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Survivor advocacy: I speak for those who can't

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ABSTRACT

The 12th Biennial Ovarian Cancer Research Symposium held on September 13–15, 2018, brought together ovarian cancer scientists, clinicians, survivors, and advocates in Seattle, Washington. The Symposium featured a panel on 'The role of advocates in ovarian cancer research' aimed at facilitating discussion between scientists and patient advocates to enable a more patient-centric approach to ovarian cancer research. Here we describe learnings from panelists that included seasoned research scientists and patient advocates.

I attended the panel discussion on 'The role of advocates in ovarian cancer research' during the 12th Biennial Ovarian Cancer Research Symposium and I learnt something new that I have actually known all along: *there aren't many ovarian cancer survivors; therefore, there aren't many ovarian cancer survivor advocates*. Ovarian cancer accounts for only 2.5% of cancer diagnoses in women, and the survival rate is much lower than that of other cancers. Of those who survive, some will not be well enough to advocate or have the mental energy to act. Therefore, I—an ovarian cancer survivor—am one of a relatively small number of people with the experience, ability, and interest to be a survivor advocate.

Survivor advocates are people who have navigated a diagnosis of cancer and its subsequent treatment, and who share the knowledge gained through their personal experience with a broader audience. The goal in disseminating the panel's collective wisdom on the topic of advocates in research is to bridge the gap between the advocate who wants to make an impact on a disease that affected them personally, and the scientist who spends their career trying to affect the same disease but without the perspective of one who has lived through it. Hopefully, by explaining some of the possible ways that advocates and scientists can interact, ovarian cancer scientists will be inspired to incorporate patients' perspectives into all aspects of their studies.

The panel emphasized that survivor advocates can and should be involved in every step along the cancer research path. Advocates bring the patient perspective to researchers for use in grant proposals to get research support. Advocates can play a critical role by posing questions to the scientists to help them better frame the topics to be examined,

and to question their assumptions. Advocates can provide feedback about the layperson's summary in grant abstracts and in clinical protocols. Advocates can also help to publicize clinical trials or spread other information through their close-knit network of survivors/friends. And, of course, they can advocate for legislative action and additional research funding. Through the process, advocates, by their very presence, emphasize the needs of the patient and the related need for urgency, paving the way to patient-centric healthcare.

There are many ways to get started in advocacy. To gain a better understanding, advocates can attend cancer research conferences to learn about the current state of research and meet those involved in it. The conferences also provide an excellent opportunity to meet other survivor advocates and scientists; that network can lead to advocacy opportunities. Additionally, several organizations, such as SHARE Cancer Support, the Research Advocacy Network, and the Ovarian Cancer Research Alliance, provide training, including online courses, and conferences specifically for those interested in advocacy. The training in basic medical research terminology and scientific concepts provides advocates with the necessary information to advocate knowledgeably. Some groups also provide advocate mentorship, pairing new advocates with those with experience. Even organizations that are not cancer-specific can provide relevant advocacy information and training.

Advocates can also contact local healthcare institutions and research centers in their area to determine whether there are existing advocacy programmes they can join. These entities may have advisory boards, advocacy networks, or survivor support groups with openings for advocates, or may welcome advocates to share their stories in educational settings. Regional and national organizations such as the National Institutes of Health and the National Cancer Institute (NCI) also have advocacy opportunities through their advisory boards or other programmes. For example, NCI's Office of Advocacy Relations specifically works to connect survivors with NCI to improve cancer research. And finally, organizations that allocate research funds, such as the Department of Defense Ovarian Cancer Research Program, use survivor advocates to review grant applications and clinical trial approvals.



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Several simple steps can be taken by advocates at the grass-roots level. Those interested in policy adjustments or funding enhancement can write to their congressional representatives to encourage change, especially by emphasizing the amount of money that comes into their districts as a result of the funds they allocate to cancer research. Advocates can themselves raise funds for research through numerous fundraising activities. They can post their survivor status on social media; spreading the word about survivorship status can help lead to advocacy opportunities. Advocates can also use social media to disseminate information about medical research, such as clinical trials, to their networks of survivors/friends. Finally, advocates can simply ask relevant organizations: "What can I do to help?"

From their experience, survivor advocates gain the opportunity to give back to the scientists who pioneered their life-saving treatment, and to give their survival a purpose. In return for their service, advocates ask only that scientists use their collective voice to inform Congress by contacting their representatives at key times and exercising their right to vote. Advocates also appreciate it when the scientists can cover their out-of-pocket expenses by including those expenses in the grant proposals.

Like the survivor advocates on the panel, *I keep losing my friends*. Once I disclosed my ovarian cancer diagnosis I became a magnet for anyone who knew someone with a similar diagnosis. Suddenly, I knew many women with ovarian cancer, who I now count among my friends. But as ovarian cancer continues its insidious attack I also have more friends who have succumbed to its assault. As a result, I have become even more passionate about advocating. *I am the voice of those who can no longer speak for themselves*.

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