



## Community Advocate Position Description

*\*\*Community advocates are valued for their front-line perspective on cancer diagnosis, treatment, and survival issues. For this reason, extensive experience in clinical trial development and cancer research is **not expected**. Advocates who have served on clinical trial review panels, on an institutional review board, or in a similar position of cancer research leadership are better suited to serve as a research advocate position and encouraged to apply for those positions.\*\**

### About SWOG Cancer Research Network

SWOG Cancer Research Network designs and runs clinical trials with the goal of preventing cancer, improving cancer treatment, or enhancing quality of life for cancer survivors. SWOG is supported by the National Cancer Institute, and is part of the nation's oldest and largest cancer research network.

SWOG is committed to bringing the voice of the patient into the process of creating and managing clinical trials – the source of all new cancer treatments and proven prevention strategies.

### Executive Summary

There are two central benefits that community advocates bring to SWOG:

The first is perspective. Unlike SWOG research advocates, community advocates do not have extensive experience in clinical trial development. They bring fresh eyes to informed consent forms, patient brochures, and other materials, as well as bring new questions and insights to SWOG trial discussions.

The second benefit is to help to address gaps in diverse patient populations' participation in SWOG clinical trials. Community advocates provide the perspective of specific patient populations, or the lived experience of a unique community. Diversity here is defined broadly, spanning age, gender, sexual orientation, race, ethnicity, socioeconomic status, type of cancer, and life and work experiences, such as living in a rural area or serving in the military. Community advocates also bring close connections to their diverse communities, either through online or in person advocacy – or both. In addition, once in the role, they should be willing and able to expand their influence more broadly.

At SWOG, community advocates will play several roles, including:

- Reviewing, executing, and improving patient enrollment plans
- Improving trial consent forms
- Building awareness of trials through social media and personal networks
- Engaging hospitals, clinics, and other sites that can offer trials
- Sharing the results of SWOG trials in their community

Community advocates are members of the SWOG patient advocate committee and serve with research advocates in that group. SWOG advocates are partners in a common quest – to improve the lives of those who have or will have cancer. Advocates are peers holding complementary roles that, together, make a bigger impact by providing different perspectives to the same problem.

### **Position Requirements**

- Have experience with, and a dedicated interest in, cancer community engagement. This experience should include holding a leadership role or having strong ties to local, regional, national and/or social media cancer advocacy communities.
- Have personal experience with cancer. This can include being a survivor of cancer, serving as a primary caregiver for a family member or friend with cancer, or having extensive experience working with cancer patients in an advocacy role.
- Have the willingness and ability to serve at least one five-year term; attend two SWOG conferences each year; and take part in monthly patient advocates teleconference calls. SWOG pays all group meeting travel expenses.
- Have the ability to uphold the ethical and confidentiality standards of SWOG.
- Have the ability to get and give feedback. Community advocates are encouraged to provide critical feedback to SWOG members and leaders on ways to improve our work. Community advocates also get feedback. Mentors provide ongoing observations and suggestions on performance, and once a year, the patient advocate liaison will conduct a formal 360 degree evaluation of community advocates. This will include feedback from mentors, members of the patient advocate committee, including the chair and vice chair, and members of disease and research support committees who've worked with the community advocate.
- Have the opportunity, if desired, to transition to a research advocate position as community advocates gain clinical trial development experience and as position openings that align with lived experience and skills. The patient advocate committee chair makes these nominations.

### **Duties of the Community Advocate**

The primary responsibility of the community advocate is sharing the perspective of the community or communities they represent. They will:

- Provide general or community-specific insights that support SWOG trials through every phase – define, review, design, implement, and share. This work can be requested by a committee or a community advocate can volunteer as an advisor.
- Partner with research advocates to support relevant disease-specific activities, such as suggesting strategies to improve patient enrollment, especially in underrepresented populations
- Work with SWOG patient advocates and staff to help create, review, and share information regarding SWOG clinical trials, especially related to under-represented patient populations.
- Provide input to SWOG leaders and investigators on how to better communicate with and meet the needs of their community(s) as well as provide feedback from their communities.
- Work as a member of the patient advocate committee, attending their calls and meetings and supporting their projects.

### **Benefits of the Position**

- Work with passionate, dedicated cancer patient advocates
- Work with experienced, engaged physicians, nurses, scientists
- Shape cancer clinical 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 American Society for Clinical Oncology annual meeting, the largest cancer conference in the world
- **Make a difference** SWOG trials have added more than 3 million years of human life to cancer patients and survivors