



**SolSurvivors Community Engagement Committee Charter
In support of the OHSU War on Melanoma
March 2016**



1. Mission

OHSU War on Melanoma/Dept. of Dermatology	Shared Mission	Sol Survivors Oregon
<ul style="list-style-type: none"> • Build research cohort • Conduct research using surveys, genetic testing, etc. • Conduct a public health campaign • Develop technology for earlier detection of lethal lesions 	<p style="text-align: center;"><i>Neither researchers nor patients can do this alone!</i></p> <ul style="list-style-type: none"> • Reduce mortality rates of melanoma in the state of Oregon • Build an active and engaged community of patient volunteers • Improve quality of life for patients diagnosed with melanoma 	<ul style="list-style-type: none"> • Bring the patient voice to research including raising awareness for issues that impact quality of life • Create awareness about melanoma in the community • Raise funds to support research • Recruit a diverse group of volunteers

2. Purpose

The SolSurvivors Community Engagement Committee, a joint initiative between SolSurvivors Oregon and the OHSU War on Melanoma, was created to ensure that the patient and caregiver perspective is taken into consideration for melanoma research and community outreach initiatives, especially those related to the OHSU War on Melanoma through the Melanoma Community Registry.

3. Responsibilities

Committee members will volunteer to assist in OHSU War on Melanoma activities:

- Help identify and prioritize potential research or outreach projects.
- Advise OHSU War on Melanoma (WOM) leadership about issues of relevance to melanoma patients and their families.
- Help recruit and retain Melanoma Community Registry members, including but not limited to community events, e-newsletters, etc.
- Work with and represent the OHSU War on Melanoma to achieve the goals and strategies in the community (research projects, education and outreach, fundraising, etc.)
- Review and provide feedback on web content, research protocols, recruitment materials, consent language, surveys, for the OHSU War on Melanoma as needed.
- Track and report volunteer hours

Serve as representatives of SolSurvivors Oregon in the community to carry out grassroots efforts such as:

- Fundraising
- Community events



- Informational website
- Social media
- Letter writing campaigns or other support for legislation to limit tanning bed use, etc.
- Developing strategic partnerships with pharmaceutical companies, sunscreen companies, etc.

4. Membership

Decision-making:

- The Committee will not serve in an official decision-making capacity for the OHSU War on Melanoma; rather, its recommendations and advice will be taken into consideration by War on Melanoma faculty and staff.
- Committee members may plan community engagement strategies independently on behalf of SolSurvivors Oregon (e.g. create patient-facing Facebook page or host a community fundraiser). However, if project intersects with the War on Melanoma initiative (e.g. conduct educational outreach in areas being targeted by War on Melanoma or utilizing OHSU War on Melanoma branding), Committee will coordinate and submit plans to War on Melanoma leadership to ensure that our common goals are carried out efficiently.
- In general, Committee decisions are made with consensus or majority vote; however, the committee chair may exercise veto power if justification is provided to the group (e.g. proposed activity is in conflict with another strategic initiative).
- The OHSU War on Melanoma leadership team may request participation or feedback on projects from the SolSurvivors Community Engagement Committee or vice versa.

Member characteristics:

- SolSurvivors volunteers who plan to work with the OHSU on War on Melanoma initiatives will complete the requirements of OHSU Research and Academic Volunteer Services (RAVS) including a background check, orientation and obtaining a badge. This will give them access to the building, computer access as necessary, and entitle them to the benefits and discounts available to OHSU volunteers.
- We will make a conscious effort to recruit for diversity (age, gender, race, disease stage, geographic, etc.)
- Specialized expertise that may be valuable to the committee may be sought, including but not limited to: public relations, graphic design, IT, law, and finance.
- Minimum of one OHSU Dept. of Dermatology staff member will serve on the committee.
- A member of the War on Melanoma leadership team or OHSU researcher will attend quarterly Committee meetings.
- The War on Melanoma leadership team will receive monthly reports on committee activities from the committee chair.
- Committee will have at least 6 members, but no more than 12 members.
- Committee members will participate in at least one team building exercise or retreat per year.



Member selection process:

- Committee members will have a track record of meaningful contributions to melanoma outreach. Members are selected based on past community contributions, such as serving on an event planning committee or contributing to PCORI P2P project.
- For the first year, currently active volunteers will have an opportunity to express their interest in joining the committee. The PCORI P2P project director will nominate committee members.
- In the first year, the Committee will develop a recommendation for how to solicit, select, and onboard new members.

Leadership:

- The PCORI P2P project director will serve as chair of the Committee for the first year.
- The chair will manage the committee and organize its meetings with assistance from the Melanoma Community Registry coordinator.
- In the event that the chairperson is indisposed, remaining members of the committee will nominate a new chairperson.
- The Committee chair will meet with War on Melanoma leadership as needed to provide updates on committee activities.
- OHSU staff (non-volunteer) will serve on the committee to provide support, recruit volunteers for projects, and provide training or access to resources needed for the functioning of the committee.

Roles and responsibilities:

- All committee members will have opportunities to contribute to various aspects of the PCORI P2P project. However, the following roles have been established to empower committee members to provide leadership in the following areas:

Role	Responsibilities	Currently assigned to
Committee chair; P2P patient project director	P2P project director; committee chair; provides strategic oversight of PCORI P2P project; serves as primary contact with CFPHE and leads reporting to PCORI	Katie Wilkes
Community/academic committee liaison; P2P project coordinator	P2P project coordinator; serves as liaison between community partners and OHSU Department of Dermatology; attends committee meetings; coordinates meeting logistics	Elizabeth Stoos
P2P academic co-investigator	P2P project academic co-investigator; provides strategic oversight of PCORI P2P project; leads OHSU War on Melanoma initiative; meets with committee at least quarterly	Sancy Leachman, M.D, Ph.D.
Co-chair of events	Plans Committee’s involvement in events such as the Community Research Forum, Skin Cancer Research Expo, etc.	Robin Zimmerman



Co-chair of events	Plans Committee's involvement in events such as the Community Research Forum, Skin Cancer Research Expo, etc.	Stephanie Heilman
Co-chair of research advocacy	Provides support for committee chair on completing deliverables required by P2P project	Pam Beck
Co-chair of research advocacy	Committee member; co-chair of research advocacy	Mary Pat Berry
Co-chair of strategic outreach	Researches and develops relationships with community organizations and other influencers who can enable SolSurvivors to expand its outreach into underserved communities	Laurie Terrell
Co-chair of strategic outreach	Researches and develops relationships with community organizations and other influencers who can enable SolSurvivors to expand its outreach into underserved communities	Cathy Law
Chair of marketing and community education	Develops marketing and communications strategies to support the mission of committee	Jennifer Millar
Chair of business management	Supports committee finances/budgeting and organizational structure development	Gale Pudlitzke

5. Procedures

Meetings:

- The Committee will meet at least quarterly at OHSU or via videoconference.
- The P2P project coordinator will provide administrative support for the meeting, such as assistance with scheduling, ordering catering, and preparing meeting documents.
- A designated officer will be responsible for the distributing the agenda, recording and distributing minutes, following up with reminders on action items, corresponding with members, etc. This role rotates on a quarterly basis amongst committee members.
- Meeting notes and corresponding materials will be saved on shared Dropbox folder for future access.

Compensation:

- Committee membership is a volunteer position; no compensation is guaranteed for participants. However, committee members may be eligible to receive compensation in exchange for committee participation, meeting attendance, and other work from a specific grant or research contract such as the PCORI P2P award.
- OHSU volunteers are eligible to many discounts to local businesses and services, including public transportation and OHSU will provide documentation of volunteer services for career or academic development.



- Similarly, committee members may be eligible to receive travel reimbursement if funding is available from a grant or contract. Travel reimbursement is not guaranteed.

Terms:

- Committee members commit to serving on the committee for a minimum of one year.
- Committee members must make their best efforts to attend all regularly scheduled meetings.
- Failing to attend more than half of committee meetings or becoming unresponsive to phone and/or email communication will nullify an individual's membership.

Conflict of interest:

- Committee members are required to disclose any perceived conflict of interest prior to accepting their nomination.