Ovarian Cancer Podcast Series – Rhode Island Ovarian Cancer Survivorship Task Force Episode Transcript

[Announcer] This program is presented by the Centers for Disease Control and Prevention.

Announcer: Welcome to our podcast series on CDC's Ovarian Cancer Demonstration Project. I'm your host, Jake Lynn.
Did you know that ovarian cancer is the fifth leading cause of cancer death among women in the United States and the second most common type of female reproductive cancer?
Today, I spoke with George Andoscia from Rhode Island and several members of the Rhode Island Ovarian Cancer Survivorship Task Force—Jennifer Scalia Rover, Linda Dziobek, and Donna MacDonald. We discussed why and how the Task Force was convened and its role with a CDC demonstration project to increase gynecologic oncologist involvement in the treatment for ovarian cancer. While there is no simple and reliable way to screen for ovarian cancer in asymptomatic women, a woman's chances of survival increases if her treatment is given or directed by a gynecologic oncologist
Let's meet our guests.

George: Hi, my name is George Andoscia and right now I am the Acting Program Manager in the Rhode Island Department of Health, Comprehensive Cancer Control Program. When this project started and for most of the project period, I was the policy systems and environmental change specialist. So, my role in the demonstration project was really just kind of to take over coordination while C. Kelly Smith who was the previous program manager was pulled full time to work on our COVID response network.

Jennifer: I am Jennifer Scalia Rover. I am the Co-Director of the Cancer Genetics and Prevention Program at Women and Infant's Hospital and Care New England systems. I was invited onto the Task Force for the Ovarian Cancer Demonstration Project primarily, I would say, to contribute my expertise and provide guidance as it relates to cancer genetics, genetic testing, risk reduction and prevention.,

Linda: Hi I am Linda Dziobek. I am a volunteer member of the Partnership to Reduce Cancer in Rhode Island, the cancer coalition here. And I've been involved with the coalition since its inception. Currently, my role on the Task Force is as an ovarian cancer survivor and there to sort of share my living experience. I am also a nurse and have for 15 years worked in healthcare for the homeless, so sharing that experience and knowledge with difficult to reach populations.

Donna: Hi I am Donna McDonald. I am a Registered Nurse, Case Manager for the program in Women's Oncology and Women and Infant's Hospital and also an ovarian cancer survivor. My role on the Task Force was as a member, took some leads on some of the projects. I was asked to be a member of this group by I think it was Linda and Kelly.

Announcer: Very good, thank you all again for joining me. One of the successes that came out of this project was the great collaboration between the demonstration sites and their partners. In Rhode Island, you convened a Task Force, separate from your State Comprehensive Cancer Coalition, to guide the planning and implementation of your strategies. I'd like to hear about why and how the Task Force was convened and the role of the Task Force within the demonstration project. George, can you start us off, talking a bit about the Department of Health's decision to create an independent Task Force?

George: Well, we kind of wanted to make sure that the folks who were at the table working on this either had professional or lived experience with ovarian cancer. We knew this project

would be most successful if it was informed by and kind of owned by what Kelly and I refer to as a coalition of the willing. So again, in this case that coalition was made up of a group of folks who, you know, have a lot of experience with ovarian cancer, either through experience as survivors or as healthcare professionals who have been helping patients for years.

Announcer: Excellent, thanks George.
Jennifer, Linda, and Donna. Tell us a bit about how you were recruited to join the Task Force for the demonstration project, and what motivated you to participate.

Linda: Well, I will jump in! Kelly had reached out to me early on when she was thinking about pursuing the funding. And we had a discussion and a number of phone calls about who were the key stakeholders in our community. And so, my personal motivation was really sort of selfish in some ways. And my own personal experiences has been exactly that, my diagnosis was initially delayed by months before a diagnosis was made, and initially misdiagnosed. So that and the fact that I have daughter, and so we wanted to be able to say I don't want my daughters or granddaughter to go through this or any other woman in our state, or anywhere to be able to go through what my experience has been.

Announcer: Donna? How did you come to join the Task Force?

Donna: Yes, so as I said before I think I was asked by Kelly and Linda. I knew that folks were talking about this, and when I was asked, I went, oh another committee. So, I had to run it through what I call the Donna test. And um, I had to really evaluate will this make an impact on the patients that I care for and other cancer survivors. And after I read about it and heard about it, I said yes and then the second Donna test is you know, will it make a difference in the care that we provide to our women that face this disease and their families. And the answer was yes, so the answer was, "Yes, I'll join the committee."

Announcer: And finally, how about you, Jennifer?

Jennifer: So, I was approached by Kelly in the Rhode Island Department of Health to work on the Task Force. Again, to kind of coordinate these projects and activities under the grant. Um, I have to say I am really excited that Linda was selfish because the Task Force wouldn't have been anything without her. She was a driving force behind this group. And what motivated me to participate, I have always been very passionate about reducing the incidences of cancer, helping find cancers, at earlier and more curable stages.

Announcer: Great, thank you all. Were there any governing documents or structures, for example a charter or by-laws, that were created to guide how Task Force members would work together to complete the work for this demonstration?

Linda: I'll sort of say that the Partnership to Reduce Cancer at the time was, being in the coalition we're part of the Comp Cancer Program at the Department of Health. And since the fall of last year, we've now become a separate organization. We have a 501(c)(3) nonprofit status. But we already had in place the support of the executive director of the partnership, and also the community manager of the partnership. And those two individuals dedicated their time to setting up the structure of the meeting schedule and maintaining, providing us with a mechanism called Base Camp to communicate. And we use that along with email and text and face-to-face meetings. But then again COVID hit, and then when we ramped up again, we sort of adapted to Zoom.
I would also say that the other piece is that we always had the support of the Department of Health. You know Kelly kept in touch with us even though, her work had to switch over to COVID and the same with George. And the part that you're saying, I think it was easy for us to sort of adapt to Zoom. And I think the positive aspect of Zoom was that it made it very helpful. We didn't have to travel, although I miss the face-to-face meetings, we didn't have to travel. It was easy to slip out of your office and get on a Zoom call or wherever you were, so geographically folks who probably couldn't have participated in

the past having to travel to meeting sites, were now able to. So, I think that also expanded and made it broader, the participation on the Task Force.

Announcer: Wow, that's interesting, so there was an unintended positive outcome from all this. George, just speaking from the perspective of the Department of Health, how did you all collaborate and interact with the Task Force to plan, implement, and evaluate certain strategies?

George: I think we followed some of the practices that we had in place just collaborating with the Partnership to Reduce Cancer in Rhode Island. You know we worked with some of the work groups that have existed under their umbrella for years. And I can't speak probably as much as others on the call to how some of the strategies were decided upon, but I think some of the strategies that were chosen might not have been initially proposed with the grant application but kind of rose organically from conversations and the needs that were identified by the people at the table.

Jennifer: I would just support George in just that you know I think the strategies definitely did kind of evolve as we kind of you know continued meeting.

Announcer: And then around the midpoint of the demonstration project, the Task Force decided to become an official project of Rhode Island's state cancer coalition, called the Partnership to Reduce Cancer in Rhode Island. Donna, can you tell us a bit about how this decision was made?

Donna: I think that it naturally made sense. It was just sort of organically happening. Um, you know we met a lot of the, we hosted here at Women and Infants a lot of the meetings, so you know the partnership doesn't have a definitely home. They do have an office, but it just organically happened that we were coming from multi organizations, and we just met together. So, it became a separate committee. But well working and we inter-collaborated quite a bit.

Announcer: Great, thanks. Now I want to switch gears and talk about the factors that made it easier or more difficult when convening the Task Force.

Donna: I think so many of our members were highly, highly invested in this project, either from being a survivor, being a community partner, wanting to get the task done, the mission was there. And I think we all worked very well together and it just, we motivated each other. I think everybody was highly motivated to get this work done. And to get it done well. And then having some of our outside partners, be it Brown University in their continuing medical education group, they were highly motivating when it came time to start the production and goals and objectives and really kept us on the pathway and moving along.

George: I'll echo kind of something that Linda mentioned. Tapping into the state cancer coalition especially, you know the partnership that we have here, they have a really active board. And their members, you know, are consistently engaged and invested in the work and the success that comes from it.

Announcers: That's great. Were there any barriers you can recall?

Donna: When I look at some of the barriers, I always try to see some of the sunshine in there. And we did have a ray of sunshine in the fact that we had a big breakfast planned for our providers and a whole education program surrounding that and then COVID hit, and we couldn't have a breakfast, so we had some extra money. So, the blessing there was we had extra money and we were actually able to do some other things.

Linda: I would say one of the things that we didn't expect was COVID-related. One of the objectives was to work with the local chapter of Rhode Island Ovarian Cancer Alliance and get that established. We had done some sessions with students. And then once COVID hit, the universities and colleges shut down, so we didn't have access to those students. It shut down for a number of months before it resumed, I think like in late fall of

last year to then start getting into the schools and that was very limited so that was sort of out of our hands.

Jennifer: I would speak to just one other big barrier. It's a bit COVID-related but I think it has to do with Zoom and Zoom platforms, which I think is going to probably be much more common moving forward. Because as we all spoke about it's such a positive, we can reach so many more people but there's also, we also had some difficulty and I guess specifically during the round table where a physician couldn't access the Zoom. So that I think was tough and I think probably will be something that we all have to think about moving forward, because I think we'll probably use these platforms more often to reach more patients and healthcare practitioners.

Announcer: Okay. Now what's the key to sustaining and building this partnership and keeping it going moving forward?

Linda: So, funding is number one. Two, having folks that still have the excitement or the passion to be able to continue the work and committed to it and to reassess. I think we're at the point right now to reassess what we want to do going forward.

Donna: Yeah, I think one of the recommendations for any group such as this is really keeping it patient centered, survivor centered, and having those folks be a major part of the committee and really listening to what they have to say, um because through their stories, that's where the work gets done and that's where it's meaningful and purposeful.

Linda: And just adding to that, the webinar that we did and the round table along with Brown University is going to be available to providers for two years. And they'll be able to get continuing medical education units for that. So, I think that's another piece that we're able to sustain over time.

Announcer: Perfect, thank you Linda. Do you all have any recommendations for other comprehensive cancer control programs that are looking to convene a Task Force, one that would help plan and implement strategies to increase referrals to a gynecologic oncologist among women diagnosed with ovarian cancer?

George: I think just being strategic about who sits at the table. You know we're lucky to have such an experientially and professionally diverse group, it really helped us ensure that the work that we were doing and the products that we were developing together were relevant and valuable and really get to the needs of the target population. And it's been mentioned a couple times already today that you know cancer survivors should really help to inform, and really just shape all the efforts to improve survivorship, really nobody has a bigger stake in our success and the success of other projects like this than they do. Their lived experience really helps us develop materials and just all the products and outcomes are much more valuable and important when they're informed by that level of experience.

Linda: I was just going to say making sure that you're inclusive and there's diversity on your work groups or your Task Forces or when you're coming to the issues, going to the people that are doing the work, or those individuals that are being impacted by that work, because they'll bring that information to the table, as George said, share their experiences. But you do really have to look at your make up of who is on there and people are passionate enough. You also have to have tasks that people can really buy into.

Announcer: Wow that is interesting. It sounds like you created a sustainable partnership and had some great success in this demonstration project. I want to thank George, Jennifer, Linda, and Donna, for joining me today and for discussing their experience collaborating on this demonstration project.

For more information, please take a look at the resources developed by Rhode Island, Iowa, and Michigan for this demonstration. You can access these resources as well as the action plan, which describes the promising strategies identified for this demonstration

project, and the accompanying toolkit which is a compilation of tools and resources addressing planning, implementation, and evaluation of the strategies included in the action plan. These can all be found at www.cdc.gov/cancer/ovarian.
Thanks again for joining us. This episode is part of a five-part podcast series that describes the activities, facilitators and barriers, lessons learned, and recommendations from the demonstration sites. Check out the other episodes in this podcast series on CDC's ovarian cancer webpage.

[Announcer] For the most accurate health information, visit cdc.gov or call 1-800-CDC-INFO.