

CancerScope

Oncology Issues in FOCUS | BY CARRIE PRINTZ



Cancer Groups Face Funding Crisis During the Pandemic

Cancer advocacy organizations around the globe have had to quickly adapt to diminished resources and other challenges triggered by the coronavirus disease 2019 pandemic

As the coronavirus disease 2019 (COVID-19) pandemic persisted through the spring and fall, Ovarian Cancer Canada worked to quickly transition its largest annual fundraiser—the Walk of Hope, held during September in 35 cities—to a virtual format. Instead of gathering for in-person events filled with cheering onlookers, participants walked alone or with just a few relatives and friends in their own neighborhoods to raise money for the nonprofit.

Ultimately, this year's Walk of Hope brought in just 55% to 60% of the revenue that it did last year, but the organization's leaders saw reason to be optimistic. "We demonstrated that our community is still very engaged," says Elisabeth Baugh, Ovarian Cancer Canada's chief executive officer. The organization followed the event with a virtual wrap party, an element that the leaders hope to continue even after the pandemic subsides. They transitioned all of Ovarian Cancer Canada's other events online as well, including a national symposium in October, and expect to continue doing so until the fall of 2021.

Ovarian Cancer Canada's quick pivot is just 1 example of how cancer advocacy organizations worldwide have had to adapt nearly overnight to the challenges of the COVID-19 pandemic. Moreover, with significant declines in corporate sponsorships and individual donations and with the cancellation of major in-person fundraising events, some organizations have been forced to make sizable cuts to their funding and services.

To better understand and illuminate just how widespread these pressures are, 5 global cancer coalitions and alliances that represent 400 patient advocacy and other cancer organizations worldwide conducted a survey of their member groups in May. The coalitions—the World Ovarian Cancer Coalition, the World Pancreatic Cancer Coalition, the Lymphoma Coalition, the Advanced Breast Cancer Global Alliance, and the World Bladder Cancer Patient Coalition—received responses from 157 organizations in 56 countries, with the majority from the United States, Australia, Canada, Italy, and the United Kingdom. The results were concerning, says Clara MacKay, the chief executive officer of the World Ovarian Cancer Coalition.

"Nearly all of [the groups] are projecting a drop in income—some up to 50%," she says. "These organizations had to change on a dime the way they operate, in terms of how they provide services, and those that fund research have all been negatively impacted in terms of how much they can continue to invest."

Indeed, the survey findings, which were published in *The Lancet Oncology*¹ in August, revealed the following:

- Ninety-two percent of the organizations provide support services to the community. The groups typically serve as a critical point of contact for vulnerable people, and this increased during the pandemic: approximately 57% of the organizations reported a rise in the number of calls and emails that they received.
- Many organizations are struggling financially, and only 5% felt confident about their current financial position.
- Seventy-nine percent predicted that their income would decline during the next 12 months. The average expected decrease was 46%, with responses ranging from 7% to 95%.
- Seventy-one percent reported the need to review budgets and available income, and more than half have already had to reduce costs.
- Eighty-nine percent of the organizations said that they had to alter their services for patients with cancer in some way. Furthermore, 68% of the organizations involved in health professional education activities had to change their services, shift materials online, or temporarily stop their programs.
- Of the organizations that fund research, only 48% expect to resume funding that research when the pandemic is over.

According to MacKay, the goal of the survey was to highlight the hardship that patient advocacy and cancer organizations are

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← experiencing and the value that they bring, particularly with regard to providing direct services to patients. Amid fears that the fall could bring another spike in COVID-19 cases, the coalitions plan to conduct a follow-up survey in December to determine how these organizations have fared 6 months after the initial survey.

“Our concern is a second wave and lack of preparation in the health care system in terms of cancer services, as well as fatigue among health care workers,” MacKay says. “We need to be in front of it.”

She adds that some of the smaller organizations that are primarily run by volunteers may stand a better chance of adapting more quickly during the pandemic than larger ones, and this improves their chances of survival. Survey organizers also issued a statement regarding the importance of following best practices for helping patients with cancer through the pandemic. These include

- Ensuring that there are hospitals in the community that have been designated as COVID-19–free centers where patients with cancer can be treated or, if this is not possible, that hospitals provide onsite separation of patients with cancer;
- Ensuring rapid catch-up to post–COVID-19 levels of cancer treatment, screening, and follow-up;
- Incorporating ambulatory services that can be delivered in a patient’s home;
- Providing telemedicine services that help to decrease the need for in-person hospital visits; and
- Developing innovative ways to involve family and caregivers in consultations, such as virtual sessions.



Karen Taylor, who has ovarian cancer, was one of the many volunteers who lent their support to a virtual version of the Ovarian Cancer Canada Walk of Hope this year. She is pictured with her husband John Hare.

Cancer organizations globally are focusing on the areas of greatest need, and in some cases, that means they have had to reduce their advocacy activities to bolster direct patient services. Over time, those reductions could have serious implications, MacKay says. Still, she notes, some positives for the cancer community have arisen from the COVID-19 crisis. For example, the coalition of global cancer organizations that conducted the survey will likely collaborate on future, shared areas of concern. In addition, the use of telephone support groups and other virtual events has enabled more people to participate than ever before.

“I’m very proud of the sector I’m working in,” MacKay says, noting that her colleagues

have been innovative and resourceful in a difficult time. “I feel strongly about acknowledging the huge contribution that cancer patient advocacy groups make, and I think local and national governments should be thinking about them as a crucial part of the health economy.”

Meanwhile, leaders of organizations such as Ovarian Cancer Canada are continuing to work hard to educate and reach out to their communities.

“Cancer didn’t go away just because of COVID-19, and we need to be a loud voice to make sure people are paying attention to their health and symptoms,” Baugh says.

Reference

1. Nelson R. Organisations for patients with cancer feel the brunt of COVID-19 pandemic. *Lancet Oncol.* 2020;21:1020. doi:10.1016/S1470-2045(20)30389-2

DOI: 10.1002/cncr.33331

Experts Say That Funding for Cancer Research Is at Risk During the Pandemic

Over the past 5 years, the US Congress has approved an increase of \$11.6 billion, or approximately 39%, for the National Institutes of Health (NIH) budget, which has enabled significant research funding. However, with the arrival of the coronavirus disease 2019 (COVID-19) pandemic, experts say that future funding and medical research progress are now at risk.

“The consequences of the pandemic on the entire medical enterprise are extremely concerning for the medical research community,” says Jon Retzlaff, MBA, MPA, chief policy officer and vice president of science policy and government affairs for the American Association for Cancer Research. “It’s why we’ve been advocating for \$15.5 billion to be included in the next COVID-19 relief supplemental appropriations bill.”

The financial challenges that universities and medical centers have been experiencing as well as significant disruptions

in laboratory and clinical research during the pandemic have all taken a toll and led to lost research opportunities, he says. Researchers are concerned that they could lose entire germ lines and mouse colonies and that fewer patients have enrolled in clinical trials. Meanwhile, many laboratories and most supplemental government research dollars have been redirected toward COVID-19 research.

According to Retzlaff, of the \$15.5 billion requested for the NIH, \$10 billion is needed to offset the expenses associated with research disruptions that have occurred during the pandemic. At press time—shortly before Election Day—he did not anticipate that Congress would approve a COVID-19 relief appropriations bill until after the presidential election.

In addition, he and fellow medical research advocates requested a \$3 billion increase in NIH’s fiscal year 2021 budget to continue the institutes’ robust research efforts. He praises

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