RESEARCH UPDATE

JANUARY 2021

FULL LIFE FOUNDATION
for Lynch Syndrome

A MESSAGE FROM OUR FOUNDER

PREYAA DOCU
FOUNDER

Welcome to our January 2021 newsletter. Our team is so glad to have you with us on this journey of education and support. What a year we've all had! The inception of the Full Life Foundation (FLF) began with my own diagnosis of Lynch Syndrome and the reality that a majority of my circle were unaware of what it meant to have the gene. In reflection, I've been humbled by the response and engagement that the Full Life Foundation has experienced in just over a year of its establishment.

Between events, both in-person and virtual, fundraising campaigns, digital content, and collaborative work with the wonderful team at Columbia, we've used this kickoff year to begin sharing our message. Lynch Syndrome may not be a dinner table conversation starter... we're aware! However, we strive to connect our donors and followers with information that may save a life. Knowledge is power. If FLF can be the stepping stone to your personal diagnosis or that of a loved one, then we can call ourselves a success.

I'd like to give a huge shout out to my team. I brought an idea to them, and they've combined strengths to create an organization that will change lives. In the next year, we'll be scouting research studies relating to genetic testing, preventative care, LS cancer cases, and creating new relationships within the LS community to allocate our funds to medical research. We're learning as we go, and welcoming new relationships along the way to educate and raise awareness within our networks and beyond.

We're not going away anytime soon, so stick with us to see what we have planned for 2021. Let's hope for some in-person fun very soon. Thanks for taking this journey with us.

Happy New Year!
Preyaa

THE LATEST ON LYNCH SYNDROME RESEARCH

FULL LIFE FOUNDATION FOR LYNCH SYNDROME RESEARCH FUND AT COLUMBIA UNIVERSITY IRVING MEDICAL CENTER

As part of our mission, we strive to maintain transparency with our donors and provide updates on the foundation's progress and efforts. This newsletter will provide a snapshot of the latest research efforts at CUIMC, our first research partner.

During Full Life's first year, we established a perpetual Lynch Syndrome research fund at Columbia University Irving Medical Center (CUIMC) with a starting donation of $10,000 made possible by all of our generous donors. The fund is led by Dr. Fay Kastrinos of Columbia.

Researchers at CUIMC have been focusing on the following three areas:

1. Improved identification of individuals with Lynch syndrome
2. Optimization of colorectal and endometrial cancer screening strategies and assessment of novel approaches
3. Estimation of cancer risks associated with Lynch syndrome

They participate in multiple national and international research efforts to promote the identification of Lynch syndrome families and aim to optimize cancer screening and preventative strategies to improve clinical outcomes and help keep Lynch syndrome patients cancer-free and healthy.

Upon establishing Full Life's research fund at CUIMC, many research efforts were stalled due to the COVID-19 pandemic. In the meantime, we would like to provide a snapshot of 5 Lynch Syndrome studies ongoing/proposed at CUIMC. Our fund will support studies similar to the below, led by Dr. Fay Kastrinos, with a near-term focus on optimizing screening strategies for Lynch Syndrome patients. Stay tuned for updates!

Development of Risk Assessment Tools to identify Individuals at Risk for Lynch syndrome: In collaboration with Dana Farber Cancer Center, CUIMC developed the PREMM model, a web-based risk calculator that determines an individual's risk of having a Lynch syndrome related gene based on personal and family cancer history. This model is part of the first-line strategy to identify Lynch syndrome carriers and is part of guidelines of the National Comprehensive Cancer Network.

Implementation of Lynch syndrome Risk Assessment Tools into Electronic Medical Records (EMRs) to Identify Individuals at Risk: Current EMRs are able to automatically extract data that has been routinely assessed in the medical record to calculate risk scores (such as personal and family cancer history). CUIMC will incorporate the PREMM model into different clinical practices and evaluate its performance in identifying new Lynch syndrome carriers.

The CARE Program: In collaboration with Ambry Genetics Laboratories, one of the largest commercial genetics laboratories in the US, CUIMC will evaluate the use of a new mobile, app-based risk assessment tool, CARE (Comprehensive Assessment, Risk and Education) that will interface directly with patients to assess their risk for inherited cancer syndromes, including Lynch syndrome. This platform will provide patient education and CUIMC will evaluate patient knowledge and uptake of genetic testing, with follow-up of newly identified Lynch syndrome carriers.

Optimization of Colorectal Cancer and Endometrial Cancer Screening Strategies for Lynch syndrome carriers: Lynch syndrome is caused by four distinct genes, each associated with different risks of colorectal and endometrial cancer. The currently recommended intensive screening with colonoscopy on an annual basis among all Lynch syndrome carriers, regardless of gene-type, may not be an optimal approach. In addition, alternative strategies to colorectal cancer screening, such as non-invasive fecal tests, may be considered in Lynch syndrome. Through model simulation studies CUIMC will determine which colorectal cancer screening strategies are most optimal in Lynch syndrome carriers as defined by the particular gene that is affected. We will extend our analyses to endometrial cancer and evaluate the optimal age to consider preventive, risk reducing surgeries for women with Lynch syndrome.

Assessment of the heterogeneity of colorectal cancer risks among diverse populations with Lynch syndrome: CUIMC participates in the International Mismatch Repair Consortium (IMRC). The IMRC includes ~273 members from 122 centers in 29 countries in Africa, Asia, Australasia, Europe, North and South America, who conduct research and/or care for Lynch syndrome carriers. Results from the IMRC support personalized risk assessment for Lynch syndrome carriers and families to optimize cancer prevention based on individual rather than average risk.

ABOUT US

The Full Life Foundation is a non-profit organization dedicated to supporting research for a cure for Lynch Syndrome and its related cancers. Through the efforts of our team, partners, and supporters, it is our goal to educate the public on Lynch Syndrome, raise funds for research, and give back to the affected communities through various volunteer initiatives.

We strive to always be transparent with our donors. Our Lynch Syndrome research projects are hand-picked by our team and conducted by universities and hospitals nationwide. When you donate to the Full Life Foundation, you can feel confident that your donation is being put to good use, directly funding one of our supported research projects.

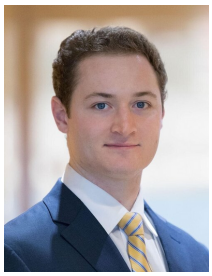
MEET THE TEAM

PREYAA DOCU
FOUNDER

JAKE STRZALKOWSKI
TREASURER

MICHELLE HUDAK
SECRETARY

MEGAN CHACON-DIAZ
DIRECTOR OF DIGITAL MARKETING



JACK FASO
DIRECTOR OF FUNDRAISING INITIATIVES

MOLLY MCDONALD
DIRECTOR OF MEDIA RELATIONS

STAY CONNECTED

HTTPS://WWW.FULLLIFEFOUNDATIONLS.ORG/

@FULL.LIFE.FOUNDATION

@FULLLIFEFOUNDATIONLS

CONTACT@FULLLIFEFOUNDATIONLS.ORG