

Enhancing Knowledge and Research in Europe for Invasive Lobular Breast Cancer: Unique Challenges across European Countries

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Introduction

- Invasive Lobular Cancer (ILC), first mentioned and documented as far back as 1941 by Foote and Stewart (1) is now classified by the World Health Organisation as the most common special type of breast cancer (2) 15% of all BC diagnoses are ILC
- 86,500 European Women were diagnosed with Lobular Breast Cancer in 2022 (3)
- It is a luminal breast cancer that mostly expresses estrogen receptor. Tumors rarely form a palpable lump. ILC cells generally grow in a distinctive linear pattern. Loss of cell-to-cell adhesion through E-cadherin inactivation enables ILC cells to infiltrate distant organs as single cells that have a tendency to remain dormant for extensive time periods (4)
- When endocrine interventions cease to be successful, it is notoriously difficult to treat ILC. *ILC can metastasize to unusual places: bone, peritoneum, ovary, digestive tract, skin, eyes, leptomeninges* (5)
- Up to 30% of ILC tumors are not identified on mammograms, ultrasound often fails to detect ILC (6) Detection of lobular breast cancer is often delayed (7) MRI is currently the most sensitive imaging tool for ILC

576,300

Breast Cancers diagnosed in Europe in 2022

15% (86,500)

were Lobular Breast Cancer



Who We Are



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Goals

- Our main goal is to work with the European, International ILC research and patient communities to better understand our unique histological and biological subtype of breast cancer, in order to:
 - Set common research priorities
 - Increase education and awareness of ILC with patients across Europe
 - Inform EU policy to recognise ILC as a distinct disease
 - Enhance education of ILC among primary healthcare practitioners
 - Ensure continued collaborative efforts with the leading ILC dedicated medical professionals and researchers

Challenges

Specific

- To operate as an organisation with a patient advocate representative in each European country
- Each European country has a different health care system, policy and economic structure
- Not all European countries are members of EU
- Ensuring there is appropriate support and finance for ELBCAdvocates to attend all major research and clinical conferences
- Organisational**
- There are no standardized diagnostic or standardized treatment protocols for ILC across Europe
- Europe has 24 official languages, even more in practice. It's an enormous challenge to streamline the translation of clinical, accurate information to patients in their national language(s) to educate, engage and empower patients and their families
- In order to apply for EU patient advocacy grants, ELBCAdvocates need both a legal entity and EU bank account. Achieving this has been hindered by current policy administrative processes

Lobular Breast Cancer is Different

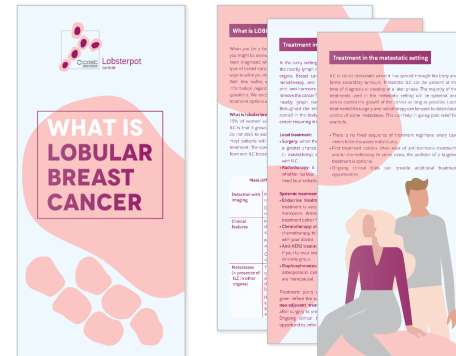


Achievements

- Established network of ILC Patients across Europe
- Attend International Conferences / Symposia
- Links with ILC researchers and scientists
- International ILC webinars
- On Steering Committees of EU Organisations and Charities
- Co authors on several ILC publications
- Collaborate on ILC grant applications
- ELBC Advocates joined the European Lobular Breast Cancer Consortium meeting in Leuven 2019 - the first time ever that ILC Patients attended a meeting of the consortium

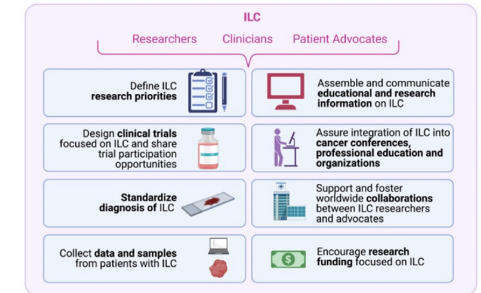


- Co designed the first European ILC Patient Education Leaflet with the ELBCC and coordinated translations into 19 European Languages



Next Steps

- Establish European Charitable Status for ELBCAdvocates
- Work to ensure that ILC is included in Clinical Trials
- Lobby to achieve >5 % funding for Invasive Lobular Cancer research and Clinical Trials, within 3 years
- A shared goal for The ELBCC and ELBCAdvocates is to find ILC dedicated EU funding



- Researchers, Clinicians and Patient Advocates must work together to accelerate research into ILC. Success is grounded in collaboration and ELBCAs are pivotal to change, patient centered research and deliverable ILC specific treatments (8)

“ Importantly, we are aiming at closely collaborating with breast cancer organisations to establish a strong EU-based ILC advocacy movement that will join us to achieve our common goal: an improved understanding, diagnosis and treatment of ILC ”

European Lobular Breast Cancer Consortium
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References/Acknowledgements

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