

Cancer activist's approach: Real, a bit irreverent

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In this Sept. 26, 2010 photo, Lindsay Avner, right, founder of Bright Pink, a breast cancer awareness organization, drives to Chicago's North Ave. Beach with her mother, Wendy, dog, Brinkley, and father, Brett. The realization that cancer would forever shape her life came early on, as young Lindsay Avner looked around the dinner table at family gatherings and saw very few women, especially on her mother's side. (AP Photo/Charles Rex Arbogast)

(AP) -- Lindsay Avner is no shrinking violet. She's a bright pink whirlwind, with a closet full of dresses cut from that very color and a cancer-fighting organization she named for it.

Bold yet calculating, she is the nice girl who knows how to get what she wants, and how to get away with saying things others couldn't, or wouldn't.

"Mind your melons," Avner, who's 28, tells any young woman who'll

listen. "Touch your ta-tas."

"Remember to check in with 'the girls' every so often."

It is an edgy approach that sometimes raises eyebrows, at least outside the young demographic she's trying to reach - not to mention the disapproval of some [breast cancer](#) researchers who don't necessarily think that self-exams are the most effective approach for detection.

But they're missing the point, Avner says. Self-exam is one tool, a way to get her peers talking about a topic they often avoid, or think no one else understands: their breast and ovarian health.

It appears to be working. Her fledgling Bright Pink organization now has 10 chapters across the country and the kind of fundraising success in a recession that would make most nonprofit executives envious. Sponsors include major brands, from Wrigley's Orbit White gum and Vespa scooters to a line of pink gym equipment sold at Sports Authority.

As she likes to say, "This is not your mother's cancer organization."

Nor is this a battle that Avner necessarily chose.

Rather, it chose her.

The realization that cancer would forever shape her life came early on, as young Lindsay Avner looked around the dinner table at family gatherings and saw very few women, especially on her mother's side.

Her maternal great-grandmother and grandmother died of breast cancer one week apart, when Avner's own mother was only 18. In those days,

people didn't talk much about the "c-word"; Avner's mother had no idea how sick her mother or grandmother were until they were gone.

Through the years, two of her mom's aunts and a cousin also died of the same disease. Then, in 1994, when Avner had just turned 12, she remembers coming home from school and seeing her father's car in the driveway of their home in Bexley, Ohio, a suburb of Columbus.

She knew something was up. It was unusual for her father to be home from work that early.

"Hi, honey," her mom, Wendy Avner, said in a gentle tone, asking her daughter to sit down with them. "We've got something to tell you."

Her mother had breast cancer, too.

Young Lindsay immediately thought the worst and wondered who would tuck her in at night, as her mother had always done. She developed odd superstitions: making sure she brushed her teeth and hair and washed her face in the same order each night so her mother wouldn't die.

"It was my way of trying to control a situation I couldn't control," she now says.

Then, 10 months later, her mother was diagnosed with ovarian cancer, too.

As Wendy Avner tells it, her daughter had always been mature for her age. Now she had a sick mom, a 3-year-old brother and a father who had to work a lot to keep the family afloat, and "she absolutely rose to the occasion."

"But lots of times, I felt guilty. I felt like I had stripped her of her

childhood," says Wendy Avner, now 58.

Lindsay took on chores around the house, cared for her little brother, did whatever she could to help. She also got involved with the Susan G. Komen For the Cure fundraising walks, but noticed that there were few people her age there.

Soon, she had half the students at her high school walking to raise funds for Komen. Then, they challenged other high schools in the Columbus area to do the same. By the time she was a sophomore at the University of Michigan, the High School Team Challenge, as it was known, was getting national recognition. Among other things, teen magazine CosmoGIRL! named her a "Girl on Top."

Her own cancer risk also was ever present. Even as she enjoyed her college years, she made sure to get regular breast screenings.

"I just sort of grew up with the belief that I would get it, too," she says.

Then, she was forced to confront the risks. In 2005, her mother underwent genetic testing and was informed that she had a mutation associated with breast and ovarian cancer.

Lindsay, who had graduated from college days before, was angry that her mother had been tested. She wasn't ready to deal with the ramifications. "It was my own control issues. But I felt like she'd shot off the gun and said 'Go!' and I was suddenly in a race I didn't want to be in," she says.

Still, she also decided to have the test. And just as she feared, she had the same mutation in the BRCA1 gene. For her, it meant she had up to an 87 percent chance of developing breast cancer and a 54 percent chance of getting ovarian cancer.

She was only 22.

Avner attempted to get on with her life. She got a job in brand management with Unilever, moved to a downtown Chicago high-rise, threw herself into work and dated - almost with a vengeance. She was certain she needed to find a husband and start a family before it was too late.

She began getting debilitating migraines: "In hindsight, it was all this nervousness. It was, 'You're going to get cancer. You gotta hurry up.'"

This was no way to live her life, she says. So she started looking for a surgeon who would consider a bilateral prophylactic mastectomy, a preventive procedure that would remove her breast tissue and replace it with implants.

Few would consider it for someone her age.

"Are you married?" she recalls one Chicago surgeon asking her, implying that she wouldn't find a husband if she had the surgery done.

She eventually went to Memorial Sloan-Kettering Cancer Center in New York City, where her mother had had breast surgery. There, she talked to Dr. Patrick Borgen, "the first one whose jaw didn't drop when I said I wanted to do this," Avner says.

Borgen had known Avner since she was 12. She'd watched her mother go through this process, knew more about breast cancer and its treatment than most people twice her age, Borgen says. Though he wouldn't recommend the procedure for just any patient, given her family history, he took her request for surgery seriously.

"Without any question, she came to the decision as educated and as prepared as any patient I've ever encountered in my practice," says Borgen, now chairman of surgery at Maimonides Medical Center in New York, where he heads the Brooklyn Breast Cancer Project.

"Frankly, when she was 12, she was pretty impressive, too."

The procedure, because of her age, became big news. TV networks contacted her. Some in the medical field also criticized Borgen, who remains steadfast in his opinion that women in Avner's position should be given all their options and allowed to choose what's right for them.

"I've seen a dozen patients who found it unbelievably helpful to be able to decide 'yes' or 'no' for themselves," Borgen says of the preventive mastectomy. "Frankly, most decide 'no.'"

But for Avner, who had her mastectomy in the summer of 2006, there are no regrets.

"I can't imagine sitting there in chemotherapy, with a drip, bald and with a husband and children, knowing I could have done this," she says. "I know how it is. I saw it with my mom. Your life goes from normal to not normal overnight."

Her desire to have children is the only reason she's waiting to have her ovaries removed, probably at age 35.

She never wanted to make a big deal out of her surgery; she emphasizes that her story is only one among many. Her point, once again, is to get young women to become more aware of their own cancer risk.

"It doesn't have to be that life-ending thing. That's the conversation we're having," Avner says. "There's much more going on than 'I had a

mastectomy.'"

Still, if she hadn't had the mastectomy, Bright Pink may have never happened.

Because of the surgery, young women started writing her letters. Many of them had similar family histories, but had felt isolated, like the only one among their peers who had to worry about breast and ovarian cancer.

Some called her "inspiring." The term still makes her uncomfortable - but, in the letters, Avner saw a need that wasn't being filled.

While still working at Unilever, she launched a small website in early 2007, known as Bright Pink even back then.

Through it, she organized yoga parties and cooking classes with a growing network of young women in Chicago who were looking for support and information about breast and ovarian health. They often ended their gatherings by dining on pink cupcakes and lemonade.

Interest in the site grew quickly, and Avner found herself working seven days a week.

"I can't do it anymore," she told her parents.

Something had to give. So a little over two years ago, she made the decision to quit her job to work full-time on Bright Pink.

Her mom remembers feeling nervous, but also thinking, "Well, she's young enough. If it doesn't work out, she could get another job."

Having witnessed her daughter's resolve, though, she also had an inkling that she just might pull this off.

This was, after all, the young woman who'd always set impossibly higher standards for herself, more than her parents or anyone else ever did. This was the young woman who, as a teen, literally got thrown from a horse during riding lessons and got right back in the saddle.

She was not easily deterred.

In Chicago circles, Avner quickly made a name for herself, dubbed by local magazines as an "It Girl" and a "Woman to Watch."

Her background in brand management was one of her biggest assets. In almost every photo taken in her role as executive director, she wore one of those bright pink dresses, all the while maintaining a laser focus on her original mission: to provide education, support and community for young women who have a high risk of getting breast and ovarian cancer. She resisted the urge to expand that mission to raise money, for instance, for breast cancer research (there are many organizations that already do that, she says, and Bright Pink partners with many of them).

At the same time, she's also clear that she doesn't want her organization to become a snobby Bright Pink clique. This is about welcoming anyone, she says. This is about meeting people on their terms.

Sure, there might be teas, pink cupcakes and lemonade. But there also are "Treasure Your Chest" seminars and webcasts, one of them with E! Television host Giuliana Rancic in which Avner showed Rancic, on camera, how to give herself a breast exam. And Avner is equally as comfortable attending a lesbian burlesque show to hand out health information.

Bright Pink volunteer Kristina Hernandez met Avner for the first time at a restaurant in San Antonio, Texas, last winter. Hernandez, now the Bright Pink San Antonio chapter "ambassador," is a 36-year-old mother of three whose own mother died from ovarian cancer two years ago. Genetic testing determined that Hernandez was at risk, too.

Hernandez was planning on having her own breasts and ovaries removed, so the conversation quickly turned to Avner's mastectomy.

"Do you want to see my boobs?" Avner asked.

"Kinda," Hernandez replied. "Is that weird?"

They went to the bathroom, where Avner lifted up her shirt and let Hernandez inspect her breasts and scars, knowing that Hernandez herself would soon have scars like those. They talked openly about the procedure, including a "nipple-sparing" technique, which meant that Avner got to keep hers.

Hernandez knows the scene might seem a bit odd. "But it was really very comforting," she says.

She knew Avner understood.

At her Chicago office, Avner kicks off her flip-flops and walks around in her bare feet. She's as likely to greet a guest with a hug as a handshake. But there's a catch to her openness, as her staff recently informed her.

"I give a lot of positive praise," she says, "but I don't always cushion the criticism."

At this time of year, she's particularly tightly wound. Fall is "show time," she says, critical for fundraising since October is National Breast Cancer Awareness Month. This fall, Bright Pink expects to bring in about \$400,000 from donations and sponsorships, nearly 60 percent of its budget. Wrigley, for instance, plans to donate up to \$75,000 for sales of Orbit White gum that carries the Bright Pink logo.

"Lindsay means business," says Leah Drew, Bright Pink's 29-year-old events and outreach coordinator. But she also isn't afraid to hire equally strong-minded and ambitious staff members, two of them full-time right now. "There are no egos here."

Sarah Halberstadt, 25, turned down a job with the Obama administration after working as a field organizer for the president's campaign, opting to work instead for Bright Pink as national programs manager. She is amazed by Avner's energy; for example, Avner insisted on handwriting a personal note to each of the doctors who received Bright Pink educational pamphlets for patients, known as "Little Bright Books." Night after night, she took the packets home in two suitcases and dropped them off at the post office the next day.

"I look at people who float through life, and it looks so boring," Avner says.

Sometimes, though, her staff must remind her to let them do their jobs, and push her out the door at the end of the day.

"Go to yoga," they tell her. "Leave us alone - please!"

There is, indeed, a constant sense of urgency, a feeling of responsibility, even when Avner is relaxing (or trying to relax) at home.

She lives in a studio apartment in the same building as her parents. And

as she sits in her parents' apartment downing Chinese noodles, she nods when asked about that need to do, do, do.

"I always felt a lot more responsibility as a kid," she says. "I still feel it now. A lot is resting on me."

She pauses for a moment - something she does rarely.

"I think I still have this warped sense of how much control I have over a situation."

And so, her schedule is insane.

One recent week, she flew to the University of Texas at Austin to speak to sororities on campus about her work; helped organize and lead an evening teleconference on Ovarian Health 101; took part in "That Stupid Cancer Show," an online radio show for young adults affected by cancer - even as she ran Bright Pink.

It doesn't leave a lot of time for a personal life. But even though she tries not to put pressure on herself or the men she dates, she does want to find a partner in life and have a family.

"I'm good luck. If we date, you'll get married - to someone else," she jokes.

Really, though, she is a hopeless romantic.

"My dream sounds kind of cheesy, but I want to be a really amazing mother. I want to be a great wife. I want to live a life where I give back constantly."

One day, she also envisions handing Bright Pink over to another "spunky

twentysomething."

"I want it to all work out," she says. "Isn't it supposed to be that if you put enough good out into the world, it comes back to you?"

She looks a little sad when she says it, as if she fears that won't happen. At that moment, it's easy to imagine that 12-year-old girl who learned that her mother had cancer.

Her mother, though, has gotten over the guilt she felt, not only for her daughter's missed childhood, but for passing on the [cancer](#) risk.

"Would she be the person she is today if she hadn't had this experience?" Wendy Avner asks.

"Sometimes things happen for a reason."

Online:

Bright Pink: <http://www.bebrightpink.org>

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