

BIOGRAPHICAL SKETCH

Provide the following information for the Senior/key personnel and other significant contributors.
Follow this format for each person. **DO NOT EXCEED FIVE PAGES.**

NAME: Siobhán Freeney

eRA COMMONS USER NAME (credential, e.g., agency login):

POSITION TITLE: Patient Advocate

EDUCATION/TRAINING *(Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable. Add/delete rows as necessary.)*

INSTITUTION AND LOCATION	DEGREE (if applicable)	Completion Date MM/YYYY	FIELD OF STUDY

A. Personal Statement

I am an active Patient Advocate for Lobular Breast Cancer Research and Lobular Specific Clinical Trials.

I was Diagnosed with Stage 3c Lobular Breast Cancer in December 2015.

I had never heard of Lobular Breast Cancer until then even though I had close friends who had been previously diagnosed with Breast Cancer. My Diagnosis came just 5 months after a 'Clear Mammogram' and I had a history of clear Mammograms going back consecutive years and Screenings.

I found it incredibly difficult to find information specific to Lobular Breast Cancer and this frustrated my natural curiosity and my need to know more about my particular subtype of Breast Cancer.

I was determined to become more involved in education and awareness of Lobular Breast Cancer and Research Advocacy.

I co-founded Lobular Ireland www.lobularireland.com with Breast Cancer Researchers from The Royal College of Surgeons, Dublin and I continued to establish excellent contacts with other Irish and International Patient Advocates and Lobular Researchers, I had wonderful support from The Lobular Breast Cancer Alliance in the U.S. also.

I was invited to attend the 3rd European Lobular Breast Cancer Symposium in KU Leuven in 2019 and I have remained actively involved as a Lobular Breast Cancer Patient Advocate and ILC Research Advocate since. Lobular Ireland meet regularly with ELBCC.ORG and LBCA.ORG

I feel very honoured to represent the Lobular Breast Cancer Community and I'm committed to facilitating progress in evidence based research and clinical trials for ILC Patients.

B. Positions, Scientific Appointments, and Honors

Employment and Current Positions

2000 - 2019

I worked for almost 20 years in the Education Sector - supporting children and young adults with special educational and behavioural needs. I took 10 months out for Chemotherapy, Radiotherapy treatment and Surgery following my ILC Diagnosis 2015. I returned to work and although I very much wanted to continue, I was forced to take early retirement due to prolonged effects of treatment, lymphedema and chronic fatigue.

2015 – Present www.beingdense.com Education and Awareness of Breast Density

2018 – Present www.Lobularireland.com ILC Patient and Research Advocacy

Other Positions

2018 I Co Hosted the 1st Irish Public Mammographic Breast Density Seminar in The Royal College of Surgeons, with Professor William Gallagher www.BreastPredict.com

2018 I was invited to join Advocates in Science, AIS - Susan G Komen

2019 I joined The European Lobular Breast Cancer Consortium as a Patient Advocate

2019 Graduated as a Patient Advocate with www.ipposi.ie - Irish Platform for Patient Organisations in Science and Industry

2020 – 2021 Irish Cancer Society Patient Review Panel – Grant Applications and Research

2020 – Current Patient Panellist with The HPRA – Health Products Regulatory Authority 200

2021 – Current Patient Advocate Steering Group Member – Irish Health Research Forum – Health Research Charities Ireland www.hrci.ie

2021 – Current PPI Focus Group Can-REACT programme National University of Ireland

Affiliations and Further Engagement planned

As of September 2021 I plan on taking an active role as a Patient educator with the following discussions and agreements in place;

- University College Dublin – UCD Medicine – Radiography programmes – Curriculum Review and Enhancement Partner
- Royal College of Surgeons – Medical Students - Cancer Module – 2 one hourly presentations to students
- Royal College of Surgeons – School of Pharmacy and bio molecular Sciences (PPI Co Author)
- Royal College of Surgeons – Molecular Oncology Research Group PPI Engagement
- IPPOSI – Patient Advocacy Engagement Opportunities - ongoing
- University College Cork – PPI Enhancement Partner (Grant Application Pending)

C. Contributions to Science/Patient and Research Advocacy

PPI Panellist with University College Dublin – Conway Institute and www.BreastPredict.ie Breast Cancer Research Programme 2018 – 2019

Designed Breast Density Patient Information Leaflet, collaborated on scientific references with Australian Scientist/Researcher and Breast Biologist [being dense flyer kev 3\(2\) \(1\).pdf](#)

I created a Down loadable PDF facilitating and educating women to request personal category of Breast Density as determined on breast screening mammogram

<https://documentcloud.adobe.com/link/review?uri=urn:aaid:scds:US:2435d644-088e-447f-bbd5-8c694bd6f4c82021>

Founder of Lobular Ireland www.lobularireland.com

Founder of www.beingdense.com

Grant Application PPI Reviewer Europe

Patient Advocate contributor/collaborator (soon to be published) Patient Information Booklet 'What is Lobular Breast Cancer' www.elbcc.org

Collaborator/Advocate/Moderator and Speaker International Lobular Breast Cancer Symposium 2021 hosted by www.LBCA.org June <https://documentcloud.adobe.com/link/review?uri=urn:aaid:scds:US:2435d644-088e-447f-bbd5-8c694bd6f4c82021>

<https://lobularbreastcancer.org/event/international-invasive-lobular-breast-cancer-ilc-virtual-symposium-2021/>

I am a Co Author on recently published work June 2021

'How Researchers, Clinicians and Patient Advocates Can Accelerate Lobular Breast Cancer Research' Leigh Pate 1,* , Christine Desmedt 2 , Otto Metzger 3 , Laurie Burgess Hutcheson 4 , Claire Turner 5 , Siobhán Freeney 6 and Steffi Oesterreich 7,8,9,*

<https://www.mdpi.com/2072-6694/13/13/3094/pdf>

Siobhán Freeney
June 2021