

# PATIENT / RESEARCH ADVOCACY

## MY RESEARCH ADVOCACY EFFORTS AND CONTRIBUTIONS

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Lynch Syndrome



### ABSTRACT

#### Focal Facts:

**Lynch Syndrome** is a condition that increases the risk of various different cancers to run in families. This condition is hereditary and has a genetic variant, or mutation, in genes identified as **MLHL1, MSH2, MSH6, PMS2, and EPCAM.**

Families that are genetically predisposed to Lynch Syndrome have higher instances of cancer than expected. This might include colon cancer, endometrial, ovarian, glioblastomas, skin and other types of cancer. Lynch Syndrome also causes cancers to happen at an earlier age.

About 1 in 279 people have Lynch syndrome and most are unaware of their risks. Not everyone with Lynch syndrome will inevitably develop cancer and regular cancer screening or preventive surgery may reduce risk of some cancers.

Genetic testing for Lynch syndrome is recommended for individuals with an immediate family member who has been diagnosed with it, as well as for those who have a family history of early cancer diagnoses of certain cancer types.

**This knowledge has driven me to advocate on behalf of myself and others who need to know about their cancer risk, hereditary pre-disposition, prevention and survivorship.**

### INTRODUCTION

**I am a 3x Cancer Survivor** - While such a diagnose is terrifying for an individual just once, having a multitude of cancers only made me realize the importance of patient advocacy in healthcare.

- Colorectal Cancer – Stage IIIB (age 44)
- Endometrial Cancer
- Basel Cell Carcinoma
- **Lynch Syndrome patient (MSH2 variant)**
- Navy Veteran
- Passionate Patient Advocate

Actively involved with various organizations who promote changing guidelines and policies, sharing knowledge about genetic testing, clinical trails and cancer survivorship.

### ADVOCACY EXPERIENCE

#### Fact 1. Share your cancer story

There is no right or wrong way to handle a cancer diagnosis. Having the courage to speak up and share my story with others helped to improve my own mental health well-being.

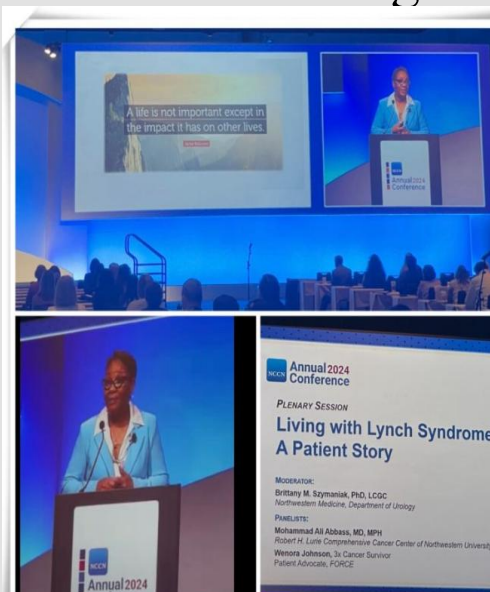
- Conquer – Patient Voice Magazine
- Local Community Newspaper
- Patient Resource Magazine
- Blogs and News Articles



#### Fact 2. Attend Conferences/Seminars

As a patient advocate, your voice and perspectives are important. By attending conferences, seminars and workshops, you gain the necessary tools and training to become effective **advocates.**

- AACR Annual Conference
- ASCO Annual Conference
- Health Equity Congress Conference
- Cancer & Careers Conference
- NCCN Patient Advocacy Summit
- PCORI Annual Conference



#### Fact 3. Presenting Abstracts

Presenting an abstract and a poster gives **patient advocates** an **important** opportunity to introduce their research to scientist, researchers and community members who have a vested interest in the patient's perspective.

- AACR Scientist Survivor Program
- The program provides advocates with special lectures using lay language, small group discussions, and other opportunities for the exchange of information on key aspects of cancer research, survivorship, advocacy, and public policy (AACR).



### ADVOCACY EXPERIENCE (CONT)

#### Fact 4. Advisory Board / Ambassador / Panel Member

Patient advocates are using their influence and expertise in many ways that include serving on advisory/review boards, as patient ambassadors and speaking at industry events as panel members.

- CAP MMR/MSI Guidelines Reviewer
- CMS Technical Expert Panel Member
- DIA – Tufts Patient Engagement Study
- FORCE Board Member, Research Advocate and PEER Navigator
- Morris & Silver Cross Hospital IRB Member
- NRG Oncology PAC Member
- NQF Cancer Standing Committee
- PCORI Ambassador
- WCG External Advisory Board Member



#### Fact 5. Patient Podcast

Podcast have become an important portal for patient advocates to keep the public connected to the changing landscape of the **patient** experience that includes discussions on cancer survivorship, clinical trials, genetics and other topics of interest.

- AliveandKickn Podcast
- #IamPatient Podcast
- Powerful Patient Podcast
- WCG Patient Podcast
- The Positive Gene Podcast
- JNott Podcast



### ADVOCACY

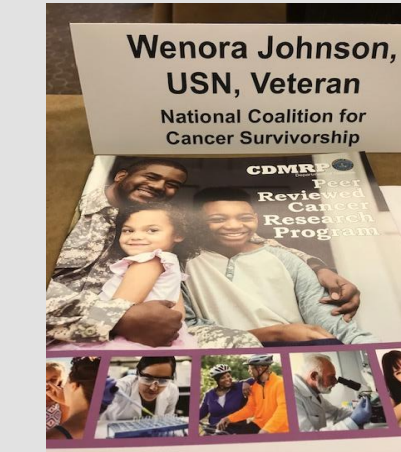
**Patient opinion leaders** - sometimes called patient advocates, are individuals who are well versed in a disease, either as patients themselves or as caretakers, and share their knowledge on the particular disease with others. (Wikipedia)



Visit Bioscience Laboratories



Meet with Congressional Members



DoD Consumer Grant Reviewer



Share my cancer story and journey



Keynote Speaker



PCORI Clinical Trials Advisory Board

### LESSONS LEARNED

One of the first, of many lessons I learned in my advocacy journey was to align myself with organizations whose mission is to help find a cure for colorectal cancer and understand hereditary cancer, while providing hope and support through your cancer journey.

I found such an organization in **Fight CRC and FORCE**, who not only gave me the tools to help share my story but taught me the importance of policy change, clinical trials, genetics/hereditary cancer and breakthrough research.

- Disparities exist in healthcare and your voice can be an affective tool in making change happen.
- To get to the root of a problem, you must address the stakeholders. This means having a dialogue with your Congressional Members who hold the key to changing policies that effect your healthcare.
- Take time for yourself to focus on your mental health - It's okay to be frustrated, sad and disappointed at times, it becomes your motivational force to make things better.
- Patient advocacy is not for everyone, but never underestimate your power to inspire and become a voice for others.



### PROJECTS & AWARENESS CAMPAIGNS

#### What I'm doing as a Patient Advocate:

- Advocacy Day Speaker for NCI/NIH
- ASCO SDOH Policy Statement Writing Group
- Guardant Shield Test FDA Colorectal Cancer Screening – FDA Committee participant
- ConnectMyVariant Board Member
- ECANA Advisory Panel Member – ROSES & ACTS Study
- Fight CRC “Path to a Cure” and Clinical Trial Curator
- Submitted/Received State of Illinois and City of Joliet Proclamation recognizing March as Colorectal Cancer Awareness Month.
- UCCCC Community Patient Advocate
  - CHEPT Program
- UILCCC –
  - Keynote Speaker
  - Dr. Gary Kruh Virtual Poster Competition



### REFERENCES

1. AACR - Scientist Survivor Program <https://www.aacr.org/patients-caregivers/patient-advocacy/scientist-survivor-program/>
2. FORCE (Facing Our Risk of Cancer Empowered) People with Lynch Syndrome (facingourrisk.org)
3. Fight CRC - <https://fightcolorectalcaner.org/about/our-mission/>
4. Wikipedia - Patient Advocacy [https://en.wikipedia.org/wiki/Patient\\_advocacy](https://en.wikipedia.org/wiki/Patient_advocacy)

