Welcome to the SWOG team.

We represent the voice of cancer patients in the design, development, and implementation of clinical trials, and the sharing of practice-changing results.

This is an exciting time to be a SWOG patient advocate. SWOG is engaging advocates like never before, and our committee has grown in size and sophistication. You’ll work with exceptional advocates and some of the best minds in cancer research as you shape our clinical trials.

To start you on your journey, the SWOG patient advocate committee developed this resource guide. If you choose, you can also work with a mentor who will answer your questions, help you navigate your first SWOG meeting, and assist with your initial interactions with your disease committee. Advocates also organize training sessions on our monthly calls, and can apply for funding to attend conferences and training sessions of their choice. You have many opportunities to learn and contribute.

Please ask questions, share your experiences and ideas, and look to improve your work and our work together as a committee. Continuous improvement must be our legacy. Finally, partner with researchers. Those relationships are critical to your success, and to ours.

On behalf of SWOG, thank you for joining the team – and making a difference.

Regards.

Rick Bangs
Chair, SWOG Patient Advocate Committee
SWOG Bladder Cancer Patient Advocate

Valerie Guild
Vice-Chair, SWOG Patient Advocate Committee
SWOG Melanoma Committee Patient Advocate
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About SWOG

OUR MISSION

SWOG’s mission is to significantly improve lives through cancer clinical trials and translational research.

OUR PRINCIPLES

We make patients our absolute highest priority. We ensure that the best science drives our research. We embrace and encourage diversity in leadership and membership to effectively solve problems in cancer. We demand integrity, accountability, and ethical behavior. We foster and mentor young investigators to ensure excellent clinical research for future generations.

Formerly the Southwest Oncology Group, SWOG is a federally funded network of researchers that designs and conducts cancer clinical trials. As one of the five groups in the National Cancer Institute’s National Clinical Trials Network, the nation’s oldest and largest cancer research network, SWOG is a major part of the cancer research infrastructure in the U.S. and around the world.

The nearly 6,000 physician-researchers in the SWOG network practice at more than 1,000 institutions nationwide and in six other countries. The network includes 32 of the NCI-designated cancer centers, as well as community hospitals, private physician practices, and group networks across the nation.

Since its founding in 1956, SWOG has enrolled more than 200,000 adults in more than 1,300 trials. Results of these studies have advanced cancer treatment and prevention – resulting in FDA approval of 14 new cancer drugs and improving and lengthening the lives of hundreds of thousands of people. SWOG also manages a biorepository of 600,000 specimens with associated clinical data – assets that are routinely used by other researchers, resulting in exciting new discoveries long after trials are completed.

SWOG is headquartered at Oregon Health & Science University in Portland, OR, and has an operations office in San Antonio, TX, and a statistical center in Seattle, WA. SWOG’s philanthropic arm, The Hope Foundation, is based in Ann Arbor, MI and raises private funds to help support the group’s research efforts.
About SWOG Patient Advocacy

Advocates have long had a home at SWOG. In 1993, the group first invited patient advocates to be part of its research activities. In 1994, the group created a patient advocate committee, and in 1997, that pilot program received full support from the National Cancer Institute. Advocates were now permanent partners in SWOG – the first NCI group to formally involve advocates in its trials.

In 2008, former Group Chair Larry Baker, MD restructured the patient advocates group in order to place one or more advocates in each disease committee – a big step toward integrating advocates into the trial planning process. Committee chairs were invited to nominate advocates based on two primary criteria:

- Advocates should have leadership experience in a cancer advocacy or survivors’ organization.
- Advocates should have intimate knowledge of what it means to have a cancer diagnosis, either as a survivor of cancer or by caring for a family member or close friend with the disease.

Today, SWOG advocates are advocacy leaders, grant reviewers, business executives, research administrators, attorneys, nurses, technology experts – accomplished professionals in the public, private, and non-profit sectors who bring significant experience in cancer advocacy, medicine, and science to the group.

Under Group Chair Charles Blanke, MD, advocates have grown in number and stature. The chair of the patient advocate committee serves on the senior leadership team, one or more advocates serve on every research committee, and advocates also serve on committees overseeing research publications, digital engagement, data safety and monitoring, recruitment and retention, and conflict of interest.
SWOG Advocate Impact

Advocates have improved SWOG research and given patients an important voice in clinical trial development. Accomplishments include:

- **Establishing** a robust and relevant role for advocates in the group, including writing advocate position descriptions and creating formal processes for selecting advocates and reviewing their performance

- **Expanding** the number of SWOG advocates to 20, the largest in the NCTN

- **Creating** Ten Questions Principal Investigators Should Ask Their Advocate

- **Implementing** an innovative process for securing and submitting advocate input on trials before they’re activated

- **Securing** training, education, and travel support for advocates from The Hope Foundation – more support for advocates than any other in the NCTN

- **Providing** mentorship and training on monthly patient advocate committee calls

- **Representing** SWOG at cancer research conferences, and bringing outside experts in to speak about advocacy at SWOG meetings

- **Serving** on the Accrual Core team, the NCI advisory group

- **Developing** and launching the TeamScience@SWOG training program on patient advocate engagement in trial development to SWOG members, and members across the NCTN
USING THE SWOG EMAIL LISTSERV
All SWOG advocates have access to the swogadvocates@ohsu.edu email listserv. This is a forum to field new ideas, discuss projects and opportunities, and gather input from other advocates.

USING THE SWOG WEBSITE
When you come on board as a SWOG patient advocate, you will be added as a member to the SWOG member roster, which controls access to the “members” section of the SWOG website. SWOG’s membership manager will send you a five-digit member ID and your initial password for access to the “members” section.

VIEWING ACTIVE TRIAL PROTOCOLS
To view the current version of the protocol for an active trial, in the “Member Resources” section on SWOG.org, go to the “Clinical Trials Search.” You can search by keyword, including trial number, as well as by disease type, phase, study chair, or other terms.

VIEWING PROTOCOLS IN DEVELOPMENT
To track protocols in development, log in and go to the “Member Resources” section and click onto the “Protocol Development Reports” tab. You can search, by committee, to track the status of trials in development. Actual protocol documents can be found on the NCI’s CTSU website.

RESOURCES
In the “Member Resources” section, you can access the “Advocate Resources” page for a member roster, travel instructions, monthly call plans, evaluation information and more. It’s your resource repository for just about everything you need as a SWOG advocate. SWOG.org also includes sections on member training, accrual reports, press releases and blog posts, and more.
Know Your Team

You have a team from SWOG and The Hope Foundation that help you do your work. Here is a list of key staff for advocates:

- **Wendy Lawton**, SWOG staff liaison to the patient advocate committee, lawtonw@ohsu.edu
- **Kyle Theige**, SWOG advocate group meeting reimbursements, theige@ohsu.edu
- **Julie Behm**, Hope advocate professional development reimbursements, julie@thehopefoundation.org
- **Dana Sparks**, SWOG director of operations and protocols who leads the “triage” trial concept review calls, dsparks@swog.org
- **Connie Barnes**, SWOG programs manager who assists with web passwords, cbarnes@swog.org
- **Jennifer Maeser**, SWOG recruitment and retention specialist, jenniferm@crab.org

For a full list of SWOG and Hope staff, and a list of SWOG committee chairs and protocol coordinators, visit SWOG.org
Advocate Checklist

ADVCATES MAKE OUR TRIALS BETTER. THEY HELP ENSURE OUR WORK IS RELEVANT AND REALISTIC AND EFFICIENT. WE WANT OUR TRIALS TO OPEN AND CLOSE QUICKLY AND, IN THE END, HAVE A BIG, POSITIVE IMPACT ON PEOPLE WITH CANCER. ADVOCATES GET US THERE.

— Charles Blanke, MD, SWOG group chair

- Complete orientation given by members of the patient advocate committee
- Get SWOG.org log-in credentials from the operations office
- Ask about when you need to sign and return conflict of interest paperwork, which happens once each winter
- Ask for an introduction to your protocol coordinator and committee chair
- Ask to receive patient advocate meeting invitations from SWOG, and committee meeting invitations from your protocol coordinator
- Complete TeamScience@SWOG training

- Request an advocate mentor, if desired
- Submit bio for patient advocate roster and schedule group meeting photo shoot

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— Charles Blanke, MD, SWOG group chair
SWOG Patient Advocate Benefits

- Work with passionate, dedicated advocates
- Work with experienced, engaged physicians, nurses, scientists
- Shape cancer trials from concept to publication
- Learn about cutting-edge cancer science and medicine
- Get the latest information on new treatments and prevention methods
- Travel to San Francisco and Chicago each year for SWOG group meetings
- Take part in free professional development opportunities, such as scientific training sessions, advocacy meetings, or major events like ASCO

**Make a difference**

SWOG trials have added more than 3 million years of human life to cancer patients and survivors
SWOG Patient Advocate Responsibilities

Your Role

SWOG PATIENT ADVOCATE MEMBER JOB DESCRIPTION

The group chair appoints advocates after conferring with the chair of the committee to which the advocate will be assigned.

Advocates are the voice of the patient throughout the design, development, and delivery of cooperative group clinical trials, promoting patient-centered advances in research, providing relevant communication with advocacy organizations and survivor communities, and helping to share research results.

REQUIREMENTS FOR BEING AN ADVOCATE:

- Experience with, and a dedicated interest in, cancer research and survivorship concerns, particularly across the disease area for which the candidate is being considered. This experience should include having a leadership role or other similar representation in a national or regional lay cancer advocacy or survivors’ organization, and having strong ties to the larger cancer advocacy network.
- Personal experience with cancer. This can include being a survivor of cancer or a primary caregiver for a family member or friend with cancer or having extensive experience working with cancer patients in an advocacy role.
- Willingness and ability to attend all semi-annual SWOG meetings and monthly teleconference calls.

DUTIES OF THE PATIENT ADVOCATES TO THE GROUP:

- Primary role is to bring the perspectives of those affected by cancer to SWOG.
- Advocates will provide input across the clinical trial lifecycle: define, review, design, implement, and share stages of clinical trials.
- Advocates attend regularly scheduled SWOG group meetings. Two meetings are held each year – one in the spring (typically April) and one in the fall (October). SWOG will pay for airfare and ground transportation, hotel accommodations, and meals for each meeting. Advocates will attend their committee’s session, the survivorship session, and the patient advocate committee meeting. The committee chair will determine the nature of participation in committee activities.
- Professional development funds are available for the advocates to attend at least one oncology conference per year.
- Advocates will be on e-mail distribution list to receive concepts, protocol drafts, and other materials from their committee when drafts go out for committee review, and provide input on these materials to their committee.
- Advocates will work with the communications and public relations manager to help create, review, and share information regarding group clinical trials to regional and local advocate groups involved in patient education and outreach efforts that extend the mission of SWOG.
- Advocates will provide suggestions on how the group can best work with the advocacy community.
- Advocates will provide the group with suggestions and feedback from the national, local and regional advocacy community.
- All advocates will agree to maintain the ethical and confidential standards of the group.
- Advocates serve for five years (renewable after first five year term for one additional term at discretion of the group chair) and receive feedback annually.
Advocate Competencies

In 2017, the SWOG Patient Advocate Committee agreed on a basic set of competencies that all SWOG advocates should possess. These skills and abilities were broken into four groups:

**CANCER AND RESEARCH TECHNICAL COMPETENCIES**

- Clinical trial design
- Immunotherapy
- Genetics and genomics
- Precision medicine
- Statistics
- Ethics
- Diversity and disparities
- Understand what an IRB is and how it works

**ROLE-SPECIFIC COMPETENCIES**

- Understand the NCI committee review process and the CIRB and its role in NCI trials
- Understand the role of the FDA in regulating trials and approving treatments
- Developing protocols
- Developing consent forms and other patient materials
- Creating accrual plans
- Managing accrual challenges
- Know how to share trial results and activations within the broader advocacy community

**SWOG PROCESS COMPETENCIES**

- Know SWOG’s mission, principles, history and impact
- Developing concepts in your committee
- Taking part in Executive Review (formerly “triage”) calls
- Understanding how SWOG biospecimens are collected, tested, and stored

**SOFT SKILLS**

- Problem-solving skills
- Collaboration
- Verbal and written communication skills
- Public speaking and presentation skills
# How Advocates Support the Clinical Trials Life Cycle

The role of the patient advocate across the clinical trial lifecycle was formalized in 2017 by the patient advocates across the NCI’s National Clinical Trial Network. Within each stage of the clinical trial life cycle, standard activities for the advocate have been defined, though more activities may be done.

## Clinical Trial Development Process

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<tr>
<th>Clinical Trial Development Process</th>
<th>Advocate’s Role</th>
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<tbody>
<tr>
<td>Define 1</td>
<td>Analyze portfolio</td>
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<tr>
<td></td>
<td>Create portfolio strategy</td>
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<td></td>
<td>Propose concept</td>
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<tr>
<td>Review 2</td>
<td>Shape and refine concept</td>
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<td></td>
<td>Prioritize concept</td>
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<td></td>
<td>Evaluate proposal</td>
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<tr>
<td>Design 3</td>
<td>Refine protocol</td>
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<td></td>
<td>Refine informed consent</td>
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<tr>
<td></td>
<td>Plan accrual &amp; operations</td>
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<tr>
<td>Implement 4</td>
<td>Activate trial &amp; execute accrual plan</td>
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<tr>
<td></td>
<td>Execute protocol operations</td>
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<td></td>
<td>Conduct data &amp; safety monitoring</td>
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<td>Close trial to accrual</td>
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<td>Share 5</td>
<td>Analyze data</td>
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<td>Publish results</td>
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<td>Develop outreach plan</td>
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<td>Disseminate findings</td>
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Additional discussion about the advocates’ role across the trial life cycle can be found in TeamScience@SWOG training materials.
TeamScience@SWOG

TeamScience@SWOG is a training program to ensure that patient advocates are consistently and seamlessly engaged in SWOG clinical trials and targeted for Principal Investigators (PI’s), Protocol Coordinators, Biostatisticians, Patient Advocates, Committee and Executive Leadership, and other members of SWOG study teams.

The curriculum trains members on when and how to engage Patient Advocates and consists of these five modules:

1) Engaging Patient Advocates for Leaders

2) Team Science and Engaging Patient Advocates

3) Engaging Patient Advocates in the Define, Review, and Design Stages

4) Engaging Patient Advocates in the Implement Stage

5) Engaging Patient Advocates in the Sharing Stage

A cross-disciplinary SWOG team, led by patient advocate chair Rick Bangs, created the self-study training including videos, slides, and exercises with a Patient-Centered Outcomes Research Institute (PCORI) grant.

Training materials and details are available on SWOG.org.
Executive Review (formerly “Triage”)

Every SWOG trial starts as a concept in a committee.

And every SWOG trial concept, before it heads to the NCI for review and approval, must pass SWOG executive review, a process formerly called “triage.”

Executive review conference calls occur most Monday mornings. They’re organized by the SWOG protocol department based at the San Antonio operations center and are led by Group Chair Charles Blanke MD, who is based at the group chair’s office in Portland. On the calls, principal investigators present their trial concept — hypothesis, trial design, patient population and related accrual forecast, endpoints, treatments and comparison(s), team, timelines, and any translational medicine or additional research components — and answer questions fielded by SWOG executive review team, which includes the executive officers who oversee SWOG committees and represent the group’s senior leadership.

After the principal investigator presents slides, the patient advocate presents a single slide summarizing the advocate’s view of the concept. The study team leaves the call, and the SWOG executive review team, including the vice chair of the patient advocate committee, vote on the concept and capture feedback that is later provided to the principal investigator.

By presenting concept feedback, advocates:

• Give concrete, actionable and comprehensive feedback to SWOG investigators and leaders that represents the voice of the patient
• Improve the success, impact, and duration of studies by incorporating the patient voice
• Bring meaningful advocate engagement to the earliest stages of study design

Here is a template for that advocate slide:

Tips for Executive Review Presentations:

• Keep in close contact with your protocol coordinator and the trial’s principal investigator so you know the presentation date and are prepared in advance
• The principal investigator should have been aware of, and integrated, your feedback as the concept matured, but if that is not the case, make certain that the PI is aware of your input as captured on the slide before executive review
• Take time to learn about the trial, and create the slide with care
• Be brief! Advocates should present for no more than one minute
• Don’t read the slide. Instead, provide a summary
• Emphasize your most important points clearly
• Don’t be afraid to express enthusiasm or concern about the concept
• Be constructive and provide suggestions for improvement, if any

Ver. 19
Capsule Triage Slide: Patient Advocate Rating Form

1. Primary objective(s) of the trial
   1 = Very important, 2 = Important, 3 = Somewhat important, 4 = Not at all important

2. Eligibility criteria
   ☐ ☐ ☐ ☐ ☐

3. Comparison arms
   ☐ ☐ ☐ ☐ ☐

4. Primary endpoints
   ☐ ☐ ☐ ☐ ☐

5. Secondary endpoints
   ☐ ☐ ☐ ☐ ☐

6. Patient-reported outcomes
   ☐ ☐ ☐ ☐ ☐

7. Number of study visits
   ☐ ☐ ☐ ☐ ☐

8. Biospecimen collection requirements
   ☐ ☐ ☐ ☐ ☐

9. Feasibility of achieving study accrual targets within the proposed timeframe
   1 = Very feasible, 2 = Feasible, 3 = Somewhat feasible, 4 = Not at all feasible

10. Provide any additional comments about the study, from the perspective of patients and caregivers.

Recommendations & Explanations for your Rating:

Click here to enter text.

Recommendations & Explanations for your Rating:

Click here to enter text.

Recommendations & Explanations for your Rating:

Click here to enter text.

Other Patient-Centered Comments/Concerns

Click here to enter text.
Protocol Development Timeline

1. Individual investigators/physicians suggest ideas for clinical trials. First formal statement is 2-3 page CAPSULE SUMMARY.

3. Capsule is submitted for review by executive officers in their weekly “TRIAGE” phone conference. Roughly 50% of capsules are approved at EO review.

5. If proposal is for a Phase II trial w/NCI-supplied drug, SWOG sends Letter of Intent (LOI) to NCI for review.

7. Staff of six protocol managers under Dana Sparks works to develop these at SWOG Operations Office in San Antonio. Work includes drafting of consent forms, data collection forms, and much more.

9. Two week turnaround timeline on Draft Protocol Title Page for S0935. You can send comments back to protocol manager or to the entire study committee. This review stage may be cycled through more than once.

11. May come back with comments for revisions and cycle back to NCI again.

Example of a CAPSULE SUMMARY for S0935

2. Appropriate committee chair reviews capsule. Full committee may discuss and refine at group meeting.

4. If proposal is for Phase III trial, SWOG submits formal concept to NCI for review.

6. If okayed by NCI, moves to full protocol development.

8. When it is complete, protocol manager sends it out for Review by study coordinators, appropriate committee chair(s), coordinators on other committees (if needed), drug company (if needed), and committee’s patient advocate.


12. After final NCI sign-off, and any needed contract arrangements with industry, protocol goes to member institutions, where informed consent forms and other materials are adapted as needed for presentation to each institution’s IRB for approval.

13. Once an IRB approves a trial, that institution’s physicians/CRAs (and physicians/CRAs at affiliates of that institution) can start signing up patients for the trial.
Protocol Review Tips

TIPS ON REVIEWING CLINICAL TRIAL PROTOCOLS
(Adapted from CALGB’s Tips for Concept Review)

PROTOCOL REVIEW STEPS
- Review informed consent form first, then schema, then objectives, then background, then rest of protocol
- Identify problems with protocol
- Focus on what this would do for the patient and what a person would have to do
- Write them down with suggested changes, if possible

POINTS TO CONSIDER DURING REVIEW
- Patient burdens
- Risk
- Tradeoffs
  - What is different from standard treatment?
  - What are they looking for in the trial (objectives and endpoints)?
  - How is it (might it be) better than what exists?
  - What is the clinical significance?
  - Are there ways to tie in QOL, correlative sciences, other patient considerations?

STUDY DESIGN
- What will patients consider or shy away from?
- Is standard of care changing so this study would be irrelevant? To doctors? To patients?
- What is the competition for this trial? For the patient population? Within institutions? Industry trials?
- What else can we learn in this trial with this group of people?
- Do we need a control arm and what is the appropriate control? Historical control?
- Does it have to be randomized? If so, why?
- Correlative science component (tissue collection and testing)?
- Survey of life assessment component?
- Immunology component?
- Can patients crossover to another arm if disease progresses?

ELIGIBILITY CRITERIA
- Are they all necessary for the trial?
- Is this reasonable? Are they too restrictive? Not restrictive enough?
- What about other health problems (for example, diabetes)? Could some be eligible?
- What about other populations? Are there health disparities that need to be addressed? For instance: Are people excluded due to factors like body mass index (BMI), etc.?
- Can people with non-measurable disease participate? If not, why? Is there something that can be changed so they would be eligible?
- What is the life expectancy criterion based on? Is it necessary for this study?
- What about the exclusion criteria? Why? Is this really necessary?

TIPS FOR PARTICIPATING IN A DISEASE COMMITTEE MEETING
(Adapted from NCI’s Consumer Advocates in Research and Related Activities (CARRA))

OVERALL STANCE
- Maintain professionalism.
- Try to avoid being openly angry or frustrated.
- Remember that your patient or family perspective is uniquely different from the scientists’ perspective and is the value you add.
- Remember that when meeting participants see you, they are reminded of cancer’s impact on patients and families, and the ultimate reason for holding the peer review meeting.
- Use your moral authority as a patient or family member sparsely and carefully so as to retain its impact.
- Maintain a sense of humor.

COMMUNICATION
- Communicate your ideas clearly and succinctly.
- Represent your community’s perspective rather than your individual situation or agenda. Example: Use “we” rather than “1.”
- Investigators in your committee represent their scientific viewpoint rather than their personal viewpoint. You are expected to represent the collective views of people affected by and at risk for cancer as opposed to your personal experience. It is very important not to voice your personal or political agenda in working with your committee.
- Avoid personal medical stories.
- Ask questions to reveal underlying assumptions that have been taken for granted. Communicating in lay terms the rationale for, or logic behind, an issue can be very helpful to the overall discussion.
- Describe the real world implications of the discussion for patients and families. Examples: Quality of life, independent functioning, insurance reimbursement.

YOUR APPROACH
- Identify an ally in your committee. Ideally this is the committee chair, but it might alternately be the vice chair or another committee leader.
- Act collaboratively with others whenever possible.
- Don’t get bogged down in trying to understand all the scientific details. Your primary role is to represent the perspective of cancer patients and others affected by cancer.
Research Committee Chairs’ Attitudes on Patient Advocates

**WHAT THEY WANT**
- Thoughtful
- Informed
- Skilled listener
- Collaborative
- Engaged
- Reads and understands the protocol
- Scientifically knowledgeable
- Medically knowledgeable
- Research experience
- Grant reviewing experience
- Integrates their experience with cancer to design symptom management interventions with quality of life outcomes

**WHAT THEY DON’T WANT**
We surveyed SWOG research committee chairs about working with patient advocates. Here’s what they say:
- Zealot with an agenda
- Single-minded and offers only personal point of view
- Dictator of research ideas and principles
- Poor networker
- Argumentative
- Uninformed
- Disrespectful
- Unfocused
- One way communicator

**WHAT COMMITTEE CHAIRS NEED**
Based on discussions with SWOG committee chairs and SWOG patient advocates, here are the norms and values that will give chairs and committees what they need.

- **Offer** solutions and ideas (be brave).
- **Provide** focus to the Committee’s work and be a catalyst – trigger actions, discussions, analysis.
- **Do** your homework.
- **Don’t** reinvent the wheel – share and network with the other Advocates (SWOG, other NCI Cooperative Groups, and elsewhere).
- **Ask** questions rather than making statements.
- **Motivate** shared urgency, not panic or frustration.
- **Be flexible** – leverage opportunities when they unexpectedly arise (“seize the moment”).
- **Establish** a relationship with your protocol coordinator.
- **Extend** yourself (introduce yourself, offer help, ask about challenges and issues that might use your insight or help, ask about a study that was presented, etc.).
- **Be patient** (put into context). Regroup and reassess if you have to.
- **Think macro**, not micro. Sometimes personal examples and personalization are not helpful, sometimes they are. Consider context and demonstrate that you understand the big picture.
- **Be visible** and accessible throughout the conference (arrive early, leave late).
- **Network** with committee members. Sometimes what happens outside of the meeting is more important than what happens in it.
- **Adapt** as the trial process shifts. Your role and input change across the lifecycle of the trial. Focus on work relevant to the stage of each trial.
- **Provide** insight on whether you would participate in a trial and why or why not.
### Education and Training Opportunities

No other NCI-sponsored group offers as much professional development support to its advocates. Here are major opportunities:

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<th>SWOG Clinical Trials Training Course</th>
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<td>Designed for clinical research associates, but also popular with advocates, this one-day course is offered each spring at the group meeting, on the Wednesday before the sessions officially begin. Leaders introduce the fundamentals of SWOG and NCI policies, procedures, and ethics. The course is also offered online. It’s free to SWOG members (and advocates) courtesy of The Hope Foundation. For more information: <a href="http://lms.swog.org/course/view.php?id=20">http://lms.swog.org/course/view.php?id=20</a></td>
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<th>Research Advocacy Network Advocate Institute</th>
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<td>RAN offers a variety of training tools and resources for advocates. This includes webinars and recorded lectures, and print materials, including the 52-page tutorial Understanding Clinical Trial Design. RAN also offers the Focus on Research Scholar Program, which offers new and seasoned advocates the opportunity to improve their skills and understanding of the research system and scientific concepts, including cancer pathways, genomics, biomarkers, statistics, and patient protections. Each selected scholar participates in preparatory conference calls and webinars, and receives learning materials and mentoring. The program culminates with attendance at the ASCO annual meeting. <a href="http://www.researchadvocacy.org/">http://www.researchadvocacy.org/</a></td>
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<tr>
<th>American Association for Cancer Research Educational Series on Science and Advocacy</th>
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<td>The ACCR offers online articles aimed at educating cancer research advocates. Scientists on Science includes scientists speaking in their own words about everything from the basic biology of cancer to the latest scientific research. Dialogues are discussions between advocates, physicians, scientists or survivors on a current topic in cancer research or advocates. Tools for Understanding includes articles that offer guidance on how to learn about cancer research and advocacy. <a href="http://www.aacr.org/AdvocacyPolicy/SurvivorPatientAdvocacy/pages/education-al-series-on-science-and-advocacy___403e94.aspx#.V2sNIEYqVy9">http://www.aacr.org/AdvocacyPolicy/SurvivorPatientAdvocacy/pages/education-al-series-on-science-and-advocacy___403e94.aspx#.V2sNIEYqVy9</a></td>
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<td>This is the National Breast Cancer Coalition's premier science training program for activists. These courses range from short, introductory sessions to long-term, competitively placed programs. All are designed to prepare graduates to engage in the wide range of local and national forums where breast cancer decisions are made. Project LEAD® graduates bring an educated consumer perspective and critical thinking skills to the important issues and controversies in breast cancer. <a href="http://www.breastcancerdeadline2020.org/get-involved/training/project-lead/">http://www.breastcancerdeadline2020.org/get-involved/training/project-lead/</a></td>
</tr>
<tr>
<td><strong>Fight Colorectal Cancer Research and Advocacy Training Course</strong></td>
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| Research Advocacy Training Support (RATS) aims to improve the ability of research advocates to effectively participate in the research process. It offers both advocate and researcher mentorship, as well as in-person and webinar training on the research review process, basic science topics such as genetics and tumor biology, and clinical and diagnostic research. This competitive program offers a limited number of slots each year, and requires a 12-month commitment.  
http://fightcolorectalcancer.org/do-something/support-research/research-advocacy-training-and-support-rats/ |

| **Free to Breathe Lung Cancer Leadership Conference** |
| This annual weekend conference brings together survivors, patients, caregivers, advocates and healthcare professionals to learn how to be a confident, effective lung cancer advocates. Interactive training sessions teach participants how to raise awareness, raise money, and understand the current state of lung cancer research and treatment. A virtual lab tour is included. Participation is capped at 160, and requires an online application.  
http://www.freetobreathe.org/get-involved/LCLC |

| **American Association for Cancer Research Scientist-Survivor Program** |
| The AACR Scientist-Survivor Program is designed to build lasting partnerships among the leaders of the scientific, cancer survivor, and patient advocacy communities worldwide. The program, launched in 1999, provides advocates with special lectures using lay language, small group discussions, and other opportunities to exchange information on key aspects of cancer research, survivorship, advocacy, and public policy. Advocates can only attend the program twice. Admission is competitive. Applicants are selected based on experience, advocacy priorities, organ-site focus, and past participation. ACR covers travel, lodging, and meals. Advocates must pay for rental cars, baggage fees, and other incidentals.  
For more information: http://www.aacr.org/ADVOCACYPOLICY/SURVIVOPATIENTADVOCACY/PAGES/SCIENTISTHARR;SURVIVOR-PROGRAM__403E94.ASPX#.VyumFXqHh0c |

| **National Breast Cancer Coalition Center for Advocacy Training** |
| National Breast Cancer Coalition Center for Advocacy Training  
The center offers both in-person and online training to teach breast cancer activists the strategic and evidence-based approach to advocacy that NBCC has pioneered. Project LEAD courses provide training on the fundamentals of breast cancer science, research design, and the critical thinking skills needed to participate in the research process. Training is offered through an intensive, six-day course, a two-day training workshop, a four-day course, and a four-day advanced course that focuses on the structure of clinical trials, trial ethics and regulation, and methods for improving trial design and outcomes. The NBCC also runs an online center for advocacy training.  
For more information: http://www.breastcancerdeadline2020.org/get-involved/training/ |
Additional Resources for Patient Advocates in Research

**American Association for Cancer Research (AACR)**

**SURVIVORS & ADVOCATES PROGRAM, AMERICAN ASSOCIATION FOR CANCER RESEARCH**

A website full of resources for advocates working with cancer researchers, from one of the premier cancer research advocacy programs in the U.S.

[https://www.aacr.org/AdvocacyPolicy/SurvivorPatientAdvocacy/Pages/educational-series-on-science-and-advocacy__403E94.aspx#W1DLq62-Lq1](https://www.aacr.org/AdvocacyPolicy/SurvivorPatientAdvocacy/Pages/educational-series-on-science-and-advocacy__403E94.aspx#W1DLq62-Lq1)

**American Society of Clinical Oncology (ASCO)**

**AMERICAN SOCIETY FOR CLINICAL ONCOLOGY**

ASCO not only hosts the largest annual cancer meeting in the world, it also is a central hub for oncology research education and training, including ASCO University, a comprehensive e-learning center that supports lifelong learning for oncologists and all ASCO members including patient advocates at a discounted rate.

For ASCO: [https://www.asco.org/](https://www.asco.org/)
For ASCO University: [https://university.asco.org/](https://university.asco.org/)

**Department of Defense (DoD)**

**DEPARTMENT OF DEFENSE CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAM’S CONSUMER INVOLVEMENT PROGRAM**

Consumers in this case meaning patients, survivors, caregivers, and those at particular risk for a disease. The program integrates consumers into the peer review process for awarding research grants.


**National Cancer Institute (NCI)**

**NCI’S OFFICE OF ADVOCACY RELATIONS**

This is the National Cancer Institute’s advocacy program.


**Research Advocacy Network**

**RESEARCH ADVOCACY NETWORK**

The mother lode. Membership gives you access to their Advocate Institute online educational materials for research advocates.


**Patient Advocates in Research (PAIR) Email List**

Moderated by Deb Collyar, this is the primary discussion and distribution forum for patient advocates in cancer research, including cooperative group advocates.

Contact Deb at [deborah@tumortime.com](mailto:deborah@tumortime.com) to be added to the list.
Acronyms & Abbreviations Used Within SWOG

ACRONYMS ASSOCIATED WITH THE NATIONAL CANCER INSTITUTE (NCI):

**ADEERS:** Adverse Event Expedited Reporting System  
**ADR:** Adverse Drug Reaction  
**CCIRC:** Cancer Clinical Investigations Review Committee  
**CEP:** Concept Evaluation Panel  
**CIB:** Clinical Investigations Branch  
**CIRB:** Central Institutional Review Board  
**COG:** Children's Oncology Group  
**CTEP:** Cancer Therapy Evaluation Program  
**DCCPS:** Division of Cancer Control and Populations Sciences  
**DCP:** Division of Cancer Prevention  
**DCTD:** Division of Cancer Treatment and Diagnosis  
**DHHS:** Department of Health and Human Services  
**DMAS:** Drug Management and Authorization Section  
**DRAS:** Drug Regulatory Affairs Section  
**FDA:** Food and Drug Administration  
**HHS:** Health and Human Services  
**IDB:** Investigational Drug Branch  
**IND:** Investigational New Drug  
**IRB:** Institutional Review Board  
**LAPS:** Lead Academic Participating Site  
**LOI:** Letter of Intent  
**MPA:** Multiple Project Assurance  
**NCAB:** National Cancer Advisory Board  
**NCTN:** National Clinical Trials Network  
**NCORP:** NCI Clinical Oncology Research Program  
**NDA:** New Drug Application  
**NIH:** National Institutes of Health  
**OHRP:** Office for Human Research Protections (formerly OPRR)  
**PIO:** Protocol and Information Office  
**PHS:** Public Health Service  
**PDQ:** Physician Data Query (publicly accessible NCI database of trials)  
**QACS:** Quality Assurance and Compliance Section  
**RAB:** Regulatory Affairs Branch  
**RFA:** Request for Application  
**SEER:** Surveillance, Epidemiology, and End Results

OTHER COOPERATIVE GROUPS:

**ALLIANCE:** Comprising former ACOSOG (American College of Surgeons Oncology Group), CALGB (Cancer and Leukemia Group B), and NCCTG (North Central Cancer Treatment Group)  
**COG:** Children's Oncology Group  
**ECOG/ACRIN:** Eastern Cooperative Oncology Group / American College of Radiology Imaging Network  
**EORTC:** European Organization for Research and Treatment of Cancer  
**NCIC-CTG:** National Cancer Institute of Canada – Clinical Trials Group  
**NRG:** NSABP (National Surgical Adjuvant Breast and Bowel Project), RTOG (Radiation Therapy Oncology Group), and GOG (Gynecologic Oncology Group)
system investigation
oncology cancer group
network protocol prevention
regulatory treatment triage
adjuvant approval control
clinical trials activation
affiliates service data
survival inclusion criteria
assurance response completed
closed agreement objectives
criteria study schema drug
evaluation modifications
impact thoughtful informed
engaged experienced
collaborative knowledgeable

survivor
SWOG Patient Advocate Resource Guide

SWOG
Leading cancer research. Together.  www.swog.org