the research behind 'alternative' supplements (including cannabis) and a wonderfully honest discussion of the sexual health impacts of diagnosis and treatment in an engaging session imaginatively titled 'Sex, drugs and rock and roll'. I was delighted to learn that tart cherry extract has been clinically proven to reduce the symptoms of neuralgia and arthralgia and began taking this as soon as I returned home! I also learned that ginseng and soya

supplements can interact negatively with Aromatase Inhibitors – something that none of the ILC patients I have spoken to knew about.

It was eye-opening to meet advocates who had shunned traditional treatment pathways entirely and chosen to follow more radical approaches. In my experience, this is much less common in the UK as we tend to put a great deal more trust in our clinicians' judgement and are less likely to approach healthcare with a 'customer' mindset. It was also wonderful to discuss the physical and psychological side-effects of diagnosis with a range of inspirational women. That aspect of the event was truly inspiring and restorative, and more than made up for the exhaustion and jet lag I felt after returning home!

I will continue to advocate for continued research and better information for women at risk of ILC. I am scheduled to attend the Edinburgh Breast Cancer Special Symposium in Feb 2025 and will use this and future opportunities to share my personal experiences and those of the women I have met to keep banging the drum for ILC patients past, present and future.

Every day that I survive beyond my initial diagnosis feels like a gift. Thank you so much – though it doesn't seem enough – for this wonderful opportunity to meet, debate and thank the specialists whose work has contributed to my survival.