



Breast Health MATTERS

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9th Annual



Women's Health Conference

Tuesday, November 12th,
8am—4:30pm

Carondelet Hospitality Center,
Latham, NY 12110

A full day of engaging,
evidence-based presentations,
and workshops with expert speakers
and panelists, featuring:

Douglas Conklin, PhD
University at Albany SUNY

David Mastrianni, MD,
Saratoga Oncology Hematology

Jennifer Lindstrom, MD
Albany Medical Center

Multiple afternoon breakout sessions
on clinical, wellness &
psycho-social topics

Register online at [www.tolife.org/
breast-cancer/calendar/2019/11/](http://www.tolife.org/breast-cancer/calendar/2019/11/)

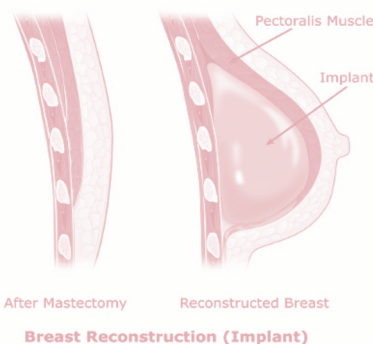
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Textured Breast Implants & the FDA recall

*What To Know & What to ask your health
care providers & more importantly,
how to decide if you want to have
or keep your implants*

On July 24, 2019, the FDA (US Food
and Drug Administration) requested
that Allergan recall specific models of
its textured breast implants and tissue
expanders from the U.S. market due to an
increased risk of patients with these specific

implants developing BIA-ALCL (breast implant-associated anaplastic large cell
lymphoma.) Allergan did then voluntarily move forward with a worldwide recall
of their BIOCELL textured breast implant products and tissue expanders that
are specified in the FDA link here: <https://www.fda.gov/medical-devices/safety-communications/fda-requests-allergan-voluntarily-recall-natrelle-biocell-textured-breast-implants-and-tissue#list>. You'll see that the link lists the recalled
implants in the medical device section of the FDA website as breast implants
are considered medical devices. The concerns regarding certain implants has
been reported in the news for over a year and in an effort to inform our survivor
community, . The speakers/panelists were: Steven Nagel, MD, FACS, Surgical
Oncologist and Medical Officer with the US Food and Drug Administration,
Andrew Warheit, MD, Diagnostic Radiologist and Medical Director, Breast
Center at St. Peter's Hospital, Danielle Krol, MD, Medical Oncologist, US Food
and Drug Administration. An event podcast is available for the Q&A portion of
the event at [https://tolife.org/education-and-resources/educational-programs/
beat-odds](https://tolife.org/education-and-resources/educational-programs/beat-odds). A brief summary of some of the program and information is
outlined below.

BIA-ALCL is a rare form of Non-Hodgkin's Lymphoma It's important to know
that not all implants from Allergan are on the recall list and that other compa-
nies make textured implants that are also not on the recall list. Accordingly,
if you already have an implant you'll want to verify what type you have
(either by looking at an identification card that you have and/or contacting
the plastic surgeon who performed your surgery) and then verifying your
implant information with the recall list to determine whether your implant
is on the recall list. You may be wondering why the FDA specifically asked
Allergan to recall their products. The FDA asked only Allergan to voluntarily
recall the specified implants because they determined that these implants
(and tissue expanders) posed an increased risk of BIA-ALCL to patients over
other implants that are not on the recall list. The FDA is not recommending
removal for patients without any symptoms but they do provide informa-
tion "5 Things to Know About Breast Implants" (summarized below but the
full information is at this link: [https://www.fda.gov/consumers/consumer-
updates/5-things-to-know-about-breast-implants](https://www.fda.gov/consumers/consumer-updates/5-things-to-know-about-breast-implants)). Additionally, the following
link provides information about various forms of breast implants as well as
potential complications: [https://www.fda.gov/medical-devices/breast-implants/
risks-and-complications-breast-implants](https://www.fda.gov/medical-devices/breast-implants/risks-and-complications-breast-implants).

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What Genes MAY Tell Us About Breast Cancer Risk

Investigation into current knowledge related to genetic influences for Breast Cancer reveals far more and different information than even five years ago. Unchanged is the cautionary note from researchers that genetic predispositions are rarely a guarantee, and that environment and lifestyle factors remain important in most cases.

In the general population, approximately 12% of women will be diagnosed with breast cancer over a lifetime. Of all those diagnosed, approximately 5-10% will have some genetic predisposition. That's a small percentage, but with a genetic issue, the chances of getting breast cancer may be significantly greater, so it's important information. In the case of men getting breast cancer, the incidence is stated as 1 in 1,000 - less than 1% of all diagnosed cases, but men also can carry gene mutations related to breast cancer. However, since men's breast cancer risk is so low, even with a genetic mutation elevating risk, it remains low, and is unlikely to manifest as breast cancer. Still, if men carry the problem gene mutation, they can pass it on to their children, so it is highly significant in that respect.

Most of those diagnosed with breast cancer wonder if there is some genetic influence. Medical practitioners look at family history of cancer to see if genetic testing is indicated. (See adjacent chart)

A recent study published in the Journal of Clinical Oncology looked at a group of nearly 1000 women diagnosed with breast cancer and administered genetic testing to all. Approximately 10% were found to have a genetic mutation that would influence their diagnosis or treatment. But, assessing each individual's history in the context of existing guidelines for testing, it was shown that nearly half of those with mutations would NOT have met the criteria to be recommended for genetic testing. This study is leading questions about the utility of the guidelines. In February of 2019, the American Society of Breast Surgeons (ASBrS) recommended giving every person diagnosed with breast cancer a genetic test with a multi-gene panel. Included was a recommendation that there be retesting for those who were tested prior to 2014.

Another area of growth related to genetic testing is the proliferation of DTC (direct to consumer) genetic testing. DTC genetic testing started as a way to make it easier to track down long lost relatives and learn more about family history and heritage. Individuals submit saliva samples, and analysis is completed by the genetic testing service. DNA variations can provide clues about ancestry and family relationships. Genetic ancestry testing, or genetic genealogy, allows users a deeper investigation. As well as geographic

Current Guidelines to Indicate Genetic Testing for Breast Cancer

Among other criteria, current guidelines recommend genetic testing for someone diagnosed with breast cancer if:

- there is a known mutation in the family
- the person was diagnosed at age 50 or younger
- the person has been diagnosed with two primary breast cancers
- a first-degree female relative (mother, sister) was diagnosed with breast cancer at age 50 or younger or was diagnosed with ovarian cancer
- two or more first-degree relatives were diagnosed with breast, prostate, and/or pancreatic cancer
- a man in the family has been diagnosed with breast cancer

Individuals who have the following situations are more likely to have an inherited genetic mutation:

- there are blood relatives (grandmothers, mother, sisters, aunts) on either the mother's or father's side of the family who had breast cancer diagnosed before age 50
- there is both breast and ovarian cancer on the same side of the family or in a single individual
- there is a relative(s) with triple-negative breast cancer
- there are other cancers in the family in addition to breast, such as prostate, melanoma, pancreatic, stomach, uterine, thyroid, colon, and/or sarcoma
- women in the family have had cancer in both breasts
- the individual is of Ashkenazi Jewish (Eastern European) heritage
- the individual is African American and has been diagnosed with breast cancer at age 35 or younger
- a man in the family has had breast cancer
- there is a known genetic mutation linked to breast cancer in the family

BREASTCANCER.ORG



Executive Director's Message

We have come to associate the color pink with Breast Cancer Awareness Month. Come October, pink decorations, pink clothing, references to breast cancer pop up all over. What does October mean to you? For many, it will signify a transition from a softer summer schedule to a busier calendar. Or maybe this is your reminder to schedule a mammogram or doctor's appointment. For others it may mean starting or continuing a treatment regime. We shout from the rooftops the completion of treatment, receiving the news of being cancer free, and other significant milestones.

To Life! is committed to be a resource for those seeking information and connections as they progress through a breast cancer journey. We field many questions about nutrition and diet. Over the past few months we have held cooking classes and shared treasured recipes. But we can do more. With input we have developed a terrific list of cookbooks that specifically focus on the nutritional challenges associated with cancer treatment. Hats off to staff members Sue and Melanie for pulling together these resources. Watch our blog for highlights or stop by the office to peruse the books yourself – they can all be signed out.

Visit the website for more on *To Life!* wellness programs, calendar of events, sign up for the Women's Health Conference, or check out our local resources.

What Genes MAY Tell Us About Cancer Risk, cont'd

and demographic information about ancestors, they may find information about various genetic quirks and sometimes the likelihood of contracting certain health conditions. While various companies offer the service, only the test company 23andMe is currently granted US FDA approval to provide genetic information, including the BRCA-1 and BRCA-2 mutations and certain other medical information.

The medical community advises caution about making any health decisions based on DTC genetic testing. A recent study of the accuracy of DTC testing results identified a 40% false positive rate for findings related to cancer risk genes. Also, an identified mutation or other risk factor does not guarantee that someone will develop the disease. As well, the absence of the mutation does not guarantee that the person will not develop the disease.

Finally, the study of breast and other cancers is ongoing and many non-hereditary causative relationships are becoming understood. They will not show up in genetic testing but should not be underestimated.

Health professional organizations and patient advocacy groups strongly recommend that individuals explore their health concerns with their primary care providers first and seek referrals to genetic counseling if warranted. If conditions warrant, based on medical and family history, or an existing diagnosis, a genetic counselor will recommend testing and health insurance is likely to cover the cost.

Visit www.tolife.org/blog for references and further information on this topic.

From Mara's Desk



President's Message *How Far We've Come!*

This October our annual fundraiser- the Pink Ball- was focused on how far *To Life!* has come in our now 21 years of providing programs and services to our community. It was never just about programs and services but about helping our clients shape or reshape their own perspectives after a diagnosis or during and after treatment. At *To Life!* we have always been about everything except medical care. We're not health care providers and we don't even play them on TV. We're Board members and volunteers and staff that help provide programs and services to educate each other about treatment options but also how to improve our quality of life. We knew instinctively that having the best quality of life while undergoing treatment and when treatment ends is about more than chemotherapy and surgery. It's about having a community around you to learn from and lean on; it's about hiking, painting, kayaking, yoga and a myriad of other options that we've offered over the years to give clients a way to explore ways to bring mindfulness and fun to their lives in addition to following physical medical regimens. We have always known that these things and more are critical to our wellbeing- even before "wellness" became the ubiquitous term that it is today.

The old axiom- if you don't have your health then you don't have anything—still holds true. What's perhaps newer is that now people who focus on wellness realize that physical medicine is only part of the package that helps us "have our health." We need to nurture our emotional wellbeing even when we're in treatment for cancer. *To Life!* knows this and that's part of the reason that we provide this plethora of programs and services including support groups as well as yoga. We were and still are your personal source for breast cancer education and support. That education comes in many forms and we want you to take from *To Life!* whatever works for you and to live your life as fully as you can. We are here for you!

Warmly,
Mara Ginsberg
Founder & President

Breast Implant Reconstruction, cont'd from page 1

Dr. Andrew Warheit (Diagnostic Imaging with Breast Implants) provided a compelling presentation addressing types of monitoring for survivors with implants, including imaging such as mammography, ultrasound and MRI. He also discussed timing of monitoring and encouraged survivors to speak with their health care providers to determine the best monitoring approach for their own health situation.

Of the extensive references provided in Dr. Nagel's talk, one may provide the most concise answer to the question "What do I need to know about this?" The FDA publication "5 Things to Know About Breast Implants" summarizes facts and concerns about implants, including discussion points to be explored during the decision process about reconstruction. The FDA publication suggests the following (presented here in summary)

1. Recognize that breast implants are not considered lifetime devices.

Like any other device or appliance, implants age and can develop problems. An implant's lifetime varies by individual and is impossible to predict. The longer implants are in place, the more likely that problems will eventually arise. An implant may last 20 – 30 years but that is not the norm.

2. Review Product Labeling

All approved saline and silicone gel filled implants come with a Summary of Safety and Effectiveness Data (SSED). Summaries provide information on indications for use of the implant, risks, warnings, precautions and studies associated with FDA approval. Look for information about serious complications that may require further surgeries. The FDA advises health care providers to give patients full product labeling and for patients to read it carefully.

3. Communicate with your surgeon.

Each patient is different and each surgery must be evaluated by the surgeon based on unique characteristics and preferences including size, type and placement of implants.

Patients should ask questions about the procedure, likely and unlikely outcomes, the healing process and living with an implant over time. Surgeons should be told about previous surgeries and any complications, such as more extensive scar tissue than expected, to help inform the surgical decision making. Many patients will have additional surgeries to change implant size. Careful planning and reasonable expectations help to achieve the best possible results from the first procedure.

4. Learn about long-term risks.

Breast implants approved in the U.S. can be filled with either saline or with silicone gel. They come in different sizes and shapes and have either smooth or textured surfaces (shells). As noted earlier, the FDA has identified an association between breast implants and BIA-ALCL, a type of non-Hodgkin's lymphoma. BIA-ALCL appears to develop more frequently in individuals with textured implants than in those with smooth-surfaced implants.

Some women with implants may have experienced health problems including connective tissue diseases (such as lupus and rheumatoid arthritis), trouble breast-feeding, or reproductive problems, but current evidence does not support a link between implants and these conditions.

5. Know that monitoring is important.

Follow your health care provider's instructions on how to monitor your breast implants and promptly report any unusual signs or symptoms.

Also, follow your provider's instructions for routine mammography screening for breast cancer. When you make your appointment, be sure to inform the mammography facility that you have breast implants so enough time is scheduled for your mammogram. Your provider may recommend other tests, such as magnetic resonance imaging (MRI). The FDA recommends that people with silicone implants get MRI screenings to detect silent ruptures three years after their surgery and every two years after that.

A To Life! Perspective

Digesting all this safety information when someone is trying to determine whether to have reconstruction and if so, what type, is challenging. It is no so when it has been years since your implant reconstruction and you want to know whether you should have it removed and possibly replaced. At the end of the day, after any or all reconstruction options are presented by medical providers based on your appropriate medical circumstances, it may boil down to personal preference. Some people want autologous tissue reconstruction, some really like the look and feel of silicone implants, and some prefer saline implants. Some survivors prefer not to have reconstruction and instead use prosthesis and bras. Others prefer to do nothing at all post mastectomy. At *To Life!* we are here to provide information and give you the tools to make your best educated but very personal decision.

Welcome New Staff!



Melanie McCulley, MS, BCC, HHP
***To Life!* Support Service**
Program Manager

Melanie is passionate about women's health and quality of life. Since early in 2019 she provides support to clients and family members, facilitates support groups, manages education and community health and wellness programs, and collaborates with regional cancer care services and professionals.

Melanie has a graduate degree in Higher Education. Additionally, she is a Certified Breast Health Educator, a Certified Cancer Coach and a Board Certified Personal and Wellness Coach. Her background includes education, training, management, advocacy, counseling, coaching, consulting, health and wellness and women's issues.



Faces of *To Life!*

Debra Macejka

Deb was inspired to volunteer at *To Life!* after being inspired by Mara Ginsberg's courageous battle with breast cancer. She had attended the annual "Beat the Odds" program shortly after retiring from a successful career with the NYS Assembly. In that time of transition, she chose *To Life!*

as a priority organization to commit her varied talents.

Deb has been active with many *To Life!* activities and fundraisers. She leads outreach with the Fabulous Fillies program sponsored by NYRA, as well as with the Pink Zone game at Siena College. Deb also volunteers with Carelinks (CAPTAIN) in Saratoga County as a driver for Senior women, and assists the reading program at Hamilton Elementary School in Schenectady. After raising a family in the Capital Region. She and her husband split time between residences in Florida and the Adirondacks.

"The best thing about being a Volunteer for *To Life!* is that it has allowed me to meet so many strong, courageous and fabulous Survivors! Once I was told by a Survivor that I made her laugh & smile and brought her joy, which was the best medicine during her journey with breast cancer!!

Deb is known for her flair for fashion. Her wardrobe is renowned for bright colors, trendy accents and flair for accessorizing. On more than one occasion, Deb has modeled jewelry and other items at a *To Life!* event. She is a one of a kind and we are grateful to have her insights and sensitivity available to callers and visitors at *To Life!* Thank you for all you do Deb!

Thank You to our Generous Donors

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May 31-Sept. 25, 2019

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Your generosity allows us to provide free-of-charge programs and services to those in our community who have been impacted by breast cancer.



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July 29, 2019
Village Pizzeria & Ristorante
Middle Grove NY*



*Tee-off 4 TaTa's
Saturday
September 14th*

A Few Highlights from Events...



*Tri-City Fitness, Latham, NY
October 6, 2019*