Introduction

The Invasive Lobular Carcinoma (ILC) symposium is an eagerly awaited event in the Lobular Breast Cancer community. 2024 was no exception with world class scientists, researchers and patient advocates descending upon the beautiful city of Leuven in Belgium. It provided an opportunity to learn and discuss how science is developing and what has and may be soon revealed in the understudied area of lobular breast cancer. Having come fresh from an enormous European Society for Medical Oncology (ESMO) conference in Barcelona, it was lovely to be a part of this more intimate symposium where much informal conversation and guided discussion is accessed and can be so enlightening.

a) Thoughts about what the recipient learned.

I learned so many things in this conference to both deepen my knowledge in some areas and discovering some new research and treatment directions. You never stop learning about cancer and you have to be prepared to change your mind about something you previously supposed to be true if new evidence comes to light. This is imperative for any member in a scientific community.

As I was involved in imaging sessions I learned quite a bit more about imaging than I knew previously. I had been aware that Magnetic Resonance Imaging (MRI) was suggested as a superior mode to find lobular disease but as I had always been very sensitive to a fluorodeoxyglucose positron emission tomography/computerised tomography (FDG PET/CT) scan in conjunction with tumour markers (which I am sensitive to) and whole body MRI is inaccessible to me and many others I suspect, I had felt discussions around this topic had always been rather ‘academic’. However, it was very interesting to listen and learn about new weighted MRI’s that I had was not familiar with.

I became aware of the surprisingly considerable discrepancy in histopathology findings. When listening to pathologists speaking about their jobs, I also felt a huge empathy for them. It was explained how much more information from our disease is expected from pathologists now and they seem to be generally combatting backlogs. They are hoping that Artificial Intelligence may begin to help address some of their challenges going forward.

Theranostics was a new area of biomedical research and precision medicine to me that personalises treatment based on the specific type of cancer and tumour cell membranes of each patient. Incredible! I had not thought of it or even been aware of the viability of injecting a radioactive intravenous drug that could travel through the bloodstream to the tumour where it can deliver a dose of radiation to the localised area. As many new areas of research in cancer treatments seem to not be an option for patients with invasive lobular breast cancer, I was very excited to learn that this developing area of treatment could revolutionise how patients with lobular breast cancer may be treated.

b) A summary of two of the sessions I attended

Breakout Sessions Part 1.2: Imaging primary and metastatic ILC September 24th 2pm.

Imaging proved to be quite a dynamic topic of discussion at the 2024 ILC Symposium with some animated debate and differences of opinion even from within the ILC community on best breast imaging/screening modality. Substantial numbers of ILC patients have disease missed or under-estimated on numerous occasions because quite frankly, the imaging technology used to assess whether they have disease or not currently is failing many of them. This is devastating for patients because they continue with their lives unaware that their disease progresses within them. The later you find disease whether it be primary, recurrent or metastatic progression, the worse the outcome for the patient. There are reasons of course for this and the gap that patients simply fall through. Dense breasts is one issue because lobular breast cancer has a diffuse web-like growth pattern, it can successfully hide in plain sight on scans and images.

During discussions where MRI was suggested as optimal screening tool, I reflected that much of this debate was 'academic'. Screening issues cannot be immediately addressed by distressed patients demanding MRI scans. Principles of equality would need to be manipulated for patients because certainly in the U.K. NHS guidelines do not currently support this and there is simply not the infrastructure in the U.K. for everybody who thinks they may need an MRI scan to access one, neither could the NHS in the U.K. sustain such demand. From what I understand, America faces similar challenges. This then thrusts patients into a cruel Orwellian reality of, "All animals are all equal, but some animals are more equal than others". Should we be subjecting breast cancer patients to this? There was certainly an urgency and unmet need to develop strategies of risk adaptive screening. It was not all bad news however as the overwhelming screening issues were mitigated by the potential use of targeted circulating tumour DNA tests which could be used to revolutionise monitoring of disease and was explored further in the second break out session.

Breakout Sessions Part 2. September 25th 11am. 2.1: Metastatic ILC

I was very glad to see a session devoted to metastatic breast cancer. With at least 30% of all breast cancer patients becoming metastatic, not to mention those with recurrent disease, it is imperative that metastatic disease be given serious consideration and designated time at conferences. Patients with mILC must also be well-represented in 'surveys' reporting on various Invasive Lobular Breast Cancer issues

This session was based around liquid biopsies, awareness and challenges regarding mILC in clinical trials and whether AI can solve misdiagnosis and late diagnosis of metastatic ILC.

Tumour informed and liquid biopsies can often be performed in the metastatic setting. It is very close to home for me as I have had extensive progressing bone metastases yet two liquid biopsies were performed with and they came back clear. If this has happened to me, my suspicions were that it will be happening to others. This made me realise that liquid biopsies are certainly not created equal so this session was very important for me to understand why this may be.
I learned that there are many types of biopsy. Some are less expensive both on time and money (shallow sequencing) but these do not provide enough depth for rare ctDNA. Other tests are expensive on both time and money (deep sequencing) and can therefore be prohibitively expensive on both counts. Targeted sequencing looking at specific coding regions may be an answer here and specific interventional studies are needed to build on existing knowledge of ILC in terms of genomics and clinical characteristics.

In metastatic Invasive Lobular Cancer (mILC), ctDNA can be present in all bio fluids and certainly could be utilised to identify resistance markers. It is very important that monitoring ILC improves as it harbours a different mutational profile and pathway alterations to Invasive Ductal Cancer (IDC) and at the moment patients with ILC can be classed as having non-measurable disease which translates into it potentially being difficult to assess response to therapy which limits trial enrolment. This was highlighted in a chart taken from the article, “Reporting on invasive lobular breast cancer in trials: a systematic review” (Van Baelen *et al.,* 2024). Signatera and Guardant Reveal could be considered to detect earlier recurrences. It was interesting to have confirmed that with mILC you experience ‘silent progression’ (widespread organ infiltration without radiographic findings) and a warning that leptomeningeal progression can be silent in the plasma translating to the fact that 2/3 patients with leptomeningeal metastases had a stable or absent ctDNA test.

The guidelines do not specify any different treatment or monitoring for Lobular breast cancer to a breast cancer of no specific type (NST). Cancers are still generally managed by their hormone receptor status and patients are left trying to educate their medical team (which does not always go down well) from information they find themselves on general and www.LBCA.org websites. The trials themselves must evolve their criteria to enable patients with both early and metastatic ILC to enter them and have their disease meaningfully represented and I believe that experienced patient advocates should be involved at the inception of trials because often by the time they are involved it can be too late for them to influence.

c) Experience working with other patient advocates

It is always good to meet other patient advocates, we can learn so much from each other. For me the patient advocates based in America have always been especially helpful because I am a patient expert for some National Institute for Health and Care Excellence (NICE) and Scottish Medicines Consortium (SMC) approvals in the U.K.

Generally I get much real world data from American advocates where sometimes they have experience living on drugs for at least a year or two before these drugs become available to Europe. I always feel they are at least one step ahead in their experiences. In America they are able to access drugs and innovative pairings of drugs and specific ctDNA tests sensitive to your profile of disease in that I can only dream of in the United Kingdom so I learn much from these American pioneers. I was very happy to meet an advocate from Switzerland too because I partly reside there and it was good to make a connection with someone who understands the specific issues we face in this country. I have learned having experience of living in France and Switzerland as well as talking to my European patient advocate counterparts, oncologists and researchers that most countries share similar issues and each one has particular idiosyncrasies that challenge patient, medical and scientific communities.

The Grasp poster walkthrough was excellent too and offered another chance to meet with other patients in different circumstances. It is always good to hear about others experiences and advocacy interests. I had someone who was new to advocacy and conferences in my GRASP group, she had the opportunity to make some meaningful interactions with scientists and I could see her confidence growing as we walked around. We were also very lucky that by chance Dr. Rita

Mukhtar was able to join us and shared excellent and comprehensive explanations for some of the scientific processes we were finding in the posters.

d) How they will use this experience and new knowledge in advancing ILC advocacy in future

Everything I experience as a patient informs my patient advocacy which has become a full time occupation. I feedback locally to patients, my hospital team, raise topics that I know concern patient communities. I am invited to speak about my advocacy at conferences and integrate my opinion that the scientific community in general both young and experienced should seek to attend the Invasive Lobular Cancer symposium where they will be able to explore and understand the specific issues of this understudied disease. We all need to be committed to advocacy as a team; oncologists, researchers, nurses, radiologists, pathologists and patients as we need 360 degree advocacy to make change happen. The ILC Symposium is so valuable as it offers a safe forum in which our communities can interact in different ways to exchange ideas and experiences.

From time to time, patients approach me fearing they cannot possibly advocate for lobular breast cancer because they do not know where to begin. I always say the first thing we can all do in meaningful advocacy is simply let people know that you have lobular breast cancer. Suggesting having a good look through the resources of the LBCA.org website and supportive resources such as, ‘Questions for your oncologist’ follows soon after. Although I advocate nationally and internationally, I am also committed to grass roots advocacy and go into local Charity centres to speak about the disease, some of its challenges, possible trials and how to get involved in advocacy.

This conference has enabled me to form new alliances with oncologists and researchers both in America and London and hope such collaboration between patients and the medical community will be key to inform and shape work from a patient perspective. I hope I can add value to any project I become involved with following on from this and look forward to helping LBCA working group in Europe as we try to gather evidence needed to inform future research. The conference successfully underlines the fact that scientific research is a continually evolving process as more discoveries are made and there is lots of cellular level adventure for lobular breast cancer awaiting.

In conclusion, I am very grateful and really thank LBCA for the opportunity their travel bursary award has given me. I am learning all the time and am passionate about allowing science to alleviate fear and misunderstanding and unleash pragmatic negotiation to facilitate patient access to kinder personalised breast cancer treatment pathways, hoping to reduce stress and improve both quality and length of lives for both early and metastatic lobular breast cancer patients and their families.