

# University of Wisconsin Carbone Cancer Center (UWCCC) Breast Cancer Research Advisory Group (BCRAN): Synergy and Collaboration Between Physicians and Patient-Advocates Prove Mutually Beneficial

Deb Tobin, Patient Advocate



## **Network Formation**

The BCRAN is the first research advisory network et the UWCCC and was created in 2015 by Jim Shull, PhD, Professor of Oncology with the McArdle Laboratory for Cancer Research and Associate Director of Laboratory Research at UWCCC; Mark Burkard, MD, PhD, Associate Professor of Medicine; and Lee Wilke, MD, FACS Professor of Surgery at the UW School of Medicine and Public Health. Breast Cancer Research Advisory Network members include breast cancer researchers and patient advocates. Most advocate members are breast cancer survivors. Constituencies include the following both at UW and beyond but primarily the Midwest: researchers focused on breast cancer; patients; survivors; advocates; end family and friends of petient-survivors. The BCRAN provides a forum for collaboration between researchers and advocates on topics of mutual interest.

# Leadership & Membership

#### Current Leadership:

- Amy Fowler, MD, PhD, Assistant Professor of Radiology at the UW School of Medicine and Public Health
- Lisa Arendt, DVM, PhD, Assistant Professor of Comparative Biosciences at the UW School of Veterinary Medicine

#### **Current Membership:**

- Approximately 40 patient advocates\*
- Representative(s) from Wisconsin Breast Cancer Coalition (WBCC)
- Physicians and researchers
- UW School of Medicine & Public Health
- UW Cerbone Cancer Center
- McArdle Laboratory for Cancer Research
- · UW School of Veterinary Medicine
- · UW School of Engineering
- \* There are currently about 12-15 active patient advocates. Membership is also open to patient advocate spouses, partners, and/or caregivers.



### **Initiatives and Successes**

- Incorporating the patient's perspective in developing research studies and grant proposals
- Bi-monthly meetings providing advocates with educational resources to further develop their scientific knowledge and advocacy skills (see topics, next section)
- Providing advocates with opportunities to receive more formal advocacy training at national meetings and conferences—San Antonio Breast Cancer Symposium (SABCS), ASCO, AACR via annual scholarships for two to three advocates for travel and expenses
- The formation of advocate-physician/research scientist teams focusing on specific topics of interest
- Universal and broad consent working group
- Fundraising on behalf of breast cancer research at UW Carbone Cancer Center and McArdle Laboratory for Cancer Research (see right)

## **Advocate Scientific Education**

- Environment end Breast Cancer Risk and Introduction to the Survey of the Health of Wisconsin
- Moving More, Sitting Less: Using Technology to Understand and Improve Patterns of Physical Activity in Breast Cancer Survivors
- · The Wisconsin Molecular Tumor Board
- · Obesity and Breast Cancer
- Optical Imaging of Breast Cancer Organoids for Personalized Treatment Decisions
- Genetic Counseling and Testing in Breast Cancer
- Breast Cancer and the Role of Radiation Therapy
- · Breast Cancer & Metastasis: What is the Role of Obesity?
- Overview of Current Breast Cancer Clinical Trials Open at UWCCC
- Estrogen, Progesterone, Prolactin: Hormones on the Dark Side in Breast Cancer
- · Epithelial Stromal Interactions and DCIS

## **Fundraising**

BCRAN supports the efforts of several individual patient advocate members who have launched highly successful events raising more then \$200,000 to date. Funds go directly to UWCCC and McArdle breast cancer research labs.

- · One Woman, Many Lakes
- · Be the Cure
- Effcansah



· Verona Area High School Night of Hope



# **Looking Toward the Future...**

#### BCRAN hopes to

- increase awareness of the network → grow our membership;
- · assist others who may wish to establish a similar network;
- provide more assistance to UWCCC staff with documentation encouraging participation in clinical trials and tissue donation when appropriate and relevant;
- reach out to share ideas with similar networks within the B1G Cancer Research Consortium; and
- consider whether and to what extent to expand our focus, including legislative outreach.

### **Contact Information**

https://cancer.wisc.edu/research/otrs/networks/beren/

Email: tobin.deborah@gmail.com

Twitter: @kilto2257