

TWENTY YEARS OF HOPE, COMMUNITY & COURAGE

By Bridget Cook

For twenty years, OutRun Ovarian Cancer (OROC) has organized grassroots fundraising and awareness efforts in Northeast Ohio. The organization hosts an annual 5K and 1 Mile Run/Walk in downtown Cleveland, focused on unifying patients, raising awareness, recognizing survivors and most importantly, fundraising for a future free of ovarian cancer. This year's race will take place on Saturday, August 5th at Voynovich Park, with a virtual option available as well.

Motivated by personal connections to ovarian cancer and a drive to generate better screening and treatment options for patients, the founders of OROC have much to be proud of as they reflect on all that's happened since 2003. By uniting patients, providers, and researchers into one community, OROC has shed light on the symptoms and impact of an ovarian cancer diagnosis, all while funding crucial research to create better outcomes. Since its inception, OROC has raised over \$2,000,000 in funds directed towards research, advocacy, and supportive initiatives for patients.

One of OROC's founding members, Gretchen Nock, reflected on the changes the organization has witnessed and contributed to over time. "Immunotherapy has come a huge way from when we first started - I think women are living longer," said Nock. "When we started OROC twenty years ago, ovarian cancer was usually caught at a later stage - the prognosis is better, and women are living and thriving longer with the disease. Treatments are extending lives, so that's good news - for all types of cancer."

Data from the National Cancer Institute shows that the rate of new cases of ovarian cancer has steadily fallen, from 15.0 new cases per 100,000 persons in 1992 to 9.1 new cases in 2020. Progress in the form of a screening test would assist this momentum even more - among researchers, patients and advocates, the development of a universal screener continues to be a top priority. "That's our biggest frustration - that there isn't a widespread diagnostic test. It's also our biggest hope, and I think that we are within five years of that coming to fruition," Nock explained.

Dr. Chad Michener, a Staff Physician in the Department of Obstetrics and Gynecology at Cleveland Clinic, is a long-term partner of OROC and a part of research endeavors made possible by OROC. He echoed the same sentiments as Nock. "We'd love to have a screening test for all women instead of just those high-risk patients," said Michener. "It's really the holy grail in ovarian cancer research to find that screening test that can be offered to everybody. We've got some work to do there."

Ovarian cancer research and treatment have evolved considerably since 2003, as Dr. Michener was able to attest. "Probably the most significant thing recently is PARP inhibitors. These were derived to help treat our patients that have BRCA mutations, really to use those as maintenance therapy for those patients," Michener explained. "That has since moved into first-line therapy. If patients carry any mutations that are in that kind of family, they'll get offered a PARP inhibitor after chemotherapy. That has shifted not only disease recurrence, but also the

long-term chance for survival. Those patients are living longer when we look at 3, 5 and 7-year outcomes, which is a significant change."

Dr. Michener also noted OROC's presence in advocacy and unifying patients. "They're educating patients about the symptoms to get checked for, going to regular checkups, not waiting when they do have those symptoms - I think that's been a really big part of OROC being in the community. It's also given patients a sense of support with one another."

Cancer research, advocacy and support of any kind is in many ways a relay race, with each generation uncovering new methods and breakthroughs. Nock indicated that OROC looks forward to passing its baton to a younger generation ready to step into the fight. "We started OROC twenty years ago as a grassroots movement - we still are! Yet we must start thinking longer term. We need to bring in the next generation, encouraging more young moms and young women to get involved - that's our call to action. We're proud of how far we've come and want to be able to pass this on. The original OROC volunteer group is still involved. It's been a 'Little Engine that Could' since the beginning."

A crucial part of that transition to the future, Nock believes, is through social media. "I think that social media can be such a force for good - we all know the downside of it, but there's also an upside. Your social media presence can be very impactful," Nock said. "Making your voice heard in the medical community, or in the political community - it's all a huge opportunity. What I love about younger generations is they're so open to learning and dialoguing - whether it's mental health or physical health. Now, everything is so open, and I think that's going to be amazing going forward with this, I really do. I'm hopeful."



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