

To Whom it May Concern,

We, the undersigned, declare October 15th as "Global Lobular Breast Cancer Awareness Day."

Invasive lobular carcinoma (ILC), also known as lobular breast cancer, comprises 15% of all breast cancer diagnoses<sup>1</sup>. Despite this incidence, there has been a lack of attention paid to the disease and a lack of funding for scientific research. October is breast cancer awareness month worldwide; declaring October 15th **Global Lobular Breast Cancer Awareness Day** – will help raise worldwide awareness of this breast cancer type.

The hallmark of lobular breast cancer is the lack of the protein E-cadherin, which helps cancer cells adhere to each other. Because E-cadherin is lost in ILC, tumor cells often grow diffusely without forming distinct masses. This makes them extremely hard to detect on mammograms, especially in women with dense breast tissue, or elsewhere in the body if metastasized. Lobular breast cancer is often only diagnosed once tumors are larger than 2cm, and sometimes already metastatic. Sadly, because many clinical trials for treatments require that participants have measurable disease, lobular breast cancer patients are often not eligible for clinical trials. In addition, there have been very few clinical trials focused on metastatic lobular breast cancer.

Many scientific studies have confirmed that lobular breast cancer is a distinct breast cancer type and that it behaves differently from the more common non-lobular breast cancers. But, for decades, in part because of the smaller numbers of patients at any one site and the insufficient standardization of the diagnosis for pathologists and radiologists, there has been a paucity of research. Therefore, though quite different, lobular breast cancer is treated the same as other non-lobular tumors.

As scientists who study lobular breast cancer, patients who live with it and clinicians who treat them, we believe that more must be done. It is CRITICAL that we raise awareness of the need for more research, share what ILC research is underway and ensure that those diagnosed with lobular breast cancer are aware of the information that does exist about their breast cancer type and of the many supportive communities of patient advocates that are there for them around the world. *Everyone* must be made aware that lobular breast cancer needs more attention.

By declaring October 15<sup>th</sup> as Global Lobular Breast Cancer Awareness Day, we aim to make sure that women everywhere undergoing mammograms or other tests to screen for breast cancer learn that breast cancer has different sub-types and about lobular breast cancer specifically. We aim to make sure that all who are newly diagnosed with ILC are aware that there is information available online about ILC, including current research and clinical trials. We want to be sure that they know that there are nonprofit organizations and advocacy groups around the world that are dedicated to education about lobular breast cancer, such as the Lobular Breast Cancer Alliance, Lobular Breast Cancer UK, Lobular Ireland, the European Lobular Breast Cancer Advocates, Lobular Breast Cancer Canada Patient Action Group, and Lobular Breast Cancer Advocates in Australia, and to be aware of the supportive communities both online and off, including several private Facebook groups specifically for those with lobular breast cancer. We also want them to be aware of the fundamental, translational, and clinical ILC research that is being done around the world and that in Europe, such multidisciplinary efforts are currently streamlined within the European Lobular Breast Cancer Consortium.

Please help us shine a spotlight on October 15th as Global Lobular Breast Cancer Awareness Day, raising awareness about the 15% of all breast cancers that lobular represents. Help us bring more attention -- and ultimately more research and improved treatments - to address the specific issues of this long-overlooked breast cancer type.

<sup>&</sup>lt;sup>1</sup> There are approximately 45,000 lobular breast cancer diagnoses each year in the US. Invasive ductal carcinoma (IDC), the more common breast cancer type represents over 80% of the roughly 241,000 breast cancer diagnoses in the US each year.

For more information about the events on October 15<sup>th</sup>, 2024, worldwide please reach out to the undersigned organizations that may represent your country.

# **Signatories and Affiliated Organizations**

## **Lobular Breast Cancer Alliance** (LBCA) Board of Directors

Executive Dir., Laurie Hutcheson (Massachusetts)

lauriehutcheson@lbca.org

Chair, Dr. Tracy Cushing (Colorado) Brenda Cunnington (Toronto) Dr. Kathryn Krantz (Pennsylvania) Judy McDevitt (North Carolina) Tanya Martin-Dick (Nebraska) Communications@lobularbreastc ancer.org

# **European Lobular Breast Cancer Consortium (ELBCC)**

Chair, Dr. Patrick WB Derksen (The Netherlands) Co-chairs, Dr. Christine Desmedt (Belgium) and Dr. Anne Vincent-Salomon (France)

Dr. George Sflomos (Switzerland)

# **European Lobular Breast Cancer Advocates**

Chair, Siobhan Freeney (Ireland) Co-chair, Silvia Knoll (Austria) Helene Bonval (France) Tone Lien (Norway) Rian Terveer-Couperus (The Netherlands) Andrea Lener (Isle of Man) Lejla Cengic (Germany)

#### **LBCA Scientific Advisory Board**

Chair, Dr. Jason Mouabbi (Texas) Dr. Patrick Derksen (The Netherlands) and Chair, European Lobular Breast Cancer Consortium (ELBCC) Dr. Rachel Jankowitz (Pennsylvania) Dr. Rinath Jeselsohn (Massachusetts)

Dr. Maxine S Jochelson (New York)

Dr. Megan Kruse (Ohio) Dr. Rita Mukhtar (California)

Dr. Fresia Pareja (New York)

Dr. Rebecca Riggins (Washington DC)

Dr. Mothaffar Rimawi (Texas)

Dr. Rebecca Shatsky (California)

Dr. Shani Paluch-Shimon (Israel)

Dr. George Sflomos (Switzerland) and ELBCC

Dr. Matthew Sikora (Colorado)

Dr. Peter Simpson (Australia)

Dr. Christos Sotiriou (Belgium)

Dr. Gary Ulaner (California)

#### **Lobular Breast Cancer UK**

Chair, Claire Turner (England & Wales) Emmo Amos (England) Anne Carey (England) Elaine Nangle (England) Hannah Phillips (England) Jane Sedcole (England)

#### **LBCA Patient Advocate Advisory Board**

Chair, Irene Jamieson (New York) Co-chair, Dr. Janice Axelrod (Pennsylvania) Co-chair, Ann Camden (North Carolina) Shay Chawla (California) Brenda Cunnington (Toronto) Karan Garrison (Missouri) Gitte Joergensen (Connecticut & Denmark) Julia Levine (California) Nancy MacGillivray (California) Diane Mapes (Washington) Judy McDevitt (North Carolina) Kathleen Moss (Oregon) Christine Mckay (Ontario) Flora Migyanka (Michigan) and

President, Dynami Foundation Barbara Neilsen (Ohio) Lori Petitti (California)

## **Lobular Breast Cancer Canada Patient Action Group**

Chair, Christine McKay lobularbreastcancercanada@yahoo.com

## **Australia Lobular Breast Cancer** Researchers

Dr. Peter Simpson Dr. Amy McCart Reed **Lobular Breast Cancer Australia** 

p.kinnon@gmail.com

Kristen Elsby Mary Lloyd

Pamela Kinnon

Prof Sara MacLennan (Scotland) info@lobularbreastcancer.org.uk











