

Pearls & Politics

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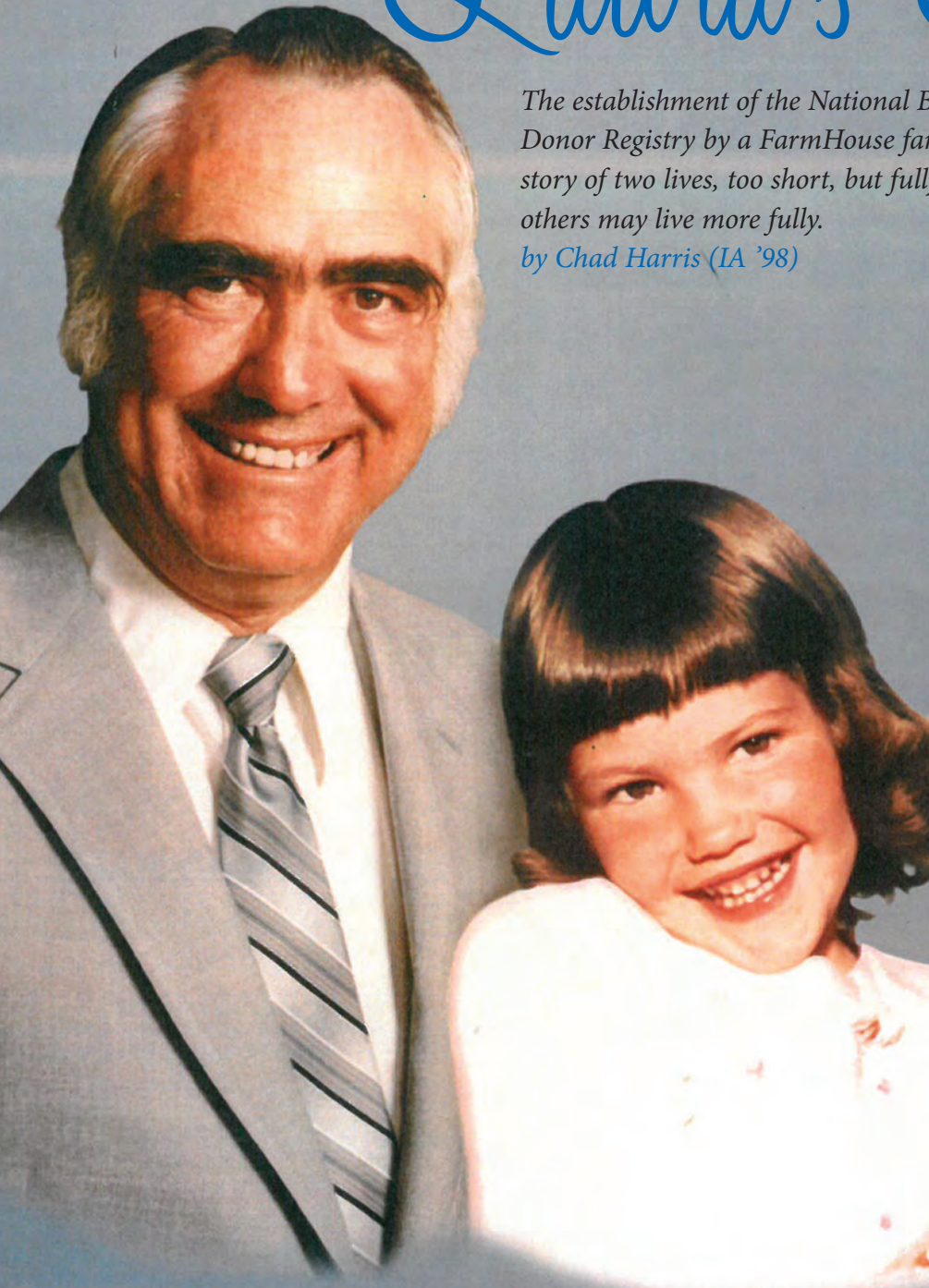


Laura's Legacy

How Bob Graves' (CO '53) crusade to save his daughter's life resulted in saving the lives of millions through the creation of the National Bone Marrow Donor Program.

Laura's Legacy

The establishment of the National Bone Marrow Donor Registry by a FarmHouse family and the story of two lives, too short, but fully lived, so that others may live more fully.
by Chad Harris (IA '98)



This portrait of Bob Graves (CO '53) and his daughter, Laura, hangs in the headquarters of Be the Match: The National Bone Marrow Donor Registry in St. Paul, Minn., as a lasting memorial and tribute to the Graves family.

“If we had to do it all over again, we would.” Such is the conviction of Sherry Graves (pictured on the cover), wife of the late Robert (Bob) Graves, DVM (CO '53), as she sits in her living room on a sunny early summer day, in Fort Collins, Colo.

“It wasn't easy, but the benefits and break through in research from Laura's treatment and Bob's efforts are remarkable. They continue to give life to so many.”

Indeed the story of Laura Graves as a young leukemia patient in the 1970s is not an easy one to hear or for Sherry to always share, but it is mightily important. Thus the reason for her phone call to FarmHouse Headquarters in 2014 following an article in *Pearls & Rubies* announcing the Fraternity's national philanthropic and service partnerships with the Leukemia-Lymphoma Society (LLS) and Be the Match: The National Bone Marrow Donor Registry.

“I was hesitant to call at first,” Sherry reflects. “But I think so highly of FarmHouse, I felt the members and the young men needed to know the FarmHouse-connection to the founding of the bone marrow donor registry.”

Such founding occurred in the basement of the Graves' home. This is the story of the origins of Be the Match and of a FarmHouse man determined to find a way to save his daughter's life.

Early Beginnings of Hard Work

“Bob Graves was perhaps the last frontier man of the Old West,” says Sherry. “He was a character with a dry sense of humor. Rugged, stubborn, blunt and never-ending in his driven work ethic,” she continues. Born in the

Depression-era, he was the fourth generation of a dairy and ranching family in northern Colorado. Bob worked hard on the family's farm and the dairy store they owned and operated in Bellvue, just outside of Fort Collins.

As many FarmHouse men may attest, dairymen work tireless hours. The demands of a dairy dictate not venturing far from a milking operation for long and time away from home is infrequent and vacations are a rarity. While education was important, it was second to hard work, thus convincing his parents to let him attend college was a tall task for Bob Graves.

"Bob was always politicking for some cause," says Sherry. "His first successful effort was perhaps lobbying his parents to allow him to attend Colorado State. They agreed so long as he promised to still help on the farm." He did so, excelled as a student and joined the local chapter of FarmHouse Fraternity, initiating in 1953. He was admitted early to the School of Veterinary Medicine and graduated in 1956.

He became a brand inspector for the State Veterinarian of Wyoming, but soon his parents inquired about his interest in returning to join the family dairy business. Bob agreed on one condition, he was to be in charge. His parents, at first reluctant, agreed and at the age of 27, he assumed control of the family dairy operations.

As his parents began to travel, for the first time in their lives, he began to grow the dairy. Every small tract of land or farm that came up for sale, he would

buy. Soon a neighbor jokingly asked, "What are you trying to do—buy to the Wyoming state line?" Bob answered bluntly, "Yes."

Under his management the multi-generation dairy grew from a modest family operation, to become one of the largest dairy operations in the state and in the West, encompassing over 20,000 acres. Graves was persistent in overcoming challenges when faced with obstacles—even at a young age.

When financial lending became tight in the early 1960s from local banks, Graves convinced six other local businessmen, a farmer, a dentist and a

mill owner to join him in starting a new bank. He became its first secretary. Clearly just running a large dairy and farming operation wasn't enough to keep him occupied. He was driven to do more.

Bob was always viewed

as being a forerunner, a big picture thinker and a determined individual. And he was viewed by many of his friends in Fort Collins as a confirmed bachelor and would likely never marry. That is until he met Sherry Girmann.

Born in Nebraska and raised in Fort Collins, Sherry Girmann also attended Colorado State and graduated with a degree in education in 1957. She began teaching elementary school, but dreamed of traveling and working overseas.

She researched opportunities and learned about teaching the children of U.S. military personnel stationed overseas. As it happened, a recruiter was coming through the area to interview and hire teachers for a limited number of positions. Sherry secured an interview

and to her surprise was hired. Sherry recalls, "I told them 'I'll go anywhere' and they must have believed me, as they came back with two options—Morocco or Iceland."

"I chose Morocco! It was perhaps the greatest year of my life," she recalls with a smile. Arriving in Morocco at the age of 23, not knowing anyone, she quickly befriended a fellow teacher named Elaine, from Hays, Kan., who, upon arrival in the country, purchased a brand new Volkswagen bug.

"Every weekend, as soon as the bell rang, Elaine and I were off on another adventure. You can imagine the surprise to so many local Moroccans when two young American females came rambling into their small villages to explore, greet them and take in the local culture."

Building a Family Together

After two years abroad, Sherry decided to return to Fort Collins, and begin her teaching career at home. The following summer in 1962, she met Bob Graves at the Summer Days Festival as he worked the creamery stand.

Sherry laughs recalling, "I had heard of Bob Graves and knew his reputation of having three dates with a girl, then not calling again." The day after they met, he called and asked for a date. Two more followed. And then true to his reputation, he didn't call again.

However, the following spring in 1963, Graves surprised Sherry when he called saying he needed a date to a dance. Sherry declined as she was dating Bob's own FH brother Bob Longenbaugh (CO '54). Finding this out, Graves said he'd ask Longenbaugh if it was okay for her to be his date to the dance.

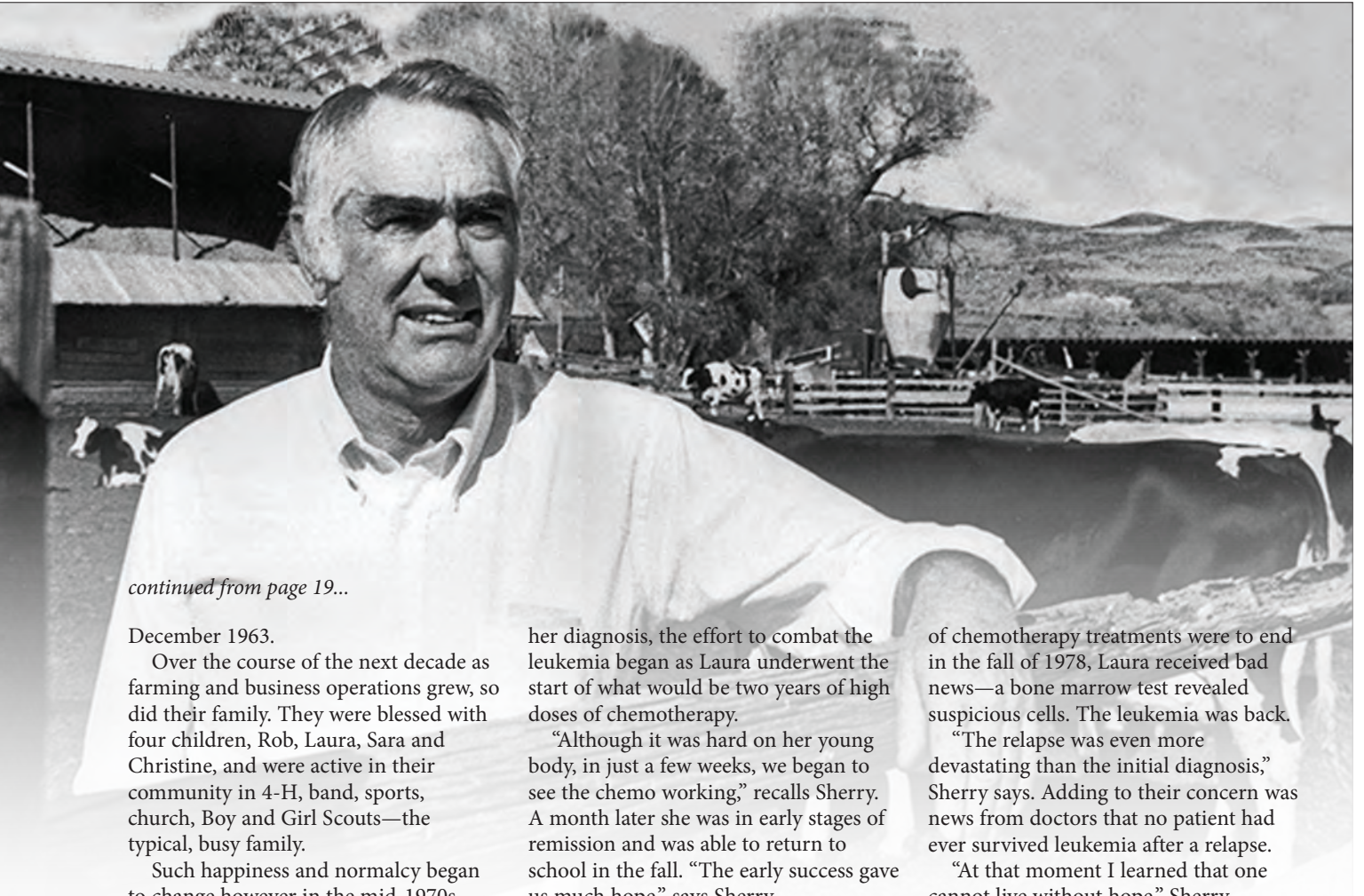
She chuckles, "Bob Longenbaugh wasn't too happy about it, but he agreed, joking that Bob [Graves] must have forgotten he'd already been on three dates with me!"

This time, however, three dates turned into many, and they were married in

"It wasn't easy, but the benefits and break through in research from Laura's treatment and Bob's efforts are remarkable. They continue to give life to so many." —Sherry Graves

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December 1963.

Over the course of the next decade as farming and business operations grew, so did their family. They were blessed with four children, Rob, Laura, Sara and Christine, and were active in their community in 4-H, band, sports, church, Boy and Girl Scouts—the typical, busy family.

Such happiness and normalcy began to change however in the mid-1970s. Laura, who had always been healthy as an infant and full of energy, developed a severe case of the chicken pox, which was followed by bronchitis, other severe colds and illnesses.

In the spring of 1976, at the age of 10, one morning getting dressed for school, Laura couldn't raise her arms above her head. Fatigue and a lack of energy followed.

By the end of the summer, Sherry noticed swollen lumps behind Laura's ears and thought she might have a case of mono. Seeing their local doctor the next day, they were referred to Children's Hospital in Denver for more tests.

Here the Graves family received the devastating diagnosis news: Laura had leukemia.

Devastating News

On August 15, 1976, just days after

her diagnosis, the effort to combat the leukemia began as Laura underwent the start of what would be two years of high doses of chemotherapy.

"Although it was hard on her young body, in just a few weeks, we began to see the chemo working," recalls Sherry. A month later she was in early stages of remission and was able to return to school in the fall. "The early success gave us much hope," says Sherry.

"Laura was so strong that fall in returning to school, even with the radiation sickness, the side effects of drugs with a swollen face and hands, the loss of her hair. That was the hardest part for her—losing her hair."

"Kids can be cruel sometimes and they didn't understand what was happening to Laura," Sherry adds.

"We saw an opportunity to help educate her classmates on this serious matter, so nurses went to the school and talked about cancer, which had not been done before."

She continues, "Back then you didn't know children who had cancer and didn't talk about it. I'm glad we've come a long way since then. I don't think children going through treatment today have to experience the teasing and taunts as much as Laura did. We're more aware."

Just three months before her two years

of chemotherapy treatments were to end in the fall of 1978, Laura received bad news—a bone marrow test revealed suspicious cells. The leukemia was back.

"The relapse was even more devastating than the initial diagnosis," Sherry says. Adding to their concern was news from doctors that no patient had ever survived leukemia after a relapse.

"At that moment I learned that one cannot live without hope," Sherry reflects. "I decided that just because the doctors said no one had survived a relapse, didn't mean that no one ever will. Bob was equally convinced we needed to explore more and new options for treatment."

Their local pediatrician, Dr. Richard Booth, along with doctors at Children's Hospital, gave them three options: to do nothing; to try new experimental drugs; or to consider a bone marrow transplant. The family decided to try the new drugs, but the impact of the high doses of chemotherapy on Laura's young body had been severe and they couldn't bear to see her experience that again.

New Treatment, New Hope

In the late 1970s only siblings of cancer patients were considered to be potential donors for a bone marrow transplant. Laura's three siblings were

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human leukocyte antigen (HLA) tested. The results came back with no match. It was January 1979 and the Graves family began to think time was running out. There seemed to be no treatment options left.

One morning a few months later, Bob read a story in the newspaper about the pioneering bone marrow research of Dr. Donnall Thomas and Dr. John Hansen, at the Fred Hutchinson Cancer Research Center (FHCRC) in Seattle.

A bone marrow transplant had been conducted using a parent as a donor match for the first time. Determined to find a treatment for Laura, Bob contacted the researchers and offered to come to FHCRC for he and Sherry to be tested. They flew to Seattle to be tested and Laura's siblings retested. Unfortunately, again, no match, and the family felt time with Laura was running out.

That spring, while still in Seattle, Dr. Hansen approached Bob in the hospital hallway and informed him that Laura had a very common HLA type. Dr. Hansen shared that for the last seven years, he and Dr. Thomas contemplated matching a non-relative donor for a bone marrow transplant, but it had never been done.

Dr. Hansen asked Bob if they found a donor match for Laura, would they consider such a transplant. Bob said yes, but not to mention it to Sherry.

"I'm a worry wart," Sherry says. "I think Bob thought I had enough on my mind and didn't want to give me false hope."

In July, the call came from Drs. Thomas and Hansen, "We have a match."

For two weeks Bob and Sherry wrestled with the difficult decision whether or not to proceed with this first-of-its-kind treatment. What might happen to Laura? They consulted with medical experts locally, at leading research universities and on both coasts.

"I remember talking with one bone-marrow specialist at UCLA and telling him about our difficult decision. His response was 'Oh my, what an interesting experiment!' That didn't go over well with me! He was talking about our 10-year old daughter!"

Sherry continues, "It sounds a bit over the top now, but we didn't want to create a monster or have her experience some kind of terrible death with this new treatment. But those were real concerns of ours and no one had real answers."

When they asked about success rate, the most optimistic estimates were 8-10 percent, but also unknown. Sherry recalls, "We decided that we had to give Laura a chance, even if it was a small one. We couldn't say no, as that gave us no future. Saying yes gave us some hope and some small chance at her future. We said yes."

On September 4, 1979, Laura Graves made medical history, when, under the care of Dr. Thomas and Dr. Hansen, she received the first-ever, non-related bone marrow transplant at the Fred Hutchinson Cancer Research Center in Seattle, three years after her initial leukemia diagnosis. Her donor was a 26-year old female lab technician who worked at Swedish Hospital across the street.

Immediately after the transplant, Laura was placed in a bubble—a laminar air-flow (laf) room—to protect her from

all outside elements and to give her every chance of survival. Sherry stayed in Seattle, while Bob returned home to Fort Collins to run the dairy and provide some sense of assurance for Laura's siblings. Most patients are in a laf-room for 30 to 40 days, but doctors requested that Laura remain in the bubble for 100 days. Eventually they agreed to 90 days, with another 20 days of transition care in Seattle.

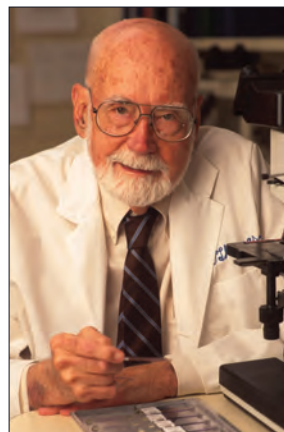
"How Laura hated that room," Sherry laments, "but she wanted to do everything just right to improve her chances for living." She continues, "The doctors were good at being as accommodating as possible and Bob took so many steps to make Laura feel like herself and to keep her spirits up.

He flew the family out twice and her teacher to help her with her school work. School was so important to Laura and she wanted to keep up. We even put books and get well cards from her class through radiation, so she could see them up close and continue in her school work as best as possible."

Another special person came to visit Laura, her bone marrow donor, Francie. "Shortly after the transplant, the medical staff asked if we wanted to meet her. We did, but had been waiting for her to ask us," Sherry recalls.

"It was a very special meeting, which took place within a week after the transplant. So much was unknown as to what might occur following the treatment that we joked perhaps Laura would now have long curly hair, like Francie. Being so close, Francie made a

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Page 20: Graves on his ranch outside of Fort Collins, Colo., shortly after the formal establishment of the National Bone Marrow Donor Program in 1987. **Left:** Medical history was made at the Fred Hutchinson Cancer Research Center in Seattle, Wash., on Sept. 4, 1979, when Laura Graves, daughter of Bob (CO '53) and Sherry Graves, became the first cancer patient to receive a bone marrow transplant from a non-related donor. **Right:** Dr. Donnall Thomas was the world's leading medical researcher in bone marrow transplantation. He and Dr. John Hansen, led the team that conducted the bone marrow transplant for Laura.

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few visits that fall and we really enjoyed getting to know her.”

On December 16, 1979, Sherry's birthday, Laura and Sherry finally came home to Fort Collins. They enjoyed Christmas as a family and in January 1980, Bob took the family to Disneyland and invited Francie to join them as well.

During this trip, Bob realized that just as Laura had great support, Francie, as a donor, needed support too, as the transplant procedure had a physical and emotional toll on her as well. In March Laura returned to school full-time and completed the sixth grade that year with straight As.

The Need to Help Others

Following the successful transplant, the phone calls began to the Graves' home. Parents were desperate to learn how the treatment worked and how to find a donor.

“After a long day working at the dairy, Bob would come home, eat a quick dinner and then retire to the basement and spend all night returning phone calls,” Sherry shares.

“He threw his energy into helping others find a match.

At the time 60 percent of patients needing a transplant didn't have a family member match. Bob saw a need and knew he needed to help.”

Bob, buoyed by the early success of Laura's transplant, began contacting blood banks across the country that were tracking HLA types. Bob became frustrated at the limits of his own network and the limited amount of time he had to help others.

Time was of the essence in these cases and he could see the need for some type of national network to track donors in a central manner, so as to quickly respond to patient needs. When he did succeed in finding a donor match, by the time he contacted the anxious parents again, the patient was dead.

In September 1980, Laura entered junior high, but the leukemia returned in October. This time drug treatment was used and helped her enter her third remission. Soon after, her health began

to severely decline.

Always a man of action, Bob convened a meeting of leading scientists, doctors, blood bank staff, patients and donors for a meeting to discuss the need for a donor registry in Denver in March 1981. Laura attended, as did Francie and Dr. Hansen from Seattle.

The outcome of the meeting was the establishment of the Laura Graves National Bone Marrow Transplant Foundation—an organization committed to finding bone marrow donors for transplantation treatments and supporting marrow donors.

As Laura's health continued to decline, Bob and Sherry sought more treatment options. They traveled with Laura to London in July 1981 to meet with doctors of the Anthony Nolan Bone Marrow Registry to learn about efforts to track and collect donor information in England. Additionally, the Graves family asked about a possible second bone marrow transplant for Laura. It was deemed too risky. Her body could not handle a second high dose of radiation.

On the flight home from London on



July 18, Laura bumped her nose causing it to bleed. Because of her low platelet count, they could not stop the bleeding. Contemplating an emergency landing on the East Coast, they continued on to Denver, where an ambulance awaited to rush her to Children's Hospital. She was stabilized with a platelet transfusion, which would continue every three days.

Laura returned home. Her pain was aided by oxygen and morphine, and the love of her family. On August 15, 1981, as she lay in her parent's bed listening to her mother read a story Laura commented, “Nothing's working, mom. Let's try some chicken soup.” Encouraged by her appetite, Sherry kissed her daughter and went downstairs to make some soup.

Laura died a short time later—peacefully, at home, five years to the day from when she started her first cancer treatment.

“The transplant she received gave her an extra year and a half of her life,” Sherry says. “We never regretted the decision to go for it.”

The Registry Crusade

Following Laura's death, Sherry turned all her energy and attention to her other children. “Laura's constant care and treatment and ultimate passing was difficult on them and they needed me and I needed them,” Sherry recalls. “Meanwhile, Bob's efforts to advocate for the national registry increased ten fold,” she adds.

With the help of Dr. Thomas, Dr. Hansen and Dr. Jeffrey McCullough, the director of the St. Paul (Minn.) Red Cross Blood Center, they collaborated on a draft proposal for a central registry. Long involved with local politics in Larimer County, Bob put his political prowess and his ability to lobby to work in a new way—in his crusade to public officials for funding to establish a national registry.

His long-time friendship with

Colorado Congressman Bob Schaeffer, led to other meetings with elected officials who were willing to listen. Senator Paul Laxalt of Nevada, became an ardent supporter.

As did Alaska Congressman

Don Young, whose wife was diagnosed with leukemia and would later die from the disease. An unlikely advocate and ultimate friend was Senator Ted Kennedy of Massachusetts.

“Our politics did not agree with Ted Kennedy's,” Sherry laughs, “but Bob was willing to talk to anyone who would listen. Senator Kennedy became a strong supporter and we enjoyed getting to know him over the course of many meetings in Washington.”

The military also supported the effort. Fearful of the fallout effects of possible nuclear war in the continuing Cold War of the 1980s, radiation and cancer treatments were of vital national security importance. Former Chief of Naval Operations, Admiral Elmo Zumwalt, joined Graves' lobbying effort, as his son was diagnosed with lymphoma in 1983.

After eight years of hard work, the National Marrow Donor Program

(NMDP), became a reality in 1987, when it received federal funding for a collaborative contract between the U.S. Office of Naval Research, the St. Paul American Red Cross Blood Center and the Council of Community Blood Centers.

Bob served as the first chairman, with Admiral Zumwalt, also serving on the inaugural board of directors. The collaborative effort immediately brought 2.8 million ready donor records together when NMDP launched in 1987.

Sherry comments, "Bob became really frustrated one time when he heard about a wealthy family who had been able to 'buy their way' to the front of the donor line for a family member in need of a transplant. In addition to the benefits the establishment of the Registry brought to centralizing donors, he was very proud of the fact that it would treat all patients equally and fairly."

Once the Registry was established, the work was not done for Bob. He traveled to Europe, China and Russia to share the story of how these regions and countries too could establish a network. Russia was in great need of donors to combat cancer following the Chernobyl disaster.

As he traveled, he remarked, "People found it impossible to believe that anybody would go under general anesthesia and have some of their marrow removed to help a total stranger. That seemed like such a remote possibility. No, Laura didn't survive, but we proved that a marrow transplant with an unrelated person is feasible. And now, hundreds of people are surviving. The program has been tremendously successful. People are giving other people a chance at life, and there's no gift more precious than that."

The decades-long research on bone marrow transplantation of Dr. Donnal Thomas was recognized in 1990 when he received the Noble Prize for Medicine.

Sherry recalls, "It was a great surprise and humbling honor when Dr. Thomas called and asked Bob and me to be a part of his delegation and join him in-person when he received his Noble Prize in Stockholm, Sweden. It was an unforgettable experience and special to think that Laura was a part of his break-through research. Laura would be so proud."

Ready for another challenge, following



Sherry Graves (fifth from left), pictured with her children, Rob, Sarah and Christine, their spouses, and her grandchildren, outside her home in Fort Collins, Colo. in 2009.

the establishment of NMDP and its secured funding for long-term future success, Bob turned his attention back to his agriculture roots and the disease in livestock and animals.

He was lobbying and working to secure funding for the creation of the Transmissible Spongiform Encephalopathies Foundation, to support research for the elimination of chronic wasting disease, "mad cow" disease in livestock and Creutzfeldt-Jakob disease in people, when he died on February 13, 1997, of cardiac arrest, while on the phone at the dining room table. He was 63.

Sherry recalls, "That last day was just as he wanted it to be. He helped birth calves and made a trip to Denver to lobby the legislature in the morning. He ate lunch with our daughter, Chrissie, at his favorite local café. And he died at home with a phone to his ear, politicking for his next big project."

Laura's Legacy Today

The National Marrow Donor Program has evolved to become Be the Match: The National Bone Marrow Donor Registry. Be the Match supports marrow transplantation needs through transplants, patient support, research/education and engaging the public to act.

Since its founding in 1987, Be the Match efforts resulted in 61,000 transplants, with 6,300 transplants in 2014 alone. Over 250 research studies

are supported annually related to cancer research. Assistance was provided to 1,800 patients in need of treatment, totaling \$3.2 million in financial support last year.

And most importantly, in 2014 540,000 new potential donors were added to the Registry, of which 44 percent were racially and ethnically diverse. What started as a select, disconnected, few donors, in files in the Graves family basement, today is a Registry of over 11 million donors in the United States and 22.5 million potential donors worldwide.

"It is remarkable to think that Bob's work from Laura's illness has grown to this level," Sherry says. "Her life was cut short. He too died too soon. But collectively they've given life to so many. That is a wonderful legacy."

It is indeed remarkable. When asked by someone what he did, Bob's first was response was often, "I'm a farmer."

That deeply rooted connection to agriculture was also reflected in his remarks at the time of the establishment of the Registry, when Graves said, "Creating this has been like planting a crop. After all the work to get it going, it is now time for the harvest."

The bounty of Bob Graves' crop is achieved every time a new volunteer registers as a donor. Every time a life is saved by a marrow transplant, his vision is confirmed and the yield of his harvest increases. And the legacy of Laura Graves lives on.