European Lobular Breast Cancer Advocates: Bridging the Geographical Gaps in Lobular Breast Cancer Education and Awareness

San Antonio Breast Cancer Symposium 2023

Introduction

- Invasive Lobular Cancer (ILC), first mentioned and documented as far back as 1941 by Foutz 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).
- Invasive Lobular Cancer (ILC) is now classified by the World Health Organization as the most common special type of breast cancer.
- 15% of all BC diagnoses are ILC.
- 86,500 European Women were diagnosed with Lobular Breast Cancer in 2022.

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.
- Ensure enhanced education of ILC among primary healthcare practitioners.
- Ensure continued collaborative efforts with the leading ILC dedicated medical professionals and researchers.

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. Organisations.
- 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.

Challenges

- To develop a Lobular Breast Cancer is Different educational leaflet.
- The leaflet is available in English and 19 European Languages.
- 15% (86,500) were Lobular Breast Cancer.

576,300 Breast Cancers diagnosed in Europe in 2022

Goals

- Established network of ILC Patients across Europe.
- Attending annual international conferences.
- Links with ILC researchers and scientists.
- International ILC webinars.
- On Steering Committees of EU Organisations.
- 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.

Achievements

- Co designed the first European ILC Patient Education Leaflet with the ELBCC and coordinated translations into 19 European Languages.
- "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."
- Researchers, Clinicians and Patient Advocates must work together to accelerate research into ILC. Success is grounded in collaboration and ELBCAdvocates are pivotal to change, patient centered research and deliverable ILC specific treatments (8).
- Work to ensure that ILC is included in Clinical Trials.
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References/Acknowledgements

(2) De Schepper, M., Vincent-Salomon, A., Christgen, M. and Charities
(3) Reed, A.E.M., Kutasovic, J.R., Lakhani, S.R. and Charities
(4) https://www.europadonna.org/breast-cancer/
(5) www.elbcc.org │elbcadvocates@gmail.com
(6) Reed, A.E.M., Kutasovic, J.R., Lakhani, S.R.
(7) De Schepper, M., Vincent-Salomon, A., Christgen, M.
(9) Mod Pathol
(10) Cancer Facts (3) De Schepper, M., Vincent-Salomon, A., Christgen, M.
(11) 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.
(12) Results of a worldwide survey on the currently used histopathological diagnostic and standardized treatment protocols for ILC across Europe.