



FOR IMMEDIATE RELEASE

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AliveAndKickn and the Colon Cancer Coalition look to empower patients LIVING WITH LYNCH on Lynch Syndrome Awareness Day, March 22, 2020.

The one-of-a-kind resource at LivingWithLynch.org offers voices of hope in the face of a Lynch syndrome diagnosis.

Minneapolis, Minn. & Haworth, N.J. (March 16, 2020) – AliveAndKickn and the Colon Cancer Coalition are pleased to launch “LIVING WITH LYNCH,” a collaboration with the goal to educate the one in 279 Americans who live with Lynch syndrome - including the 95% of those who don’t know they have it. This resource is launching in advance of **LYNCH SYNDROME AWARENESS DAY, Sunday, March 22, 2020.**

In November 2019, 13 Lynch-positive patients, seven women and six men, eight cancer survivors and five previvors, met for the first time in Houston at a weekend sponsored by Promega Corporation. While together they had the opportunity to talk with experts in the field of genetic counseling, oncology, research, treatment, and immunotherapy. They were also given the opportunity to connect with each other and bond over shared experiences.

“Lynch syndrome is a genetic condition that increases a person’s risk for certain cancers, the most common being colorectal and endometrial,” said Dave Dubin, founder of AliveAndKickn, Lynch positive, and colon and kidney cancer survivor. “The Living with Lynch weekend was designed to empower patients living with Lynch syndrome to be advocates for themselves, their families, and others with a shared diagnosis. Our goal is to increase awareness of this genetic condition and provide support and hope for those with the Lynch syndrome gene in their family.”

The experience is captured at LivingWithLynch.org. The microsite features videos and photos of patients sharing how their Lynch syndrome diagnosis impacts them, their family, and their outlook on the future. AliveAndKickn and the Colon Cancer Coalition hope to help patients Living with Lynch make informed decisions about health and provide a community to relate to as they navigate future health needs.

“The Living with Lynch weekend was an amazing and inspiring experience,” says Jean Edelstein, Living with Lynch participant, Lynch positive, and a cancer previvor. “As a previvor, I know what a Lynch diagnosis means for me, I understand that I have an elevated risk for many cancers in my future. This weekend and meeting these amazing advocates gave me strength to face whatever comes next in my Lynch journey.”

“It was a privilege to be a part of the Living with Lynch weekend,” adds Sarah DeBord, stage IV colon cancer patient (non-Lynch related) and communications and program manager for the Colon Cancer Coalition. “To hear the stories of individuals and families impacted by Lynch syndrome has opened my eyes even wider to the realities of a hereditary cancer diagnosis. Many individuals with a Lynch mutation develop related cancers much younger than the general population. It is important for individuals to know their family history and begin screening earlier for those with a known Lynch mutation.”

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About the Colon Cancer Coalition

The Colon Cancer Coalition is a non-profit organization based in Minneapolis, Minn. dedicated to encouraging screening and raising awareness of colon cancer. The organization's signature Get Your Rear in Gear® and Tour de Tush® event series are volunteer-driven in communities throughout the United States. Money raised at these events are granted back into local communities to help build and sustain programs and research encouraging early prevention, screening, and patient support for this disease. By making the words *colon*, *colorectal* and *colonoscopy* a part of the everyday language, we believe we can overcome the fear and decrease deaths from this largely preventable cancer. For more information visit ColonCancerCoalition.org.

About AliveAndKickn

AliveAndKickn's mission is to improve the lives of individuals and families affected by Lynch Syndrome and associated cancers through research, education, and screening. It is the only nationally recognized patient advocacy organization to provide resources, education and awareness for patients with Lynch syndrome hereditary cancer genetic mutations. AliveAndKickn is the go-to patient advocacy resource for patients, clinicians and researchers. In launching the HEROIC patient registry, AliveAndKickn has developed the first RWE patient driven database and worked with the top Lynch syndrome researchers around the country to support and advance research in the field. To read more about AliveAndKickn, please visit www.AliveAndKickn.org.