Family loss prompts Beau and Gail Lane to support genetic testing at Kentucky Children's Hospital in the fight against cancer

A HEART FELT CAUSE

By William Bowden
Photos by Joseph Rey Au

Horseman Beau Lane and his wife, Gail, have made a significant donation to Kentucky Children's Hospital.

Making a Difference

KENTUCKY CHILDREN'S HOSPITAL

The Project Inherited Cancer Risk clinical research study at Kentucky Children's Hospital gives doctors the chance to improve diagnoses and provide more effective treatment.

The heartache that cancer can bring to a family is all too real for Beau and Gail Lane. The disease struck Beau's three daughters (Gail's stepdaughters) — Lauri tragically died of it at age 45, while Mendy and Julianna have successfully fought it off through surgery and other treatment.

"We have been directly slammed by this thing," said Beau, owner of Beau Lane Bloodstock on Woodline Farm in Bourbon County near Paris. "Gail and I decided we wanted to try to help [keep] others from having to lose someone they love and go through what we went through."

That resolve led them to become significant donors to a new genetic testing program at Kentucky Children's Hospital (KCH) at the University of Kentucky. Begun two years ago, the Project Inherited Cancer Risk (PICR) clinical research study can reveal a predisposition to cancer, giving doctors the chance to improve diagnoses and provide more effective treatment.

"About one in every 10 children, adolescents, and young adults who get cancer has a genetic reason that put them at increased risk for the disease," said Dr. John A. D'Orazio, chief of the division of hematology/oncology, Department of Pediatrics at KCH. "Once we identify someone with a cancer risk, we can enroll them in a surveillance program where we look for cancers early and can sometimes take steps to prevent the cancer."

Medical insurance does not cover the $1,000 cost of each

test. It's philanthropy such as from the Lanes that helps make the testing free to all patients. That's why their donation is so critical, both on its own merit and to encourage others to donate and ensure the program continues. (See sidebar.)

OPPORTUNITY NEARBY

The travails of the Lanes' daughters began long before the PICR program was started at KCH, and for the most part, their diagnosis and treatment took place away from Lexington. But when the family looked for a way to help others, they turned to the opportunity near at hand.

"The Kentucky Children's Hospital is a place where you can give your money to people who can actually do something about the problem," Beau Lane said. "Dr. D'Orazio and his colleagues are the real deal. Gail and I decided that this is worth getting into."

One such colleague in a key position is Dr. Amanda M. Harrington, who runs the Pediatric and Young Adult Cancer Predisposition Clinic in coordination with a genetic counselor from UK's Markey Cancer Center. She often deals with the inherited gene mutation known as BRCA1, which markedly increases the likelihood of developing breast and ovarian cancer. Beau is a carrier of that gene and passed it on to his daughters, making his and Gail's support of KCH all that more personal and meaningful.

"Once we've identified someone with a cancer predisposition syndrome, my job is to educate the family about what cancers they may be at risk for," Harrington said. "Sometimes the child is the first person in the family to be affected by this."

D'Orazio offered the example of a young adult who came to KCH afflicted with bone cancer, was tested, and was found to have a BRCA1 mutation. This was a surprise as that mutation is not directly associated with bone cancer. His mother was subsequently tested and found to be a BRCA1 carrier.

"That led to the discovery of stage 1 breast cancer in her, before anyone would have thought to do a mammogram," D'Orazio said. "She had the mastectomy, and her life was saved."

Dr. John A. D'Orazio heads KCH's cancer risk program.

The other part of Harrington's job is to create a surveillance program tailored to the patient and family. Such was the case for Jenny Scott. All six of Scott's offspring have been tested (known as "cascade" testing) for inherited genetic dispositions, and four have had various encounters with cancer. Harrington provides the family with a "continuum of care," as D'Orazio puts it, that includes guidance for preventive measures and any needed treatment.

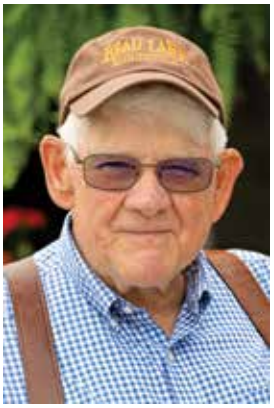
Two of Scott's daughters — Amiriss and Alyssa — are patients of Harrington's and have been treated at KCH in the DanceBlue Hematology and Oncology Clinic. (The clinic is named for the 24-hour dance marathon that is the key fundraising event that completely funds the clinic through the widespread volunteer efforts of students.)

Along with D'Orazio, Dr. Amanda M. Harrington plays a key role in KCH's fight against childhood cancer.

Beau Lane's daughter, Julianna (with her husband, Michael Orem, at the Keeneland September yearling sale), is a cancer survivor as is her sister Mendy.

"In 2020 I had half of my thyroid gland removed because it was enlarged," said Alyssa, 19, who was found to carry the DICER1 mutation that is associated with thyroid, ovarian, lung, and kidney cancers, among others. "We were keeping an eye on the other half, and just a few months later I had it removed."

Amiriss, 20, benefited from the knowledge that her twin sister, Aurora, was discovered in 2017 to have ovarian cancer and the DICER1 mutation, which Amiriss also has. "I was having pain on my left side," Amiriss said. "With my normal scans they weren't looking at my ovaries." Her small tumor was caught early and removed before it could become a major problem.



From a busy mother's standpoint, the surveillance program is a blessing. "It if were left to me, I'd get lost as to what scan should come next, but they have it all down pat," Jenny Scott said. "They keep us on track so that nothing gets missed. And the comfort we feel while at the hospital, their caregiving, is so relaxing. It takes away any worry on our part."

The testing can also reveal situations that have a significant impact on how a cancer is treated. "There are variances in genes that affect how well cells can recover from damage," Harrington said. "Chemotherapy and radiation are two of the big tools we use to treat cancer, but they are damaging. If we discover that you have one of those genetic defects where your machinery to handle damage is broken, we don't want to use those tools."

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>
> **—Beau Lane**

RESEARCH IS KEY

Research is an important part of D'Orazio's and Harrington's roles at KCH. From a patient's blood sample, the PICR program can look for up to 81 genes in the main panel, with over 160 additional genes in an investigational panel. More than 120 KCH patients have been invited to take part in the research thus far, and over 90% of them have opted in. The goal is to find keys to preventing cancer in any form.

"I am a physician/scientist, and I love both worlds," D'Orazio said. "Since we started this program, we're taking the mutations we find in our patients back to the lab to study how they cause cancer

and what we can do about it. We've already seen that some of the mutations make the cancers vulnerable to a new class of drugs."

For a broader context, the Cancer Predisposition Advisory Council, run by the Markey Cancer Center, was created to take an overall view of how the disease can affect individuals and families in a variety of ways. Harrington participates in the group, which meets outside of business hours several times a year and comprises patients, family members, caregivers, doctors, and nurses.

"We talk about research and cancer predisposition in general," Harrington said. "Our purpose is to figure out what we can do better and to learn what patients and families want us to be focusing on. One thing we've learned is that the psycho/social needs of the patients are high and something we need to meet. Learning about a family history of cancer can be scary."

PRESCRIPTION FOR HOPE

Summing up the lifesaving work of the KCH, and the genetic testing and research program in particular, D'Orazio said, "The majority of kids who get cancer survive. All the work we do here is about giving people hope and a better future."

That's what Beau and Gail Lane wanted to be a part of and why they've decided to increase their giving and make it an annual priority. They have become much more aware of the fact that, as

D'Orazio puts it, "We really are a product of our ancestors and their genes, for good and for bad."

"I am a BRCA1 carrier, and I got it from my grandmother," Lane said. "One day I hope they can give a child a sheet of paper and say, 'At this age, you need to look for this.' To me, the lives it would save make it worth whatever we can give." **KM**

As a carrier of the BRCA1 gene, Beau Lane is motivated to give children with the same genetic mutation tools to fight cancer.

PRIMING THE PHILANTHROPY PUMP

"Sometimes it just takes somebody to take the first step," said Megan Crouch, associate director of philanthropy for Kentucky Children's Hospital at the University of Kentucky.

She was referring to the sizable gift to KCH from Beau and Gail Lane that made it possible to create two endowed funds to support the hospital's genetic testing program and its research component.

"Anyone can contribute to these funds, which have grown to over $90,000," Crouch said. "The Lanes' gift paved the way for others to make a targeted donation for this vital cause."

Crouch explained that in addition to helping make the tests available free for all children, adolescents, and young adults who come to KCH, the funds allow the hospital to work on adding its sequencing results to the Cancer Data Commons database maintained by the Markey Cancer Center at UK. That allows deidenti-

Dr. Harrington meets with patients Amiriss (left) and Alyssa (second from left) and their mother, Jenny Scott (second from right).

Dr. D'Orazio (standing) is shown with the research members of his KCH laboratory, from left, lab technician Berina Halilovic, Hong Pu, Ph.D., and Nathaniel Holcomb, Ph.D. They are characterizing mutations in the PICR study to learn how those variations may make patients at an increased cancer risk.

fied data to be available to other researchers.

As owner of Beau Lane Bloodstock, which specializes in breeding and foaling mares, Beau is particularly motivated to share in Keeneland magazine his family's story of dealing with cancer. He wants his peers in the Thoroughbred industry to know of the opportunity to support KCH and the important work it does to combat childhood cancer.

After all, when it comes to genetics and bloodlines, he knows the language well. "I spend half my life planning matings with stallions whose bloodlines show they are a good match for breeding with my mares," Beau said. "I started this operation with six mares, and three of them were stakes-winning producers within five years."

The gift Beau and Gail made to KCH also reflects a broader commitment to philanthropy in the Thoroughbred industry, exemplified by the Keeneland Foundation and its support of many causes located primarily in Central Kentucky.

For more information on giving to Kentucky Children's Hospital, contact Megan Crouch at crouch.megan@uky.edu

Beau Lane wants his colleagues in the Thoroughbred business to know they can support KCH's work to fight childhood cancer.