So you Want to be an advocate?
How advocacy groups and individuals can promote & educate others about cancer research

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Founder Montreal BRCA Support group
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Public Speaker

Types of Advocacy

Education, Outreach and Support
Public Policy / Legislative & Regulatory
Research Advocacy

ALL are critical to the HBOC community!

What is a patient advocate?

Patient advocacy is an area of lay specialization in health care concerned with advocacy or patients, survivors, and care givers. The patient advocate may be an individual or an organization, often, though not always, concerned with one specific group of disorders. The terms patient advocate and patient advocacy can refer both to individual advocates providing services that organizations also provide, and to organizations whose functions extend to individual patients. Some patient advocates work for the institutions that are directly responsible for the patient's care.

Typical advocacy activities are the following: patient rights, matters of privacy, confidentiality or informed consent, patient representation, awareness building, support and education of patients, survivors and their care givers. Patient advocates give a voice to patients, survivors and their care givers.

~ Wikipedia
It's important to empower, inform and educate the people you speak with, not frighten them.

Qualities to be a successful advocate

Passion
Honesty
Good communication skills
Empathy
Sensitivity and understanding
Objectivity
A drive for knowledge

Being a patient advocate requires empathy not a specific solution.

It's really important to be approachable. I am often asked all types of questions and being able to answer honestly and truthfully allows others to feel comfortable.
Who to reach out to when making connections

- Doctors
- Hospitals
- Genetic Counsellors
- Genetic testing companies
- Patient advocates
- Support groups and other Cancer organizations
- Local Media

I personally find humor helps, especially when dealing with such serious issues.

Patient advocacy goals

- Provide support and information
- Raise public awareness
- Education in regards to genetic testing and counselling and its importance
- Patient empowerment
Social media helps create a larger reach

Why is patient advocacy so important?
- Gives us control over our choices
- Helps gain self confidence facing challenges
- Allows you to reach out to others
- Improves quality of life
- Creates control over our decisions

You are not always going to understand what others are going through but allowing them to be honest and forthcoming instills a sense of trust.

As an advocate, our role is not to agree with their decisions but to be there to offer support for their choices. You should never judge anyone.
Advocacy is not about telling people what to do, it's not about finding answers for them. It is being able to provide all of the options and information available to them so that they are able to make informed and educated decisions for themselves based on what is best for them.

“I told the doctor I broke my leg in two places. He told me to stop going to those places.”

There is no right way to handle things, only what is right for you.

- Karen Malkin Lazarovitz

“Be the change that you wish to see in the world”

- Ghandi
In the past, the only role for patients and non-scientists was as a participant in research studies. Increasingly, researchers are recognizing the value of including input from the general population and patient communities being researched to weigh in on the shape and direction of research.

A web-based course for patients (consumers) and other stakeholders with limited knowledge about hereditary cancers who do not have advanced medical or research training. Helps laypeople understand the research process so they can represent the hereditary breast and ovarian cancer (HBOC) community to scientists and in clinical and patient-centered outcomes research.
FORCE Research Advocate Training Program (FRAT)

- By training advocates to participate in the research process, the FRAT program helps assure that research studies are:
  - relevant,
  - ethical, and
  - responsive to our community’s needs

Why is the FRAT Program Needed?

- People affected by hereditary cancer are significant stakeholders in cancer research and carry a disproportionate cancer burden
- No other training program focuses on the HBOC community
- Consumer input in cancer research is needed to guide direction, relevance, recruitment, and protections
- FORCE and the University of South Florida are partners in the ABOUT Network, which provides many opportunities for consumer stakeholder involvement

Why Participate the Research Process?

- We still have much to learn about HBOC and how to best manage cancer risk
- Patients and their families deserve a voice in ensuring that research being funded answers our questions and considers our unique needs
FRAT Program Goals

- Prepare stakeholders from the HBOC community to understand the basics of cancer and research
  - Provide researchers with meaningful insights into:
    - research priorities
    - messaging
    - study design
    - human subject protections, and
    - accrual

FRAT Program Goals

- Keep research priorities of importance to the hereditary breast and ovarian cancer community front-of-mind for researchers
- Help define and refine patient-centered research questions that will help people make informed decisions about their health care

Why Participate in FRAT?

- To be an effective voice for the hereditary cancer community, advocates need a basic understanding of:
  - the science behind cancer
  - how clinical research works
  - “behind the scenes” processes that drive medical research
FRAT Curriculum

Expert-led webinars covering:
- Cancer basics
- Breast and ovarian cancer
- Genetics and cancer risk
- Panel testing/Other genetic mutations associated with HBOC
- Statistics
- Intro to clinical trials and research
- Patient protection and ethics
- ABOUT Network and patient-centered outcomes research

Utility of Training

Research advocates participate in a variety of activities including, but not limited to:
- Grant review panels
- National Cancer Institute (NCI) working groups
- Institutional Review Boards (IRBs)
- Data and Safety Monitoring Boards (DSMBs)
- ABOUT Network committees
- PCORI grant review and advisory panels
- Patient advisory boards (hospitals, professional societies, etc.)

Facilitation of roles for FRAT graduates

FORCE will:
- Help you gain an understanding of how you can be effective in providing input to guide the research process
- Provide resources to aide you in preparing for and securing advocate positions
- Biosketch
- Letter of cooperation
- Ongoing opportunities
Facilitation of roles for FRAT graduates

FORCE will:

- Work with the medical/research community to identify opportunities and match qualified individuals
- Offer engagement in the ABOUT Network steering committee and working groups
- Assist in applying for research advocacy positions, additional training, conference scholarships, etc.

You are an important part of the HBOC community.
You can make a difference!
So you want to be an advocate?

**Disclosures**

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**What Type of Advocate are You?**

- Political
- Support
- Fundraising
- Research
Who are Cancer Patient Advocates in Research?

- People who have had cancer, been a care-giver of someone with cancer or affected by someone who had cancer.
- People who were motivated to reach out to others also suffering from cancer.
- People who are motivated to make a broader impact by self-educating in understanding the science behind cancer and its treatment.
- People interested in research become trained in scientific methodology, research design, basic statistics, etc…

“…more seasoned advocates can bring a more sophisticated understanding to the research enterprise…constantly grounded…in patient experience.”

Mayer, 2012

Patients bring urgency…

“Not only does my face and my story inject reality into the cancer research enterprise, it seems to add some sense of urgency…We need to get the job done now without quibbling and without egos.”

~ Kate

We still lose too many wonderful people to cancer – no early

We are in desperate need of better treatments...NOW

Advocacy in Research

- Basic Research
  - Bench research in laboratories
- Translational Research
  - Pre-clinical research in animal models
- Clinical Research
  - Clinical trials in patients
- Epidemiology Research
  - Studies of associations in populations
- Approval
  - FDA panels
How do you become an advocate?

I’ll tell you my story:
Becoming a RESEARCH ADVOCATE...

Tips

- Start LOCAL (if you can)
- Cancer Organizations (e.g. FORCE) always need volunteers
- Only participate if you know you can do it!
- When asked to participate – do the work, do it on time and contribute.
- Meet as many people as you can – those who can be mentors!
- Stay up to date
- Take advantage of training opportunities
# Research Advocacy Programs

- FORCE Research Advocate Training (FRAT) Program
- Research Advocacy Network Focus on Research Scholar Program
- Komen Advocates in Science (AIS) Program
- National Breast Cancer Coalition (NBCC)
- YSC Respected Influencers through Science and Education (RISE) program

Programs for research advocates providing trainings, resources and a community of advocates learning together.

# Trainings for Advocates

- Human Subject Protection Training Certification
- US Cochrane Center: Understanding Evidenced-Based Healthcare
- Cancer Information and Support Network (CISN)
- 2015 online Webinars developed for National Clinical Trials Network Advocates by CISN
- Research Advocacy Network/Advocate Institute
- Glossaries (FDA, NCI, CISN, many)

# Trainings at National Meetings

- Alamo Breast Cancer Foundation at San Antonio Breast Cancer Symposium (SABCS)
- Scientist <-> Survivor Program at American Association for Cancer Research (AACR) Annual Meeting
- Focus on Research Scholars Program at American Society for Clinical Oncology (ASCO) Annual Meeting
- Accelerating Anti-cancer Agent Development and Validation (AAADV)
- Scholarships for Patient Advocates
Opening Session – learn about the S->S program, AACR meeting and the science of cancer in a simplified but detailed presentation.

Working Groups – small groups are given a topic to learn more about and present their findings to the entire class at the end of the meeting.

Mentors – each group has a scientific and advocate mentor to help you navigate the meeting and guide your presentation.

Special Interest Sessions – key scientific leaders present current topics to the advocates in special sessions.

Other Initiatives Involving Advocates in Clinical Research

- Clinical Trials Transformation Initiative (CTTI)
- Multi-Regional Clinical Trials Center
- The Center for Information & Study on Clinical Research Participation (CSCRIP)
- FDA Patient Programs
  - Patient Representative Program
  - Patient Focused Drug Development Program
  - Patient Engagement Advisory Committee

Research Advocacy Publications

- Patient Advocacy in Research, Musa Mayer, 2011. 4(2) 69-71.
What is important to me?

~find your passion~

❖ Patient Reported Outcomes (PROs)
❖ Data Sharing
   ❖ Change.org (http://tinyurl.com/sharethedata)
❖ Patient-Centered Clinical Trials
❖ Real World Trials

You are an important part of the HBOC community. You can make a difference!