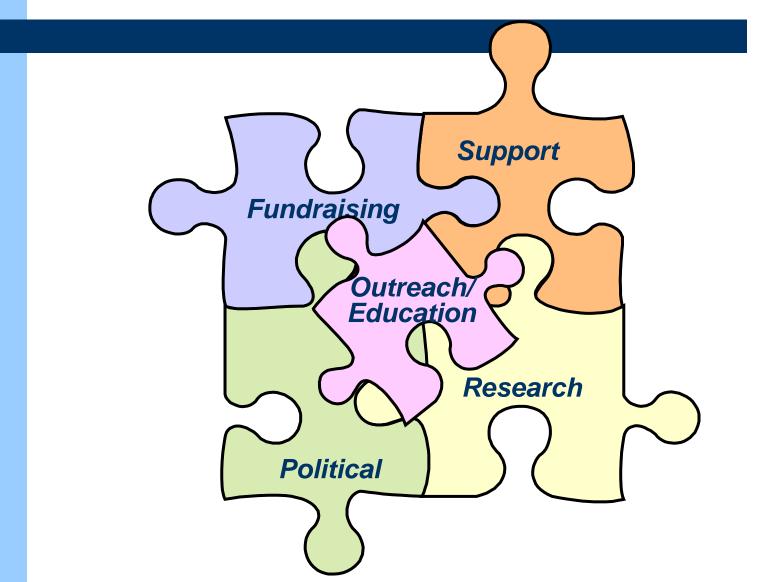
# A Roadmap through Cancer Advocacy

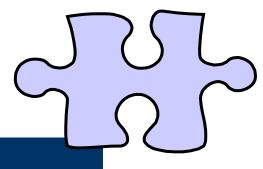


Jane Perlmutter janep@gemini-grp.com

#### **Five Types of Cancer Advocacy**

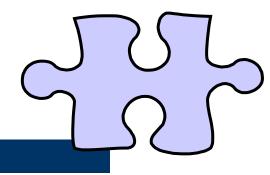


### **Fundraising Advocacy**



- Goal: Raise and distribute money worthy organizations involved in patient support, research and public outreach/education
- Example Approaches:
  - Events—races, golf tournaments, luncheons
  - Co-marketing
  - One-on-one solicitation

## **Primarily Fundraising Organizations**



- Susan G. Komen Breast Cancer Foundation http://www.komen.org
- Breast Cancer Research Foundation http://www.bcrfcure.org
- Lance Armstrong Foundation http://www.livestrong.org

#### **Support Advocacy**



- Goal: Help people who are facing cancer
- Example Activities:
  - Hotlines
  - Support groups
  - Patient navigators

## **Getting Star**ted in Support Advocacy



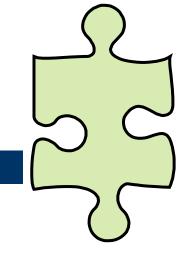
- Contact local hospital support groups, volunteer, or outreach office
- Become a certified Y-ME hotline counselor
- Become a local Reach-to-Recovery Volunteer

## **Primarily Support**Organizations



- Y-ME National Breast Cancer Organization <a href="http://www.y-me.org">http://www.y-me.org</a>
- Reach to Recovery program of American Cancer Association <a href="http://www.cancer.org">http://www.cancer.org</a>

#### **Political Advocacy**



- Goals: Impact public policy through lobbying
- Example Issues:
  - Research funding
  - Health care policy
  - FDA authority
  - Environmental issues

## **Getting Star**ted in Political Advocacy



- Become a member of NBCC and attend Quality of Care LEAD
- Attend NBCC's annual meeting and lobby day
- Contact the local ACS organization and ask about lobbying activities
- Find an issue that you are passionate about and discuss with you local congressional representatives (state and local)

## **Primarily**Political Organizations



 National Breast Cancer Coalition http://www.natlbcc.org

#### Research Advocacy



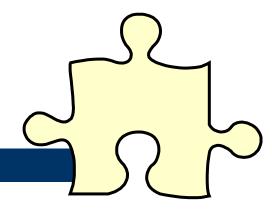
- Goals: Ensure high quality research that is sensitive to the priorities of patients is
- Example Activities:
  - Sitting on grant review panels, Institutional Review Boards (IRBs), and Data and Safety Monitoring Boards (DSMBs)
  - Working with researchers to develop grant proposals and implement funded projects
  - Reviewing clinical trial protocols, patient recruitment and education material
  - Assisting with patient recruitment, compliance and retention for clinical trials
  - Participating in Cancer Cooperative Groups and other NCI Working Groups

## **Getting Star**ted in Research Advocacy



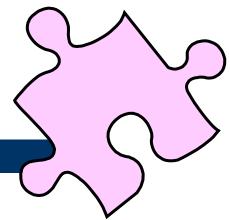
- Become a member of NBCC and attend Project LEAD and Clinical Trials LEAD
- Apply to be a stakeholder reviewer for a research granting agency (DOD, ACS, Komen, etc.)
- Volunteer to be on a local IRB
- Volunteer to work with local researchers

### Research Advocacy Websites



- SPORE Advocates <a href="http://www.sporeadvocates.net">http://www.sporeadvocates.net</a>
- Research Advocacy Network (RAN) http://www.researchadvocacy.org
- National Cancer Institute (NCI) Office of Liaison Activities <a href="http://ola.cancer.gov">http://ola.cancer.gov</a>
- Department of Defense (DOD) Congressionally Directed Medical Research Program (CDMRP) http://cdmrp.army.mil/cwg/default.htm
- Cancer Cooperative Groups <u>http://www.cancertrialshelp.org</u>
- Specific Cancer Cooperative Groups <u>http://www.ecog.org/general/iglink.html</u>

#### **Outreach & Education**

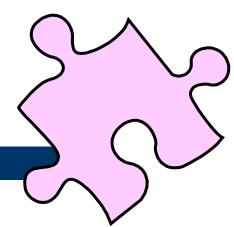


 Goals: Increase public awareness of risks and realities of cancer as well as methods and progress of research

#### • Examples:

- Breast Cancer Awareness Workshops targeted at women's groups, high school students, etc.
- Public Forums
- Newspaper and magazine articles
- Websites
- Teleconferences and webcasts

### **Getting Star**ted in Outreach & Education



- Almost all other advocacy organizations do some outreach and education
- If this is your primary are of interest, get involved with an organization that does other work you believe is important and volunteer to write and article, give a public talk or become involved in other outreach activities

#### **Words of Wisdom**



- Find causes, organizations and people with whom you resonate and offer your time, energy, and expertise
- Be flexible and willing to have their agenda take priority over yours
- The more involved you become, the more competent and confident you will become and the more opportunities will open to you

#### **Good Luck!**

