A new model for training patient advocates to advance the adoption of research results in community oncology practices.

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BACKGROUND
The advocate community has been identified as an influential component in disseminating the results of research reported at ASCO. A pilot program offered by Research Advocacy Network represents a new model of training for advocates. It prepared advocates to better understand the common concepts in oncology, improve statistical skills to interpret the presentations and identify the influences and barriers to adoption of research results in clinical practice.

PARTICIPANTS
Advocates were selected based on their ability to disseminate results reported at ASCO to a patient constituency. The program involved 15 advocates with representation from six cancer sites, six of which attended ASCO for the first time.

- Breast - 7 advocates
- Lymphoma - 2 advocates
- Sarcoma - 1 advocate
- Pancreatic - 2 advocates
- Brain - 2 advocates
- Colon - 1 advocate

ACTIVITIES/METHODS
- Background pockets were sent to the participants prior to all teleconferences.
- Pre-ASCO teleconferences emphasized some of the “common concepts” in oncology:
  - Targeted Therapies
  - Drug Safety and Approval Process
  - Statistics for Advocates
  - Understanding Treatment Guidelines
  - Managing the Logical Aspects of the ASCO Meeting
- Post-ASCO teleconferences concentrated on disseminating research results:
  - A panel discussed changes to clinical practice from the evidence presented at ASCO.
  - “Tell Your Story”: participants shared their individual accomplishments.
  - Participants were responsible for reporting their efforts in disseminating the results that could change clinical practice in their disease sites.
  - All teleconferences in the course are digitally archived and available for synchronized audio and video playback with web access.

RESULTS
Participants reported an increased:

- understanding of scientific concepts and language
- increased confidence in discussing with researchers
- improved ability to translate research results for their constituencies

Participants provided the research results:

- through educational programs for:
  - staff and volunteers
  - new member organizations
- increased awareness of patients and caregivers on a one-on-one basis through teleconferences and online patient support groups
- to survivor hotlines
- through articles in newsletters that reached close to 125,000 readers
  - Young Survival Coalition
  - YMNE National Breast Cancer Organization
  - National Brain Tumor Foundation
  - PanCAN
  - Breast Cancer Research Program

- through reports to their member organizations:
  - Korean network of over 100 affiliates
  - PanCAN Team Hopes
- on their Web sites, listservs
- to the GI SPORE and Interprofessional clinical trial committees
- to Cooperative Group Advocate Committees
- to advocates serving on the Cancer Survivorship Advisory Council at the USC/Norris Cancer Center
- to the media
- to their Board of Directors
- to other organizations they work with including:
  - The Wellness Community
  - American Cancer Society
  - Beatitudes Health Ministry

CONCLUSION
Preparatory lectures help advocates maximize the experience of interpreting and translating the results from the ASCO meeting.

More prepared advocates:

- help to advance the dissemination of research results through their formal and informal distribution channels.
- are able to translate the information more rapidly to their constituencies.

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