



Alliance Patient Advocate Committee (PAC)

Patty Spears

Raleigh, NC

Co-Chair

Pat Gavin

Grand Rapids, MI

Co-Chair

Alliance Group Meeting, Chicago IL on May 11, 2017

Patient Advocate Committee (PAC)

ROLE: Patient Advocates in the Alliance for Clinical Trials in Oncology (Alliance) represent the perspective of patients and their families in the development and delivery of innovative clinical trials.

GOAL: Patient Advocates work together with multidisciplinary cancer professionals to develop and advance outstanding research in the treatment and care of cancer patients and the prevention of cancer.

Who are we?

Cancer patients and caregivers from all walks of life with the common goal of helping researchers develop and implement clinical trials that address patient issues through advancing the science.

Members of Alliance disease and modality committees. Patient Advocates attend and participate in scientific meetings, review study concepts and protocols, and assist in designing study accrual strategies.

Patient Advocate Committee



May 2016

21 Patient Advocates

Members of the Alliance Patient Advocate Committee (PAC) participate in most committees of the Alliance and continue to bring the voice of the patient to all work conducted by the Alliance.

- **Pat Gavin Co-Chair**
- Laura Cleveland
- Deborah Collyar
- Coleen Crespo
- Jo-Ellen DeLuca
- Karen Durham
- Bob Harrison
- Kay Kays
- Shelly Kuhlmann
- Pam Moffitt
- **Patty Spears Co-Chair**
- Phyllis Nassi
- James Omel
- Jane Perlmutter
- Hank Porterfield
- Ivis Sampayo
- Yasmeeem Watson
- Jack Whelan
- Sara Whitlock
- Peggy Devine (NT)
- Karl Schwartz (NT)

Representation on Disease Committees

- **Breast**
 - Patty Spears*
 - Jane Perlmutter
 - Ivis Sampayo
- **GI**
 - Kay Kays*
 - JoEllen Deluca*
 - Yasmeem Watson*
- **GU**
 - Hank Porterfield*
 - Bob Harrison*
 - Jack Whelan
- **Leukemia**
 - Laura Cleveland*
- **Lymphoma**
 - Jack Whelan*
 - Karl Schwartz
- **Myeloma**
 - Jim Omel*
- **Neuro-oncology**
 - Shelly Kuhlmann*
- **Respiratory**
 - Pam Moffitt
 - Sara Whitlock

Representation on Modality Committees

- **Experimental Therapeutics**
 - Deborah Collyar
- **Radiation Oncology**
 - Sara Whitlock
- **Transplant**
 - Jim Omel
- **Ethics**
 - Deborah Collyar
 - Jane Perlmutter
- **Publications**
 - Deborah Collyar*
- **Data Safety Monitoring Board**
 - Patty Spears
- **Leukemia Correlative Science**
 - Laura Cleveland
- **Pharmacogenomics**
 - Phyllis Nassi

ACS Committees

- **Cancer Care Delivery Research**
 - Deborah Collyar
 - Pat Gavin
 - Jane Perlmutter
 - Patty Spears

Representation on Cancer Control Committees

- **Cancer in the Elderly**
 - JoEllen DeLuca
 - Pam Moffitt
- **Community Oncology**
 - Karen Durham
 - Pat Gavin
- **Health Disparities**
 - Coleen Crespo*
 - Ivis Sampayo*
 - Phyllis Nassi*
- **Health Outcomes**
 - Karen Durham*
 - Jane Perlmutter*
- **Prevention**
 - Coleen Crespo
 - Hank Porterfield
 - Patty Spears
- **Symptom Intervention**
 - Jim Omel
 - Jane Perlmutter

What we do

Actively engage in the Alliance clinical trial process.
Patient Advocates' participation ensures inclusion of patient perspective and concerns as trials are developed.

Volunteer at the local, regional and national levels.
Involvement may be in research advocacy or other advocacy areas such as support or fundraising. Through these activities, Alliance Patient Advocates keep close affiliation with patients and are uniquely qualified to bring the patient voice and perspective to the research table.

We are here to help...

EXAMPLES

- **Concept:** We are willing to review concepts before they are officially submitted to the SCRC for review, and provide feedback.
- **Protocol:** Once a trial is approved, we can be a resource when you write the consent form, to ensure the reading level is appropriate and the protocol is understandable.
- **Accrual:**
 - If you have a study idea that you are not sure will accrue well, the PAC can be a resource for feedback during pre-concept development.
 - The PAC can be a resource in patient material development for complex trials, which can enhance participants understanding of the trial and therefore accrual.
 - If a trial is not accruing as planned, the PAC can be a resource to identify potential patient barriers.

We are here to help... (cont.)

EXAMPLES

- **Results:** We support returning research results to participants. We have been involved in publishing study result summaries on the Alliance website and are continuing this endeavor (Deb Collyar).
- **Patient Materials:** We are a resource to all committees and the NCI for patient facing materials development.
 - **Brochures:** We have helped to develop and SOP on the inclusion of patient brochures in all Alliance clinical trials.
 - **Participant Thank You Letters:** We have helped to develop and SOP on the inclusion of participant thank you letters in all Alliance clinical trials.
 - **Accrual Checklist:** We helped develop the current Alliance Accrual Checklist and have been involved in developing a more comprehensive accrual checklist for all NCTN trails

We are here to help... (cont.)

EXAMPLES

- **Data Sharing:** We support sharing data from current and completed Alliance and all NCTN trials. We initiated a resolution that was signed by all NCTN advocates and over 200 supporters.
- **PCORI projects:** We are a resource to all Alliance run PCORI projects and provide a patient perspective to their development, conduct, analysis and dissemination.
- **Publications:** Several of our members have been contributing or senior authors on a variety of cancer and clinical trial publications.
 - There were a total of **13** publications from November 2015 to 2016.
 - Ten PAC members have published **over 80 articles** that range from personal stories to ASCO Guidelines.

Recognition

Jack Whelan was recently awarded the AACR Distinguished Public Service Award in April 2017.

- The Distinguished Public Service Award honors the extraordinary contributions of an individual or group whose groundbreaking, innovative work exemplifies the AACR's mission to accelerate the prevention and cure of all cancers through research, education, communication, and collaboration. Distinguished public service takes many forms, and past winners have included generous philanthropists, government officials, advocates, and members of the media. **Whelan embodies the substance and spirit of this award.**



Put a face on your research



Conclusion

- Questions from Audience
- Answers from Presenter