

Enhancing the Value of NCI Task Force and Steering Committee Patient Advocates via the NCI Patient Advocate Steering Committee: 2016-2020

CTAC Meeting

November 4, 2020

Presenters



Kim Norris
President/Co-Founder
Lung Cancer Foundation of America



Rick Bangs, MBA, PMP
Chair, SWOG Patient Advocate
Committee

Agenda

- ❑ Patient Advocate Steering Committee (PASC) Background
- ❑ Improvement Actions
- ❑ Discussion and Input
- ❑ Defining Success: a PASC Leadership View
- ❑ Next Steps

Patient Advocate Steering Committee (PASC)

The Patient Advocate Steering Committee (PASC) works to ensure that advocates involved with the Scientific Steering Committees (SCs) and their Task Forces (TFs) are effectively and consistently integrated with the evaluation and monitoring of clinical trials within those groups.

PASC membership is composed of the patient advocate members of the NCI Scientific Steering Committees and their respective Task Forces.



PASC Mission

❑ The PASC functions to

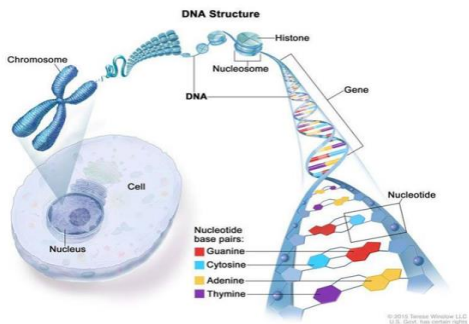
- Develop and share best practices for patient advocate interactions in SCs
- Identify common concerns and potential solutions to address the concerns
- Identify training needs and work with appropriate bodies to develop and implement training
- Communicate information to and from SC and TF advocates



Getting to Success: 2016-2020

- ❑ **Clarified scope of role**
 - NCI vs. NCTN roles
 - Task Force (TF) vs. Steering Committee (SC)
 - Research advocates vs. general advocates
 - Patient advocate skills and knowledge

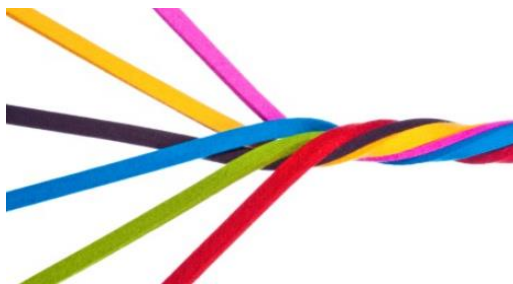
SC and TF Patient Advocate Focus Competencies* (Skills and Knowledge)



Cancer & Research Competencies



TF & SC Role Competencies



NCI Process Competencies



Effective Engagement Competencies

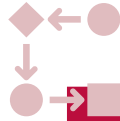
**Competencies can range from familiarity to expertise*

Improving the PASC



Inputs

- Surveys



Methods

- Working Groups
 - ✓ Orientation
 - ✓ Mentoring
 - ✓ Concept Review



Outputs

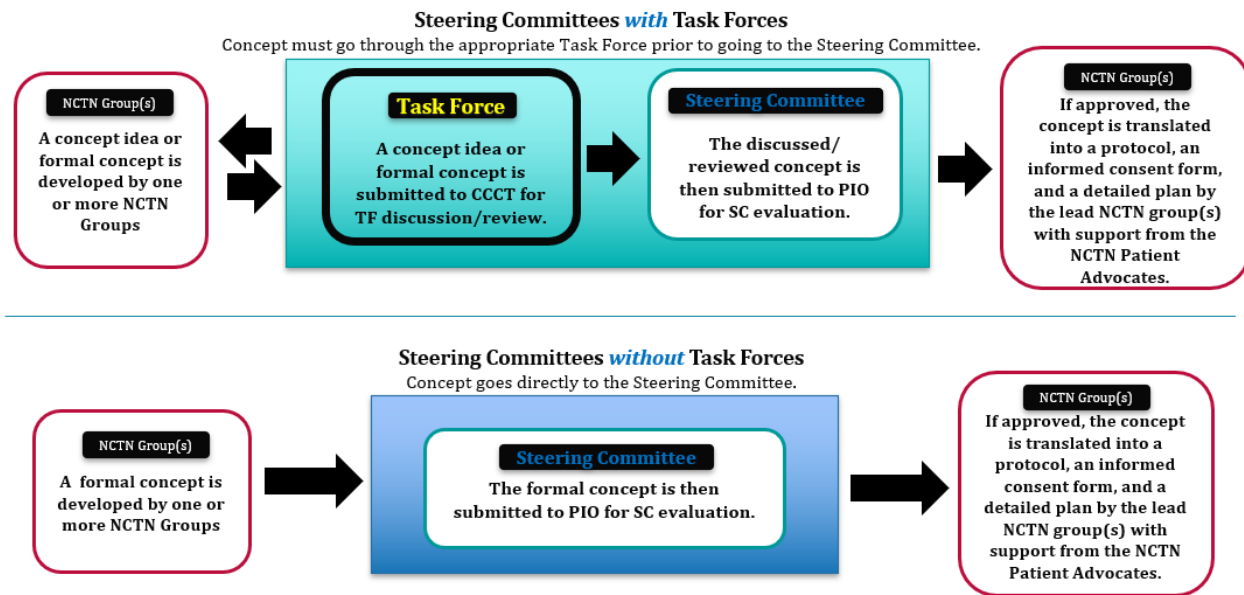
- TF and SC role and job spec
- New Concept Review Form
 - ✓ Guiding questions
 - ✓ Samples
- Onboarding
 - ✓ Training/Guidance
 - ✓ Videotaped review guidance
- Mentoring
- “Presentation Brief”

Materials are stored centrally, organized for ease of use, and available 24x7 in OneHub.

Getting to Success: 2016-2020

Clarified scope of role and relationship to NCTN

Concept Review Process

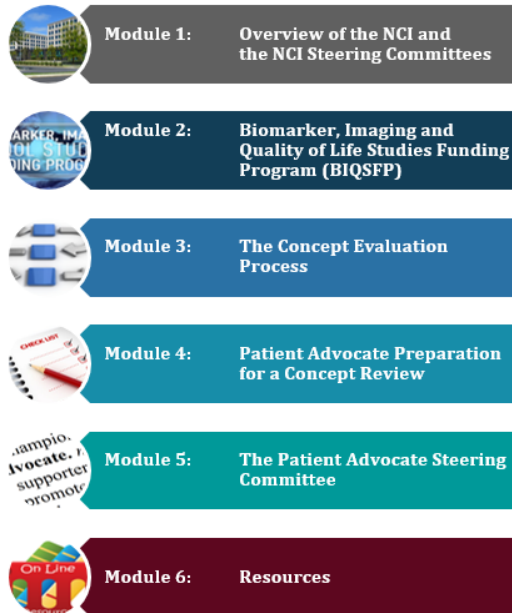


Getting to Success: 2016-2020

- ❑ **Created a presentation brief for speakers to guide their presentation and maximize relevance to TF and SC work; includes these questions:**
 - ❑ *What part of their work does your content relate to?*
 - ❑ *What new information can they apply to their work tomorrow when a new concept is provided?*
 - ❑ *What changes in the way they work or provide input will your content trigger?*
 - ❑ *What future concepts will the PASC likely see resulting from your content?*
 - ❑ *What concerns might your content expose and how should the PASC approach those concerns?*
 - ❑ *What further actions or education should the PASC consider?*
 - ❑ *What lessons learned can the PASC apply?*

Getting to Success: 2016-2020

- ❑ Developed in-depth orientation, training and development, and related mentoring programs including self-assessment



Concept Review Form Questions

7. Patient Advocacy Evaluation Questions

- 7.1 How important is this trial to people who have been or will be diagnosed with this disease?**
- 7.2 What aspects of this trial design might attract patients or be of concern to patients?**
- 7.3 How well does this trial balance the risk, benefits, and burdens of the patient and/or the caregiver?**
- 7.4 What effect will the eligibility/inclusion and exclusion criteria have on the target patient population?**
- 7.5 Is this study likely to be able to meet accrual goals and retain patients through completion?**
- 7.6 Are there other patient-related issues that should be considered?**

Getting to Success: 2016-2020

- ❑ Provide resources via one-stop shopping on a secure website (OneHub)

The screenshot shows the OneHub interface for the Patient Advocate Steering Committee (PASC) workspace. The top navigation bar includes the OneHub logo, a 'DASHBOARD' button, a 'FILES' button, and a dropdown menu for 'Patient Advocate Steering Committee'. The main content area is titled 'Welcome to the NCI Patient Advocate Steering Committee (PASC) Workspace!' and contains a paragraph explaining the PASC's role. Below this, there are sections for 'NCI Contacts', 'PASC Co-Chairs', 'PASC Meetings', and 'NCI Meetings'. A 'Recent Activity' section at the bottom shows 'No recent activity.' On the right side, there is a green sidebar titled 'PATIENT ADVOCATE STEERING COMMITTEE' with a 'LINKS' section listing various resources such as 'Monthly Meeting Materials', 'Organization and Structure', 'Orientation', 'Concept Evaluation Form', 'Guiding Questions', 'Written Concept Evaluation Samples', 'Concept Review Prep. Videos', 'Focus Competencies and Resources', 'Key Topics', 'Acronyms and Abbreviations', and 'Face-to-Face Meetings'.

onehub DASHBOARD FILES Patient Advocate Steering Committee

Welcome to the NCI Patient Advocate Steering Committee (PASC) Workspace!

The Patient Advocate Steering Committee (PASC) works to ensure that advocates involved with the Scientific Steering Committees (SSCs) and their Task Forces (TFs) are effectively and consistently integrated with the development, implementation, and monitoring of clinical trials within those groups. This site provides many resources relevant to Steering Committee and Task Force Patient Advocate activities. Links to some of the most useful resources on this site can be found in the right sidebar.

NCI Contacts

Jean Lynn, PASC Program Director, NCI Coordinating Center for Clinical Trials (CCCT) (lynnje@mail.nih.gov)

Evelyn Obot, NCI Liaison, NCI CCCT (obote@mail.nih.gov)
Deborah Jaffe, NCI Liaison, NCI CCCT (jaffed@mail.nih.gov)
Laurie Cynkin, NCI Liaison, NCI Office of Advocacy Relations (OAR) (cynkin@mail.nih.gov)
John Freimuth, NCI Liaison, NCI OAR (john.freimuth@nih.gov)
Sherill Smallwood, PASC Coordinator, The EMMES Corporation (ssmallwood@emmes.com)

PASC Co-Chairs

Annie Ellis (2annieellis@gmail.com)
Danielle Leach (dleach@braintumor.org)
Rick Bangs (Emeritus) (chezrick@comcast.net)

PASC Meetings

PASC: Monday, October 5, 2020 (12:30 - 2:00 PM ET)
PASC Agenda Planning: Monday, December 14, 2020 (12:30 - 1:30 PM ET)

PASC Virtual Meeting: Monday, August 24, 2020 (11:00 - 4:00 PM ET)

NCI Meetings

Clinical Trials & Translational Research Advisory Committee (CTAC): Wednesday, November 4, 2020

Recent Activity

PATIENT ADVOCATE STEERING COMMITTEE

LINKS

- Monthly Meeting Materials
- Organization and Structure
- Orientation
- Concept Evaluation Form
- Concept Evaluation Form
- Guiding Questions
- Written Concept Evaluation Samples
- Concept Review Prep. Videos
- Focus Competencies and Resources
- Key Topics
- Acronyms and Abbreviations
- Face-to-Face Meetings

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Defining Success of the PASC: Co-Chair View

- ❑ **The PASC is successful when TF and SC Advocates:**
 - Provide clarifying questions to the study team as part of the pre-meeting preparation
 - Participate in the review process of the TF or SC
 - Offer opinions and their opinions are valued
 - Provide input reflected in the documented decision to the NCTN Group Chair and the PI

Defining Success of the PASC: Co-Chair View (cont'd)

❑ The PASC is successful when TF and SC Advocates:

- Are part of a multi-disciplinary team that is interested in the perspectives of all stakeholders, including the Patient Advocates
- All advocates provide input
- Bring a familiarity and interest in research to the role
- Receive an onboarding that clarifies expectations and establishes a solid starting point for their relationship with TF or SC

Current PASC Leadership & Support Team



**Annie Ellis, PCPI-UCPI
PASC Co-Chair**



**Danielle Leach, MPA
PASC Co-Chair**



**Deborah Jaffe, PhD
Associate Director of NCI
Steering Committees**



**Jean Lynn, MPH, RN
PASC Facilitator**



**Sherill, Smallwood, MS
PASC Coordinator**



**Evelyn Obot, PhD, PMP
PASC Co-Facilitator**

Next Steps

- ❑ Publish manuscript of evolution and supporting activity
- ❑ Consider how to leverage process and tools beyond PASC





“Research advocates play a vital role in shaping NCI’s work. They challenge us and ensure that we never lose sight of what we are here to do – which is to improve patient outcomes by advancing cancer research.

We can’t do this without the unique perspectives research advocates bring.”

*– Dr. Douglas Lowy,
Principal Deputy Director, NCI*