

Patient Assistance Program

Focus: Supporting those with hereditary breast and ovarian cancer concerns

When we provide support for an individual we consider this to be a primary service of the organization and one that has several different variables. Clear communication as patient advocates and not medical professionals is key to providing the best support possible. When an individual approaches NothingPink requesting support and resources, we assess where they are and initiate patient pathway process.

Connection and Patient Pathway

We receive referrals from the following sources: Medical Providers: Genetic Counselors, Nurse Navigators, Ob/GYN, Surgical Oncologist, High risk clinic. The following locations are currently partners with Levine Cancer Institute and Novant Healthcare Systems, Carolina Pines Medical Group, in the Greater Charlotte Region. Community Events: Baxter, health fairs, RV, etc Community Partners: area nonprofits including, Carolina Breast Friends, GoJenGo, Teal Diva, 24 Foundation Patient to Patient: from friend/family Online sources: Social media (platforms), NothingPink.org

Patient Pathway

- 1. Patient completion of NothingPink Support Form
- 2. Patient Navigator reaches out via email or phone asking patient how NothingPink can best support them at this time common responses include care packages, recommendations of local physicians, peer to peer connectivity
- 3. Send introductory email with invite to bimonthly support meeting, BRCA Navigator forum and next upcoming event
- 4. Send monthly invitations to support meetings and quarterly socials
- 5. If they are going into genetic testing process we provide phone/ e-mail support
- 6. If they have scheduled preventive surgery(ies) we have them apply for a support package
- 7. Case management following recovery from surgery

Support Groups

Currently we have two support group meetings monthly. These meetings are currently virtual. A facilitator is present to lead the group through a time of updates, sharing stories, resources and contact info that will aid each other with their current needs. Set topics and guest speakers are occasionally present for more in depth discussions. Often individuals that are on a similar path of preventative screening/surgery or navigating a cancer diagnosis make connections during support meetings and proceed to meet up and connect outside of the meetings to further their connections. Engagement events are planned 3-4 times per year to bring the group together in person to build community connections.

Support topics include:

Do you have an OBGYN you are comfortable with and feel like they are aligned with your priorities for care?

Do you feel like you understand BRCA? Book and Facebook group 'Understanding BRCA' FORCE (Facing our Risk of Cancer Empowerment) Updates on what's new in Hereditary Cancers

Are you ready for Genetic Testing, you cannot unknow this information? Consider your support system

You are your best health advocate! You know your body, and your health the best. Get informed read up and research before your doctors appointments. Especially with preventative measures, your doctors are consultants, you know what is best for you and your family at this time.

Revisit your Life Insurance coverage, you may want to consider increasing your coverage prior to testing. If you receive BRCA+ result it will be a preexisting condition for life insurance.

Book review: "Prepare for Surgery Heal Faster" By Peggy Huddelston Research shows they significantly reduce anxiety before surgery by mind and body techniques.

Previvor Discussions: Scans vs. Preventative Surgery

Talking with your family about Genetic Testing. Respecting each person has a personal decision to make.

Self Image: Feeling comfortable with my body, post surgery/treatment, Intimacy
Take time to consider options and get informed. If you don't like the way a doctor has spoken to
you or you didn't connect well, consider visiting another doctor. It is important to have a good
understanding of their practices and how they align with your needs and desires.

Care package: As a primary form of support, Nothing Pink has a curated multiple care packages for women who are going through preventative or diagnostic breast and/or ovarian surgery. The packages are a combination of practical hygiene products as well as NothingPink branded items customized to their surgery/treatment needs. We provide a personalized and encouraging note to the patient as well.

Post surgery care: NothingPink provides a post surgery meal package for the patient and family. This is delievered ~3 days after proceedure.

Continued follow up support: This includes meeting with the patient, emails, 1:1, text, phone calls to support them in their current needs.

Financial Assistance: To provide financial assistance to individuals requesting aid for genetic testing, cancer diagnosis and preventive surgeries.

Our goal is to provide \$150,000 in assistance to our support group community in 2023. In 2022, we were about to provide 51 post surgical meal packages, 41 surgical care packages, 35 medical planners, and \$98,650 in financial assistance. We evaluate on a quarterly grant cycle to ensure our assistance is being utilized effectively and efficiently.