

Father, kids learn they share cancer gene

Children take different stances with testing

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In some ways, Jim Adams' genetic legacy to Lynn Riestenberg is written all over her face, same brown eyes, same curve of the nose.

But this year, medical advances revealed a genetic clue for cancer in the Lebanon family, presenting Adams, his adult daughter and his son with a challenge confronting thousands of other families nationwide who get similar news.

What do you do with the information?

Genes are units that pass traits from parent to child, like height or left-handedness. Mutations in genes cause changes in the body.

For decades, the BRCA1 and BRCA2 genes have been known as tumor suppressors. Inherited mutations in those genes can raise the lifetime risk of breast cancer, which is one reason women have been encouraged to track health histories of mothers, aunts, sisters.

In recent years, though, researchers have found that men with aggressive forms of prostate cancer also have a BRCA mutation and can pass it on. Recent research has shown mutations can trigger not just breast cancer but also the deadliest cancers of the ovaries and pancreas.

The Urology Group in Norwood cares for most of the prostate cancer patients in the region. Dr. Gary Kirsh, president of the practice, is a specialist in advanced cases. He has urged patients with aggressive cancers to test for the BRCA mutation. The recommendation is easier now that the price for the test dropped from several thousand dollars to about \$250.

"It's a complete shift in mindset, one that most doctors or even most urologists don't yet appreciate," Kirsh said. The testing "has real implications for how we treat families."

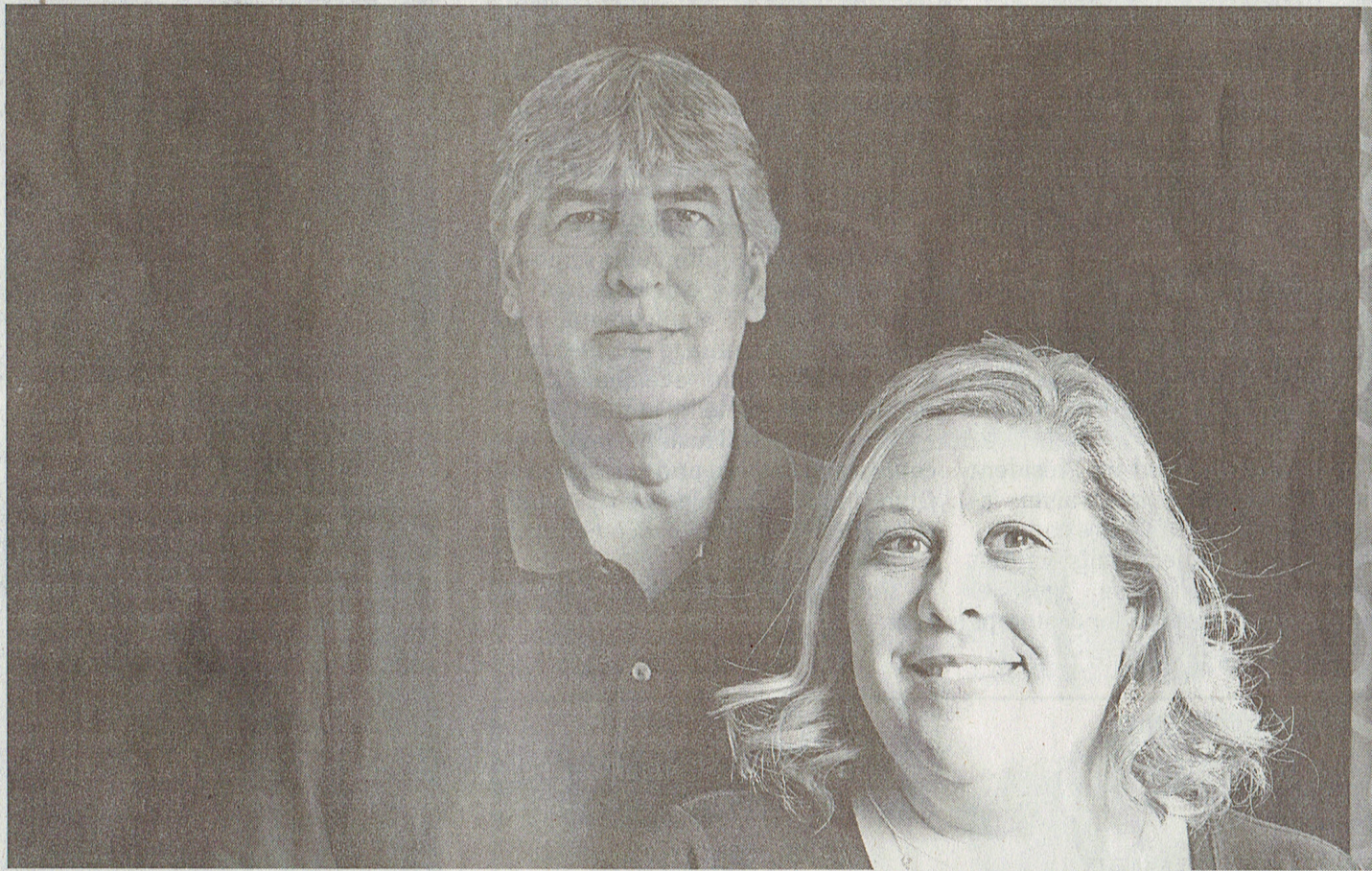
"Where I'm passionate about this is that if a man has a mutation, he needs to tell his daughter. It's no longer simply telling your son to get his (prostate tested). Because if your daughter has the mutation, her lifetime risk of breast cancer is 85% higher."

Sharing the news

In early 2018, Jim Adams, 62, a husband, father of two, manager in a local beer distributorship, learned he had prostate cancer from out of nowhere at stage four. Prostate cancer is the second-leading cause of death in men.

Given the seriousness of his case, his doctors offered the gene-mutation test. Adams said he worried about what the results would mean for his family.

"I've had a good life. I've seen my children grown and raised, married,



Jim Adams of Lebanon and his daughter, Lynn Riestenberg, have been tested for an inherited genetic mutation that can increase the risk for certain cancers. Riestenberg says she is glad to know she has got the mutation because "now I can be proactive." ANNE SAKER / THE ENQUIRER



Dr. Gary Kirsh, president of The Urology Group, is now urging patients with aggressive prostate cancer to undergo testing for an inherited genetic mutation. PROVIDED

with grandkids. I've made my peace," he said. "Then when the doctor suggested the test, I was like, well, here we go, it's hereditary. OK, so how do I tell my children?"

In the spring of 2019, the test showed that Adams has the BRCA mutation. He broke the news to his children, who responded differently.

"Knowledge isn't a burden," said Riestenberg. "Forewarned is forearmed. I'm not going to use this as a woe-is-me. This is what I have, and this is what I need to do. I'm going to take the steps to reduce my risk as much as possible."

"I understand that knowledge is power," said her brother Jim Adams, "but knowledge can lead not to speculation but to a lot of worry. It's one of



Jim Adams of Flora, Indiana, is the son of Jim Adams and brother of Lynn Riestenberg. He has decided not to undergo testing for an inherited genetic mutation. PROVIDED

those things that at this point, I'd rather not know. I'd rather not be focused on every little ailment that I get."

Getting aggressive

Riestenberg, 39, a health care administrator, got tested and learned she has the mutation. She responded with action.

She rounded up a care team at Tri-Health to craft a plan with drastic measures, including a hysterectomy scheduled for right after Christmas that will also remove her ovaries. She will undergo a stepped-up breast-imaging schedule, with the prospect of a double mastectomy in the distance.

Riestenberg, married with a 3-

year-old daughter, said some people don't understand her aggressive plan.

"They're right, I don't have cancer now," she said. "But I need to be aware."

Jim Adams the younger lives in Flora, Indiana, about 70 miles north of Indianapolis, with his wife, their 14-year-old daughter and 8-year-old son. At 36, he is an Army veteran and an automobile technician. He chose not to get the test now.

"Even if I do have the mutation, that doesn't necessarily mean I'm going to get cancer," he said. "For my sister, there's preventive stuff they can do. But for me, (the test will) just let me know that I have the mutation and further past that, there's not much to do."

Picking right moment

Riestenberg said she wants to test her young daughter now. But the experts have counseled that she wait until her daughter is old enough to make the choice.

"I'll encourage her, try to give her all the best information that I can, to help her make that decision," Riestenberg said.

The younger Jim Adams said, "My kids can decide what to do when they come of age."

Jim Adams the elder, is responding well to his prostate cancer treatment and still working. He advocates with his co-workers to explore family medical histories and learn more about the legacy that comes through their genes.

"That way, when you go to the doctor, you know who had what, you'll know the options," he said, "and you can do what it takes to keep from being a statistic."