

# Bright Spot on Collaboration and Partnership: Rhode Island's Ovarian Cancer Survivorship Task Force



The Rhode Island Department of Health (RIDOH) Comprehensive Cancer Control (CCC) Program implements policy, systems, and environmental (PSE) change public health strategies to reduce the statewide burden of cancer. While most efforts focus on improving survivorship, screening, and early detection, the CCC Program works closely with the Rhode Island Cancer Registry and health care providers to identify other opportunities for improvement of outcomes. These include timely access to diagnostic workup and stage at diagnosis, both of which directly affect ovarian cancer survivorship.

Annually, ovarian cancer accounts for about 2% to 3% of all new cases of cancer diagnosed among women in Rhode Island. Although it is the second most common gynecologic cancer diagnosed among Rhode Island women, ovarian cancer is the primary cause of death from gynecologic cancers in the state. Overall, 51% of patients diagnosed between 2004 and 2017 had metastatic disease, illustrating the

difficulties in early diagnosis of ovarian cancer.<sup>1</sup> Survivorship outcomes can be improved through an expedited diagnosis and referral to a gynecologic oncologist for treatment when that is possible.

## Ovarian Cancer Demonstration Project

To increase survival from ovarian cancer, CDC funded a demonstration project in 2019 to build evidence for strategies to increase knowledge and awareness of gynecologic oncologists' roles in ovarian cancer treatment and to increase receipt of ovarian cancer care by a gynecologic oncologist. The RIDOH CCC was one of three National Comprehensive Cancer Control Program awardees selected for this project.

## Convening the Task Force

RIDOH CCC Program staff worked with The Partnership to Reduce Cancer in Rhode Island (The Partnership) and the state's cancer prevention and control coalition to



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convene the Rhode Island Ovarian Cancer Survivorship Task Force (Task Force). These entities collaborated to enlist a core group of survivors, caregivers, advocates, and health care providers who agreed to share their lived and professional expertise to help develop and implement the work plan for this demonstration project. This group was formalized as the Rhode Island Ovarian Cancer Survivorship Task Force and continues to serve as a working group of The Partnership following completion of the demonstration project.

### Engaging the Task Force

The Rhode Island Ovarian Cancer Survivorship Task Force met and deliberated about what activities would best meet the project's goals. It settled on four strategies:

- **A program for health care professionals in-training to increase their understanding of the human toll of ovarian cancer.** The Ovarian Cancer Research Alliance's (the Alliance's) Survivors Teaching Students® program exposes future health care professionals enrolled in degree-granting programs to survivors of ovarian cancer, the health effects that ovarian cancer can have on women's lives, and the prognostic toll caused by delays in referral and diagnosis in women who present with ambiguous symptoms. Task Force members invited the Alliance to facilitate trainings for nursing, physician assistant, and social work students, and networked to identify Rhode Island college and university faculty whose students might benefit. The Alliance trained 167 students through eight workshops at five institutes of higher learning, three of which have since requested additional workshops.

### Members of the Rhode Island Ovarian Cancer Survivorship Task Force:

- **Joseph Dziobek, MSW**  
*Director, The Partnership*
- **Megan Daniel**  
*Administrator for Community Partnerships, The Partnership*
- **Linda Dziobek, RN**  
*Ovarian cancer survivor and advocate*
- **Norma Hardy, MEd, CHES**  
*Ovarian cancer survivor and health educator*
- **Donna MacDonald, BSN, RN, OCN, CCM**  
*Case Manager in Oncology at Women & Infants Hospital*
- **Diane Martins, PhD, RN, FAAN**  
*Professor, University of Rhode Island College of Nursing*
- **Jennifer Scalia Wilbur, MS**  
*Clinical Program Manager of Women & Infants Hospital, Cancer Genetics and Prevention Program*
- **Matthew Oliver, MD**  
*Gynecologic Oncologist, Women & Infants Hospital*
- **C. Kelly Smith, MSW**  
*RIDOH CCC Program Manager*
- **George Andoscia, MPH**  
*RIDOH CCC PSE Specialist*

**Many other providers, survivors, and educators volunteered their time and expertise as presenters and panelists for project activities.**

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- **Two provider education events.** The Task Force created and hosted two provider continuing medical education opportunities, **Identifying Ovarian Cancer Symptoms: Promoting Early Diagnosis, Treatment, and Improved Outcomes Through Rapid Referral** (<https://cme-learning.brown.edu/RapidOnDemand>), a live webinar event, and **Making a Difference: Expediting Diagnosis of Ovarian Cancer: A Virtual Roundtable Discussion** (<https://cme-learning.brown.edu/DifferenceOnDemand>), a live roundtable discussion. Task Force members enlisted panelists and presenters with expertise and insights to help motivate Rhode Island providers to improve early detection of ovarian cancer. Task Force members Dr. Matthew Oliver and Jennifer Scalia Wilbur, shared expertise as roundtable panelists on the roles that gynecologists and genetic counselors can play in expediting patients' referrals to gynecologic oncologists. Task Force members also helped market the events by identifying relevant organizations and professional associations to target with promotional material.
  - **A tool kit.** Thanks to members of the Task Force, content for the **RIDOH Ovarian Cancer Survivorship Tool Kit [PDF-243KB]** (<https://health.ri.gov/publications/toolkits/2020RI-Ovarian-Cancer-Resources.pdf>) was curated by members of the audiences for whom it was created. Survivors, caregivers, nurses, and a genetic counselor in the group identified resources valuable to providers, survivors, and caregivers. Task Force members identified 34 resources for providers and patients, many available in more than one language. This tool kit was shared with the 73 individuals who registered for the live Roundtable and with the 467 members of The Partnership's mailing list.
- Task Force members recognize the value of continued efforts to educate providers, caregivers, survivors, and the public about ovarian cancer diagnosis and survivorship. They are continuing their work through The Partnership and are striving to increase use of genetic counseling and testing for ovarian and other hereditary cancers.

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## Considerations for Establishing and Working With an Ovarian Cancer Task Force

To succeed in completing a project such as this, it helps to create a diverse and multidisciplinary public-private partnership. Convening this diverse group of individuals with professional expertise and lived experience allowed for well-rounded efforts to address the needs of health care providers and ovarian cancer survivors, whom this project sought to support. Meanwhile, paid staff from The Partnership provided administrative support for planning meetings and documenting progress, which allowed most members to volunteer their energies for the collective good of the project's goals and objectives.

The COVID-19 pandemic in 2020 exacerbated challenges that are typical of convening voluntary work groups. Public health measures abruptly prevented biweekly in-person

meetings, and RIDOH CCC staff's sudden deployment to the pandemic response unit led to the pause of meetings for six months. While this break delayed implementation of project activities, the eventual solution improved subsequent participation. The Task Force used a virtual platform to resume meetings safely, which allowed recording, and the convenience of telecommuting increased members' participation.

Forming a multidisciplinary planning body added quality and depth to the project's educational products and empowered the survivors who participated. Because all Task Force members contributed diligently to the project's implementation, goal accomplishment was team-focused and investment-driven. The project's results included one unplanned success—formation of a committed group of partners determined to sustain their momentum for years to come.

## More From Rhode Island's Ovarian Cancer Demonstration Project



**Identifying Ovarian Cancer Symptoms: Promoting Early Diagnosis, Treatment, and Improved Outcomes Through Rapid Referral**  
(<https://cme-learning.brown.edu/RapidOnDemand>)



**Making a Difference: Expediting Diagnosis of Ovarian Cancer: A Virtual Roundtable Discussion**  
(<https://cme-learning.brown.edu/DifferenceOnDemand>)



**Rhode Island Department of Health Ovarian Cancer Resources Tool Kit**  
[PDF-243KB] (<https://health.ri.gov/publications/toolkits/2020RI-Ovarian-Cancer-Resources.pdf>)

<sup>1</sup>Rhode Island Cancer Registry. (2020, October). The Burden of Ovarian Cancer in Rhode Island. Retrieved from <https://health.ri.gov/publications/databriefs/2020GynecologicalCancers.pdf> [PDF-1.3MB]