



2019 Alliance Patient Advocate Committee: Adding Value to the Alliance Clinical Trial Process

Patty Spears and Coleen Crespo

Alliance Patient Advocate Committee

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Patient Advocacy in the Alliance

Patient Advocacy

Committee Aims

Participation

Who We Are

Follow Up

Patient advocacy is an integral part of the Alliance for Clinical Trials in Oncology.

Alliance Patient Advocates are cancer survivors and caregivers, and come from all walks of life. They play an active role in cancer research by bringing the patient's perspective to the investigative and clinical environment. Patient advocates help clinical researchers find better answers for people with cancer more quickly.

Alliance Patient Advocates:

- Attend and participate in scientific meetings
- Review study concepts and protocols
- Assist in designing study accrual strategies
- Develop plain language study results summaries
- Make presentations to interested groups of scientists and clinicians

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Committee Aims

The Alliance Patient Advocate Committee has three specific aims:

1. to promote patient advocate participation as full members of Alliance disease and modality/discipline committees;
2. to communicate individually with constituent patient populations to maintain currency of input and validity of voice for the collective patient experience; and
3. to allow Alliance patient advocates to remain current on the science of cancer research.



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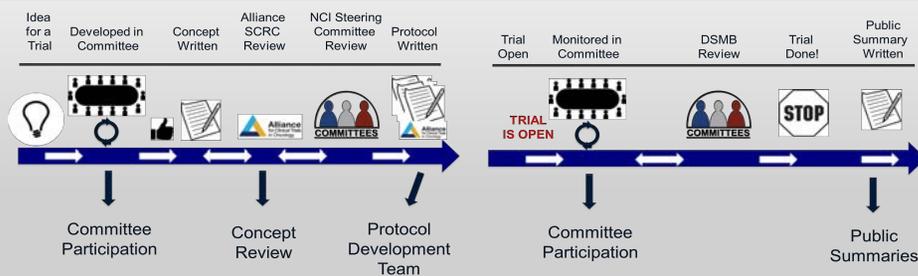
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How Patient Advocates Participate within the Alliance



Participating in Committee Meetings

- Attend all primary committee meetings, in-person and by teleconference.
- Actively participate in discussions.
- Provide the patient perspective.
- Bring a broad community perspective to the conversation.



Concept Review

Alliance patient advocates serve as evaluators of phase II or III clinical trial concepts. Below are the suggested topics reviewed by patient advocates. Points of emphasis will vary from concept to concept. However, the following five main headings are criteria used to guide the advocate review.

- Study Impact
- Study Feasibility
- Level of Innovation
- NCTN Relevance
- Study Design



Protocol Review Committee

- Review the protocol as it is written.
- Look at eligibility criteria.
- Review questionnaires.
- Review schedule for patient burden.
- Review the consent and re-write parts when necessary to ensure a good readability level.



Patient Perspective

- Think about the outcome and whether it will be important to patients and make a difference.
- Will participation be hard for patients? (lots of visits, mandatory biopsies, etc.)
- Is there randomization? If so, will it be acceptable to patients?
- Is the trial complicated? Is there a need to help explain to patients?
- Will there be high "costs" to patients? Are scans covered?
- What is the patient population? Who is excluded/included? Is it appropriate? Will special outreach be needed?
- What are the eligibility criteria? If it seems unnecessary, ask why it's there. (brain mets exclusion, prior therapy, line of therapy, age, sex)

Public Summaries

- Publications Committee (via Deb Collyar)
- Template (via Deb Collyar)
- Written in plain language
- Written after or at the same time as the publication
- Written by a "team" including a patient advocate
- Posted on the Alliance website

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Patty Spears
Chair
Breast



Coleen Crespo
Vice Chair
Health Disparities



Mike Abrams
Lymphoma



Dena Battle
Genitourinary



Vernal Branch
Genitourinary



Deborah Collyar
Publications



JoEllen DeLuca
Gastrointestinal



Sandy Finestone
Health Outcomes



Carmen Gillis
Neuro-Oncology



Julie Krause
Gastrointestinal



Bunny Leach
AYA Liaison



Paul Leech
Leukemia



Barbara LeStage
Cancer in Older Adults



Eva May
Translational Research



Pam Moffitt
Respiratory



Phyllis Nassi
Health Disparities



James Omel
Myeloma



Jane Perimutter
Health Outcomes



Ivie Sampayo
Health Disparities



Yasmeem Watson
Gastrointestinal



Sara Whitlock
Respiratory

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