The importance of patient advocates in research: A scientist’s perspective on value and implementation

Alana Welm, PhD
Professor
Department of Oncological Sciences
Remember: We do health sciences research for the benefit of current and future patients, and to prevent disease.

Understand the disease you are investigating

- Even “basic scientists” should understand the clinical questions that are most important.
- Resources: clinicians and patient advocates.
- Educated patient advocates provide a voice of experience that goes beyond their own unique situation.
- Ensures that scientific and medical advances are patient-centered and relevant.
- Advocates ask the “hard” questions that scientists sometimes forget to address, e.g. “if this all works, what will it mean for patients?”
- Result: better projects, better grant applications, better outcomes.
The role of advocates is more common in clinical trials research but the same principles can, and should, be applied to discovery research.

Advocates can support the entire research life cycle:

- Define
- Review
- Design
- Implement
- Share
- Community Engagement
- Letters of support
- Inclusion/exclusion criteria
- Recruitment
A practical example of how we got this started

1. Advocate co-leader to launch the initiative with me
   • Dr. Carla Lloyd, retired professor of communications and breast cancer survivor
2. Exploratory research
   • Within HCI
   • Outside HCI (Georgetown)
3. Develop committee (with advocacy training and monthly meetings)
4. Trial run
   • DOD grant: presentation to PA committee, questions, letter of support. Funded!!
5. Continued collaboration
   • Other DOD grants, Komen grant
   • Very high funding rate
6. Educational activities
   • Research on clinical trials participation
   • Progress on funded grants
7. Postdoc scientific liaison
8. Expanding membership
Additional Resources

American Association for Cancer Research
SURVIVORS & ADVOCATES PROGRAM, AMERICAN ASSOCIATION FOR CANCER RESEARCH
A website full of resources for advocates working with cancer researchers, from one of the premier cancer research advocacy programs in the U.S.
https://www.aacr.org/AdvocacyPolicy/SurvivorPatientAdvocacy/Pages/educational-series-on-science-and-advocacy___403104.aspx?W1Id=521&q=1

American Society of Clinical Oncology
AMERICAN SOCIETY FOR CLINICAL ONCOLOGY
ASCO not only hosts the largest annual cancer meeting in the world, it also is a central hub for oncology research education and training, including ASCO University, a comprehensive e-learning center that supports lifelong learning for oncologists and all ASCO members including patient advocates at a discounted rate.
For ASCO: https://www.asco.org/
For ASCO University: https://university.asco.org/

Department of Defense Congressionally Directed Medical Research Program's Consumer Involvement Program
Consumers in this case meaning patients, survivors, caregivers, and those at particular risk for a disease. The program integrates consumers into the peer review process for awarding research grants.
http://cdmrp.army.mil/cip/

NATIONAL CANCER INSTITUTE
NCT'S OFFICE OF ADVOCACY RELATIONS
This is the National Cancer Institute's advocacy program.
http://advocacy.cancer.gov

PATIENT ADVOCATES IN RESEARCH (PAIR) EMAIL LIST
Moderated by Deb Colyar, this is the primary discussion and distribution forum for patient advocates in cancer research, including cooperative group advocates.
Contact Deb at deborah@tumorline.com to be added to the list.

Research Advocacy Network
RESEARCH ADVOCACY NETWORK
The mother lode. Membership gives you access to their Advocate Institute online educational materials for research advocates.
http://www.researchadvocacy.org/

National Breast Cancer Coalition
http://www.stopbreastcancer.org/get-involved/training/