CANCER PREVENTION & RESEARCH INSTITUTE OF TEXAS

Award ID:
PP160103

Project Title:
Detecting Unaffected Individuals for Lynch Syndrome (DUAL): Screening, Diagnosis and NavigationNavigation

Award Mechanism:
Evidence-Based Cancer Prevention Services - Colorectal Cancer Prevention Coalition

Principal Investigator:
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Entity:
The University of Texas Southwestern Medical Center

Lay Summary:

Need: In the US there are approximately 150,000 colorectal cases per year that result in 50,000 deaths [1]. Lynch syndrome (LS), the most common hereditary colon cancer syndrome, affects approximately 1/300 individuals. Diagnosis and management of LS is a tier 1 CDC recommendation for colon cancer prevention. Remarkably, only 2% of individuals with LS have been diagnosed in the United States [2]. In the DFW area there are approximately 12,387 individuals with LS, and about 400 of these have been identified. Underserved patients are less likely to undergo genetic testing and their access to genetic counseling services are limited [3-8]. By use of telephone and telemedicine counseling we hope to reduce barriers to LS identification and management in rural areas. Our coalition will target patients from safety-net hospitals (Parkland and John Peter Smith), UT Southwestern (UTSW) and underserved patients from 23 counties that are participating in a CPRIT coalition colon cancer screening grant.

Overall Project Strategy: We will identify individuals at increased risk for LS with a multipronged approach, building on our existing coalition of screening programs at UTSW. Screening and genetic counseling services will be delivered by 1) expanding our existing population-based genetic screening of mammogram patients (we screen for a family history suggestive of Hereditary Breast and Ovarian (HBOC)) to include LS, 2) partnering with the CPRIT CSPAN Coalition grant (PP120229) to add self-identification of LS risk in testing kids mailed to rural and underserved patients and 3) incorporation of a family history of cancer screen of patients seen in our GI clinics at Parkland and UTSW. Risk Assessment of patients will allow us to educate both patients and physicians regarding cancer screening intervals for those at high risk. We will also measure the expected increase in compliance with early colonoscopies for high-risk individuals. Genetic counseling will be in-person or by telephone or telehealth based on a network of established clinics. Genetic testing will be performed at a reduced cost from the patient's home. Education to the community and physicians about LS is key to our program's success.

Specific Goals: 1. Screening of approximately 334,000 people over 3 years to identify patients at high-risk for colon cancer based on their family history to detect 316 cases of the LS. Provide education about colon screening intervals specific for their family history.

2. Improve compliance of 8,408 high-risk individuals for early colon surveillance based on a family history of colon cancer. 3. Promote education and dissemination of information about LS. 4. We expect to reach 461,189 individuals and serve 16,705 people.

Innovation: The identification of LS is needed and will require a creative approach by both clinicians and patients. Our grant will build on an existing coalition of partners, using technology to automate the identification of high-risk patients for LS testing and provide an effective service delivery model for genetic counseling. We will develop a sustainable program that will be continue long after the grant. By using initial telephone counseling during the day and evening, we hope to increase the frequency of genetic counseling and testing, especially for at-risk underserved patients. Currently LS is identified by a striking family history of colon and endometrial cancer using the Amsterdam I, II or Bethesda guidelines [9-11], but these strict criteria fail to identify many patients with LS and rarely identify LS before a cancer diagnosis [10]. Our approach, using the NCCN guidelines and family cancer history to identify individuals with LS before a cancer diagnosis and to help these individuals to take action, will save lives.

Significance and Impact: This program will advance cancer prevention, knowledge and screening and serve as a model to identify unaffected individuals at risk for LS. There are currently no large scale programs in the US that screen for LS in unaffected individuals. Even though LS is more common than HBOC, the screening for LS is less common. For HBOC, 50% of all individuals that are tested are currently without a cancer diagnosis. In contrast, only 9% of individuals tested for LS are without a cancer diagnosis (Personal communication, Ambry Genetics). In addition to this need to screen unaffected individuals, the reach of our screening program will extend to 23 counties in Texas. It will cost less than $9.46/person screened and the cost to diagnose one case of LS will be less than $9,985 per person. The latter is significantly less than the cost-effectiveness ratio of $22,522 per identified LS case calculated by a recent study [12]. We predict we will identify approximately 316 individuals with LS. With only 400 individuals currently identified with LS in North Texas, the proposed population based screening will lead to a 288% increase in identified LS cases.