Cancer Care in Delaware: A National Model

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This issue of the Delaware Journal of Public Health is devoted to cancer.

In January of 2017, I was interviewed by Michael Nedelman from CNN. I related that despite being the second smallest state, Delaware had the highest rate of cancer deaths in the country during the early 1990's. This certainly was not a top ten list you wanted to be listed on. However, that all started to change in 2001 largely due to the Delaware Cancer Consortium established by Governor Ruth Ann Minner and directed by William Bowser, Esq. Aside from several of the manuscripts in this issue of the Journal that have contributed to the decline in cancer mortality, I would like to discuss programs that are not in this issue that have led to the cancer mortality rate in Delaware continuing to drop twice as fast as the national average. There is no question that the model in Delaware for cancer care and prevention can be replicated in any state in the country.

The contents in this issue of the Journal discuss many aspects in the cancer care arena. They span from the American College of Surgeons Commission on Cancer outcome measures, to improving access to cancer genetic counseling through telegenetics, to the psychosocial care for patients with cancer and, of course, a brief discussion of the Delaware Cancer Consortium and the Delaware Cancer Treatment program. The latter is an example of national cancer health insurance covering all cancer patients in the state.

However, it is important for readers of the Journal to understand that major efforts have occurred over the last decade that have resulted in a projection made by the American Cancer Society, dropping the state of Delaware to number 18 in cancer mortality in the United States in 2017. I'd like to discuss several programs that have contributed to this cancer mortality decrease. The first is the grant funded National Cancer Institute Community Oncology Research Program (NCORP) under the direction of Gregory Masters, MD and Kandie Dempsey, DBA, MS, RN, OCN, at the Helen F. Graham Cancer Center and Research Institute. This program together with the Tunnel Cancer Center at Beebe Hospital and Nanticoke Hospital has given patients access to over 100 clinical trials in areas of treatment, cancer control, prevention, translational cancer research and trials available through the pharmaceutical industry. Because of this nationally recognized program, patients receive better care on clinical trials. It is also important to note that all the physicians that participate in these trials do so on a voluntary basis without receiving any financial support.

Another major program in the state is the High Risk Family Cancer Registry at the Helen F. Graham Cancer Center and Research Institute under the direction of Zohra Ali-Khan Catts, MS, CGC. Prior to 2002, there was not one full-time adult genetic counselor in the state of Delaware. Following the recruitment of Zohra Ali-Khan Catts in 2002, this statewide program under her direction has five full- time genetic counselors. These counselors travel to Kent County, specifically, to the Tunnel Cancer Center at Beebe Hospital and Nanticoke Hospital, so patients can undergo genetic counseling and gene testing close to their own cancer centers and hospitals. This family cancer risk assessment program is the first and only one that is statewide. The High

Risk Family Cancer Registry has over 8,253 individuals with over 250,000 family members. It also has a biorepository of 690 samples for translational cancer research under an Institutional Review Board protocol. This genetic counseling program is the ultimate in cancer prevention. These talented genetic counselors have the ability to take detailed family histories and then counsel and gene test individuals at high risk for developing cancer.³ Subsequently patients can be counseled for prophylactic surgery, chemoprevention, or increased screening starting at a younger age than the general population. Also under the leadership of Zohra Ali-Khan Catts, State Bill #259 was passed in Delaware on June 30, 2010 which requires the licensing of all genetic counselors in Delaware. In January of 2017, Zohra Ali-Khan Catts in conjunction with colleagues at Thomas Jefferson University successfully completed an application for an accrediting program for an advanced degree in genetic counseling. There are only 37 genetic counseling training programs in the United States. A Task Force led by Zohra is now preparing for a Medical Center of Genetics at the Helen F. Graham Cancer Center and Research Institute to encompass all areas of genetics in prenatal, adult, cancer, cardiovascular, neurology and other clinical areas.

There is no question that when it comes to cancer care there are disparities.^{4,5} The establishment of robust community cancer outreach programs in the Hispanic, African American, Asian and Hindu communities is a model in the state for addressing small scale disparities. Outreach programs in all the cancer centers in the state and the Federally Qualified Health Care Centers are working hard to end the disparities in cancer care. These programs over the past 15 years through the Center for Disease Control Screening for Life grant have produced more than 48,000 breast cancer screenings, more than 44,000 cervical cancer screenings and more than 4,900 colonoscopies. Under the direction of Stephen Grubbs, MD, Chair of the Early Detection and Prevention Committee of the Delaware Cancer Consortium and Nora Katurakes, RN, MSN, OCN, Director of Cancer Outreach at the Helen F. Graham Cancer Center and Research Institute, a statewide program of colorectal screening for all Delawareans 50 years of age and older started in 2001. This program resulted in Delaware's mortality in colorectal cancer to decrease by 30% from 1999-2001 to 2010-2011. A greater drop in the mortality rate was seen among African Americans compared to Caucasians (55% versus 23%). Importantly, in 2008 the disparity between African Americans and Caucasians in colorectal screening ended due to this statewide colorectal screening program.

The Early Detection and Prevention Committee of the Delaware Cancer Consortium in April of 2015 took on the second statewide screening program in lung cancer based on the National Cancer Institute Phase III clinical trial which demonstrated a 20% decrease in lung cancer mortality with low dose CT scanning in patients meeting the criteria of a 30-pack year history of cigarette smoking. Cancer care is multidisciplinary. It is not only the combined knowledge of the major disciplines of medical, surgical, and radiation oncologists, but all of the subspecialties that are necessary for high quality cancer care. In 2002, the first of 14 multidisciplinary disease site centers was established at the Helen F. Graham Cancer Center and Research Institute. At these multidisciplinary disease site centers, a patient and their family members are seen by a team of experts consisting of medical, radiation, and surgical oncologists along with subspecialties dependent on the disease site. For example, in the head and neck multidisciplinary center, aside from the three major disciplines, there also is a dentist, speech therapist, psychologist, nurse navigator, nutritionist, and clinical trials nurse. It is important to note that the nurse navigators and clinical trial research nurses are members of all of the multidisciplinary disease site centers. Patients receive their treatment plan in one visit as opposed to waiting three to four weeks to

establish a plan. Cancer care is not only multidisciplinary,⁷ but it is very complex and having a high quality team approach to cancer care leads to better outcomes.

Lastly, I would be remiss if I didn't mention the partnership that the Helen F. Graham Cancer Center and Research Institute has with the Wistar Institute in Philadelphia. This partnership, which began four years ago, has led to translational research programs for Delawareans in a collaboration between clinicians at the Helen F. Graham Cancer Center and Research Institute and scientists at the Wistar Institute. This collaboration has provided the opportunity to bring cutting edge research into the community, creating strategic value for both organizations with strong joint institutional commitment. The Center for Translational Cancer Research at the Helen F. Graham Cancer Center and Research Institute, along with the work of scientists such as Eric Kmiec, PhD, who established the Gene Editing Institute, and the research of Bruce Boman, MD, PhD in cancer stem cells for colorectal cancer, as well as the research of Jennifer Sims-Mourtada, PhD in triple negative breast cancer in the African American population, collectively demonstrate that an independent academic hybrid community cancer center can make major contributions to the diagnosis and treatment of cancer.

In view of the manuscripts in this edition of the Journal related to cancer care and the description of the programs described above, there should be no doubt in anyone's mind that Delaware continues to serve as a model for successful cancer care and prevention. The Delaware Cancer Consortium and collaborative efforts of all cancer centers/hospitals, Federally Qualified Health Care Centers, the Delaware Breast Cancer Coalition, American Cancer Society and the Cancer Support Community, continue to move forward in problem areas of cancer care and prevention. Although a lot of hard work and effort remains, there is no question that the future cancer care of all Delawareans is in good hands. Politicians and business people in the state of Delaware need to take a hard look at this statewide model of cancer care and prevention which in less than a decade has dropped Delaware out of the top ten in cancer mortality. They should be looking to do the same in other areas of health care in our state, including obesity, mental health, drug addiction and homicides.

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