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Training and Support for Patients and Consumers Engaged in Research

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Training & Support

- 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

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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

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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.

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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

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Additional Support Activities

- 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

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Advocacy Training: The NBCCProject LEAD® Story

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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 a 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

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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

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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

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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)

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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

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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

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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

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Faculty Criteria

- 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

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Curriculum:

- Basic Science
- Epidemiology
- Clinical Medicine
- Advocacy Development

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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

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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

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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