2021 NPCR WASHINGTON SUCCESS STORY

Washington State Cancer Registry: Mahesh Keitheri Cheteri; Nirupama Shridhar; Philip Crain; Johna Peterson; Patti Migliore Santiago

Reducing Morbidity and Mortality for Washington State Residents Impacted by Heritable Cancer Syndromes (HBOC And LS) by Enhancing Public Health Surveillance and Increasing Appropriate Referrals for Genetic Services

National Program of Cancer Registries
SUCCESS STORY

SUMMARY

Hereditary cancer syndromes, such as hereditary breast ovarian cancer syndrome (HBOC) and Lynch syndrome (LS), are caused by genetic mutations that confer a high probability for cancer development to those who inherit the mutation. These syndromes significantly increase the risk for several types of cancers among those who inherit the mutation. Additionally, these individuals are often diagnosed with cancer at younger ages than those without the syndromes. Thus, diagnosing hereditary cancer syndromes in these individuals represents a significant public health issue because of the opportunity for prevention and/or early identification and better managing patient care. Unfortunately, these syndromes are also largely undiagnosed – less than 2% of people with Lynch Syndrome are diagnosed, for example (Hampel, 2011). That is why the Screening and Genetics Unit (SGU) and the Washington State Cancer Registry (WSCR) at the Washington State Department of Health (DOH) collaborated and utilized WSCR pathology reports. The criteria established by the National Comprehensive Cancer Network (NCCN) was used to identify the potential hereditary cancer syndrome cases (Daly, 2020; Gupta, 2020). To identify potentially inherited cancer cases, we used the NCCN criteria to select women with breast cancer age 50 or younger, men with breast cancer, women with ovarian cancer, any person with colon cancer age 50 or younger, and women with endometrial cancer age 50 or younger. The collaboration helped the SGU initiate active surveillance for HBOC and LS and increase provider awareness regarding clinical guidelines for genetic testing in patients at risk for HBOC or LS. The SGU was also able to advocate referrals of these cases by notifying the reporting healthcare providers about the potential risk for the patients and where to refer their patients.

CHALLENGE

The main challenge in obtaining cancer cases from the pathology report has been that the path reports do not list a health care provider who would typically be responsible for referring the patient to a genetics counselor. Often the pathologist listed has no relationship with the patient and only examined a tissue sample for biopsy. Sometimes we can get the name of the patient's Primary Care Physician (PCP) or oncologist from the pathologist but if they do not respond, we are unable to identify and fax an appropriate provider.

SOLUTION

We are trying to overcome the challenge by faxing clinics instead of individual providers when we know they do not see the patient directly to ask for contact information for the appropriate provider.

RESULTS

We used the Electronic Mapping, Reporting, and Coding (eMaRC) Plus tool provided by the Centers for Disease Control and Prevention (CDC) to read the cancer path reports. The WSCR path reports provided the potential hereditary cancer cases with provider and reporting facility information. Providers or clinics received a faxed letter explaining that the patient might benefit from an appointment with a genetic clinic. This letter has a form with options for respondents to check and fax back the form, so we know what actions were taken (e.g., the patient was referred to genetics). So far, we have sent 91 faxes and received 24 responses. Of the 24 responses received, only 3 providers reported sharing the recommendation for genetic services with their patients. One (1) additional provider reported referring a patient to a genetic clinic and meeting with a Genetic Counselor. A total of 7 patients had already undergone genetic testing for LS/HBOC and /or met with a Genetic Counselor.

SUSTAINING SUCCESS

WSCR plans to provide recent diagnosis year data once the consolidated cancer records from the Fred Hutchinson Cancer Research Center are received. The Cancer Surveillance System (CSS) of the Fred Hutchinson Cancer Research Center provides data on cancer cases from thirteen counties in Western Washington, covering most of the state's population, including the largest urban center of Seattle. CSS has been in operation since 1974 as a regional registry participant in the Surveillance Epidemiology and End-Results (SEER) Program of the National Cancer Institute. Including these records will expand the scope of the SGU's work to include cases from across all of Washington State, allowing for greater potential public health impact.

REGISTRY CONTACT INFORMATION

360-236-3669
https://fortress.wa.gov/doh/wscr

REFERENCES

Daly, M. B., et al., (2020). Genetic/Familial High-Risk Assessment: Breast Ovarian. In *NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines)*. Retrieved from https://www.nccn.org/professionals/physician_gls/pdf/genetics_bop.pdf

Gupta, S., et al., (2020). Genetic/Familial High-Risk Assessment: Colorectal. In *NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines)*. Retrieved from https://www.nccn.org/professionals/physician_gls/pdf/genetics_colon.pdf

Hampel, H., de la Chapelle, A., The Search for Unaffected Individuals with Lynch Syndrome: Do the Ends Justify the Means?, *Cancer Prev Res*, January 1, 2011, (4) (1) 1-5; DOI: 10.1158/1940-6207.CAPR-10-0345

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention