Training and Support for Patients and Consumers Engaged in Research

Presented By: Amy Bonoff
• Training and continued learning opportunities are a key element for success

• Methods to support patient and consumer involvement are evolving
  – NBCC Project LEAD
  – FDA Patient Representative Program
  – Congressionally Directed Medical Research Program Consumer Representative Program
  – Consumers United for Evidence-Based Healthcare
Principles for Training Programs

• Set appropriate goals
• Target training for the specific project and roles
  – The FDA provides training on regulatory processes as it is specific to the activity
  – Cochrane Consumer Network provides training manuals for preparing plain language summaries
• Take into account level of knowledge & experience
• Understand motivations of learners
• Provide on-going and mixed training methods
  – Lectures, small group breakouts, problem solving, & case discussions
Principles for Training Programs

• Employ established principles of adult learning
  – (e.g., repetition, use of plain language)
• Identify engaging and skilled faculty members for training courses
• Ensure that training is evaluated and continuously updated
• Advise on applied learning
• Provide information in small quantities in order to avoid overwhelming the individual.
Content for Training

• Content should be relevant to the project at hand

• Key content areas to consider include:
  – Basics of research
  – Context of research organization
  – Applied training in public speaking
  – Training in critical thinking
  – Training in how to negotiate
In addition to training opportunities, support offered includes:

- Establish mentorship programs
- Foster ongoing engagement (updates on research, newsletters, information on opportunities for involvement)
- Provide networking opportunities
- Reduce barriers to participation
Advocacy Training: The NBCC Project LEAD® Story
What is Project LEAD®?
Leadership Education Advocacy Development

• Science training for consumer advocates: learning concepts and language of science to influence research and public policy

• Students paired with mentors to help during the teaching as well as guide in their advocacy careers

• Collaborative: designed by NBCC with scientists, academics, and consumers

• Select participants: renowned faculty and committed students

• Adult learning: lectures, study group sessions, case studies, role play, homework, personal action plan, and continuing education

• Held several times a year in different locations; different levels and foci for variety of courses
Why Project LEAD® is Important for Advocates

• Enables advocates to play integral role in breast cancer decision-making in research, policy, healthcare systems

• Gives advocates tools to critically appraise research proposals and scientific reporting

• Builds bridges between the consumer advocacy and scientific communities

• Builds credibility for the consumer advocacy community
Center for NBCC Advocacy Training

• Created in 2008
• To consolidate, expand and enhance the range of NBCC research advocacy and public policy training
• Includes:
  – Full range of Project LEAD domestic and international science and quality care courses
  – Annual Advocacy Training Conference
  – Team Leader training
  – Emerging Leaders
  – Continuing Education – web community, advanced sessions
  – Mentoring
• Over 2000 graduates, 74 courses – since 1995
Types of Project LEAD Courses

- **Project LEAD® Institute** - an intensive science and research methodology course to prepare advocates to serve on breast cancer decision-making bodies and to critically analyze information (1995)

- **Clinical Trials Project LEAD®** - advanced course to improve design, implementation, outcomes of clinical trials (2001)

- **Quality Care Project LEAD®** - applies NBCC’s core values towards creating systems-wide improvements in quality breast cancer care. (2004)

- **International Project LEAD®** - bringing science and clinical trials training to international advocacy community to support advocate/researcher collaborations (2004)
Types of Project LEAD® Courses

• Project LEAD® Workshop – introductory level course on basic scientific concepts and language; critical skill-building to understand scientific research reported in the media (2008)

• Over 2000 graduates, 74 courses – since 1995
Identifying Need for Educated Consumers

• Dept. of Defense Breast Cancer Research Program
  – NBCC required that educated consumers work as peers with scientists from start of DOD BCRP - as co-chairs, reviewers, etc
  – Identified need to train advocates in concepts and language of science

• NBCC principles align with Project LEAD:
  – Evidence-based health care
  – Consumer perspective to shape research agenda
  – Keep efforts focused on mission to end breast cancer

• Health care reform legislation -
  – NBCC helped assure “educated consumer involvement on committees” language added to and remained in bill
Educational Principles of Project LEAD®

• Set bar high – for student selection, curriculum

• Belief in adult ability to learn complex scientific concepts and critical appraisal skills

• Ground program in adult learning principles:
  – Repetition, small study groups, safe learning environment for weakest to learn most, risk zone theory, graduate action plan

• Offer continuing education, mentoring
• Faculty
  – Outstanding teaching skills – key requirement
  – Ability/willingness to commit significant time
  – Commitment to Project LEAD’s goal of training educated consumers to sit at all breast cancer decision-making tables
  – Continue to work with advocates and staff to update and refine curriculum
Curriculum:

• Basic Science

• Epidemiology

• Clinical Medicine

• Advocacy Development
Curriculum: Advocacy Development

- Overview of research process
- Critical appraisal skills
- Centrality of evidence-based healthcare
- Grant review process
- Influence strategies
- Role playing in advocacy situations
- Advocacy opportunities
- Graduate Action Plan with mentors
Summary

• Research advocacy continues to grow and advance

• Training and support is a critical component for meaningful engagement

• Organizations with training programs in place are valuable resources for researchers
  – Project LEAD
  – Research Advocacy Network
  – CDMRP
  – Cochrane Consumers Network
  – FDA Patient Representative Program
Resources

• Consumers United for Evidence-Based Healthcare (CUE)
  – Online Course: Understanding Evidence-based Healthcare: A foundation for action
• Cochrane Consumer Network: http://consumers.cochrane.org/resources
  – Consumer guides to commenting on Systematic reviews
  – Consumer guides to writing Plain Language summaries
  – Glossary of terms
• Research Advocacy Network: www.researchadvocacy.org
  – Roadmap to Research Advocacy
  – Advocate Institute
• Food and Drug Administration Patient Advocacy Program
  – Role of Patient Advocates in FDA Advisory Committees
  – Overview of the FDA
  – Webinar training