Reflections on the ILC Symposium
2024
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The ILC Symposium, held in Leuven Belgium, was attended by clinicians, researchers, and patient advocates. I attended the 3-day event as a patient advocate. There were just under 190 people in attendance. There are three main points I took away from the Symposium. Imaging for ILC is not very good and needs a lot of improvement. There are new opportunities for understanding an individual patient's ILC/disease using circulating tumor cell technology. There are many people passionate about ILC and working to move the needle both in treatment and awareness. I found the opportunity to network with other patient advocates to be very good on Monday. We traveled to the university hospital and the time together on the bus allowed for very informal conversations. On the way back from the hospital we discussed what we saw and how the treatment there differs from the U.S. I found the lunch period another good time to network. It was rather difficult though for me personally to manage lunch because I have mobility issues and a cane and there were no tables to sit at. Because of this I ended up sitting elsewhere initially during lunch and then working to join conversations after.

I attended a breakout session devoted to “Imaging primary and metastatic ILC.” Breakout sessions ran concurrently and attendees could self-select which they wanted to join. There were approximately thirty attendees in this breakout session. The overall message was that imaging needs to be improved to be able to diagnose and monitor lobular breast cancer. It was interesting to hear from multiple people on the panel that there is also a shortage of radiologists, causing delays for patients. Patient concerns were shared with researchers and clinicians and among the top concerns were access to imaging, exposure to radiation, contrast exposure and difficulty with IV placement.

The second session I’lll summarize was focused on Tumor Microenvironment, specifically in Metastatic ILC. Here there was a presentation about circulating tumor cells (liquid biopsies) and how that may be a future way to monitor metastatic progression. There needs to be more research and clinical trials into liquid biopsies in various biofluids (beyond blood). This is an area that really needs more focus. Also discussed in this session was to promote research on misdiagnosis and delayed diagnosis in ILC as well as addressing patient-identified concerns through targeted research. I found those two discussions very interesting, and somewhat frustrating. It is clear we have a long way to go when it comes to diagnosing and treating metastatic ILC.

I’ve already had the opportunity to share what I’ve learned. I attended a metastatic breast cancer event the week after the Symposium and shared with other patient advocates what I learned. In addition, I’m the moderator for two facebook groups (one focused on lobular bc) and I shared some information already and will share more in the coming weeks. I also posted on social media during the Symposium, reaching several hundred followers. My hope is not only to educate but to prompt others to become ILC advocates in the future.