So you Want to be an advocate?

How advocacy groups and individuals can promote & educate others about cancer research

Karen Malkin Lazarovitz
Founder BRCA Sisterhood
Founder Montreal BRCA Support group
Local Leader Pink Day Montreal
Public Speaker

Types of Advocacy

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

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.
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

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

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.

There is no right way to handle things, only what is right for you.
- Karen Malkin Lazarovitz

So you want to be an advocate?

Patty Spears
October 7, 2016
Orlando, FL
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 caregiver 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...continually grounded...in patient experience

Mayer, 2012
Patients bring urgency…

Quote from a Patient Advocate

"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 in Mayer, 2011

We still lose too many wonderful people to cancer – too 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
- Epidemiology
- Studies of 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
- Fight Colorectal Cancer Research Advocacy Training and Support (RATS) program
FORCE Research Advocate Training Program (FRAT)

A web-based course for patients (consumers) and other stakeholders

- Limited knowledge about hereditary cancers
- Do not have advanced medical or research training
- Helps lay people 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.

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 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

✔ Keep research priorities of importance to the hereditary breast and ovarian cancer community front-of-mind for researchers

✔ Help define and refine patient-centered questions that people make 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
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)

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)

Scientist <-> Survivor Program

- Learn what's new in cancer research
- Meet others
- Meet and talk to influential scientists
- Learn what you need to know
- Network with others
- Advocates in special sessions

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 on key topics relevant to the meeting.

- Scholarships for Patient Advocates
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

Research Advocacy Publications


What is important to me?

- 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!

So you want to be an advocate?

Cheryl Jernigan
Patient Advocate in Research

It's a journey...not a destination!
A patient perspective is created when a person goes through personal or professional experience with the breast cancer.

A collective patient perspective is created when the person has knowledge of others' disease experiences and conveys this collective patient perspective, rather than just their singular experience.

In research advocacy, a “collective” patient perspective is essential!

What is it like to be a research advocate?

A personal perspective

- Educating/Networking
- Raising funds and friends for research
- Participating in peer-review
- Influencing public policy
- Participating in research policy development
- Participating in research design

Once you make a decision, the universe conspires to make it happen.

~ Ralph Waldo Emerson
Insights gained…
- Seek out opportunities!
- Nurture your passion for learning!
- Step out of your comfort zone… early & often!
- Build bridges…
- Seek FIRST to understand
- Ask questions.
- Strive to be impeccable/dependable in word & deed.
- Do your homework AND establish PCOR goals for each meeting, project, and relationship

Is this a journey for YOU?!
... What's your passion???
- What is/are my personal mission & goals?
- How much time do I have?
- Do I enjoy continually learning/educating?
- What constituency connections do I have?
- How do I get started on this journey?

What is my passion?
- Bringing research back to its reason for being: improving health, function & survival
- Engaging Patient Voices… Patient-Energized Research
- The Call to ARMS
- PIVOT: Patient Investigator Voices Organizing Together
- Sharing Knowledge… Research Results
- PCORnet/Greater Plains Collaborative (GPC)
- Cancer Collaborative Research
- Creating Patient-Centered Care
- Financial Toxicity
- CTI: Informed Consent
- Medical Heroes... Clinical
Advocates, Researchers & Mentors
an initiative of Susan G. Komen

Purpose:
• Build & cultivate productive & lasting Advocate Researcher relationships
• Assess what worked well & what could be improved to achieve effective, mutually rewarding long-term relationships

Building & Cultivating meaningful relationships...

Key beliefs & principles:

1. **Mutual respect** of time, qualifications, perspective... allowing sufficient time to mutually understand, modify, integrate perspectives, and effectively communicate with.

2. **Mutual benefit** by working together & co.

3. **Common goals** in the relationship

Some common sense guidance:

Building Advocate Researcher Relationships

Resources/Tools

1. Building Advocate Researcher Relationships to Strengthen Research
2. Testimonials/Stories demonstrating successful Advocate Researcher Relationships (Awaitie on report)
3. Suggestions for Patient Advocate Involvement Plan
4. Patient Advocate Letter of Support
5. Webinars:
   - Advocates & Researchers Working Together
     - https://youtu.be/1YWqTggKs-o
   - The Call to ARMs
     - https://youtu.be/wUEi-RN2kwc
6. Guidelines for Advocate Involvement
7. Writing a Lay Abstract

These documents were included in the handouts for this session.
What is PIVOT?
- An initiative to infuse greater community and patient engagement into all aspects of the Cancer Center
- An evolving community of patients, families and caregivers learning and working with researchers/investigators

Why do we need PIVOT?
- Patients, caregivers and communities need to inform, collaborate, support and shape cancer research to better serve patients

How will PIVOT work?
- Patients, families and caregivers will bring their lived experiences and a collective patient perspective to all stages of the research process

Vision
Patients, families, caregivers and researchers accelerating innovative approaches to re-define cancer research together!

Patient-centered research

Impact of Financial Toxicities

- 69% of Americans have less than $1000 in savings
- Cancer survivors 2.7 times more likely to file for bankruptcy than individuals without a cancer history
- 2007 study showed:
  - 82.7% of all bankruptcies have a medical basis
  - Most medical debtors were well educated & middle class
  - 75% had health insurance
  - 2001-2007...Bankruptcies attributable to medical problems rose by 50%
Financial Toxicities & our aging population

- About 50% of those diagnosed with cancer are 65 & older.
- Average medical expenses: 2nd largest expense in retirement.
- 4 out of 5 people cannot accurately estimate how much they expect to pay for healthcare in retirement.
- The average 65-year-old couple will spend $295,000-$392,000 over a 20-year retirement.
- Medicare covers only about 1/2 of total health care costs.
- Drug costs...no out-of-pocket limits...FOREVER coinsurance & the gapping Part D "Donut Hole".
- Note: This is only U.S. data.
- About 50% of those diagnosed with cancer are 65 & over.
- Highest breast cancer incidence rates are in women >70.
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Patient-centered research

Articles, Studies, Links
- More info:
  - NCI: Financial Toxicity & Cancer Treatment Costs.
  - Tyler W. Warren, Finacial Toxicity Facts (University of Chicago).
- "Financially toxic patients" - a new patient-centered term.
- "How to Talk to Your Doctor About Financial Toxicity," in Cancer Network.
- "It's Not Just Nausea and Vomiting: Cancer Docs Now Worry About 'Financial Toxicity.'"

Searching Knowledge & Research Results & Data

PCORnet
National Patient-Centered Clinical Research Network
http://pcor.net/
Desire to make things better for patients
Communication and critical thinking skills
Ability to represent "all" patients... not just your story
Willingness to learn the basics of science, treatment strategies, & the research process
Ability to work collaboratively with others
Ability to honestly self-evaluate to improve your effectiveness

"Your success, as an advocate, is only as strong & enduring as the relationships you build & cultivate."