THE MISSION OF
A LIFETIME

Turning Cancer Into a Calling

Erin (Geddis) Cummings ’79 unites, supports and educates fellow Hodgkin lymphoma survivors and medical professionals on the later-in-life effects of youth cancer treatment.

STORY BY
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Children diagnosed with **Hodgkin lymphoma**, a **cancer** that affects the **lymphatic system**, are often told that it is a “good” cancer, meaning it’s more curable than others. That was true 50 years ago and more so today.

“How ironic is it, then, that the cure for this cancer could end up costing us so much?” asked Erin (Geddis) Cummings ’79, at the opening general session of the first-ever **Hodgkin’s International Symposium on Long-Term Survivorship**, an event she organized and hosted. Held in **Boston** in June 2024, the weekend was Cummings’ dream for at least eight years and the then-culmination of 50 years and counting of survivorship.

At age 15, Cummings was diagnosed with **Stage IV Hodgkin lymphoma**. While she was told it was a “good” cancer, she was never told that the five subsequent surgeries, followed by multiple rounds of radiation and chemotherapy, would lead to health complications that would follow her for the rest of her life.

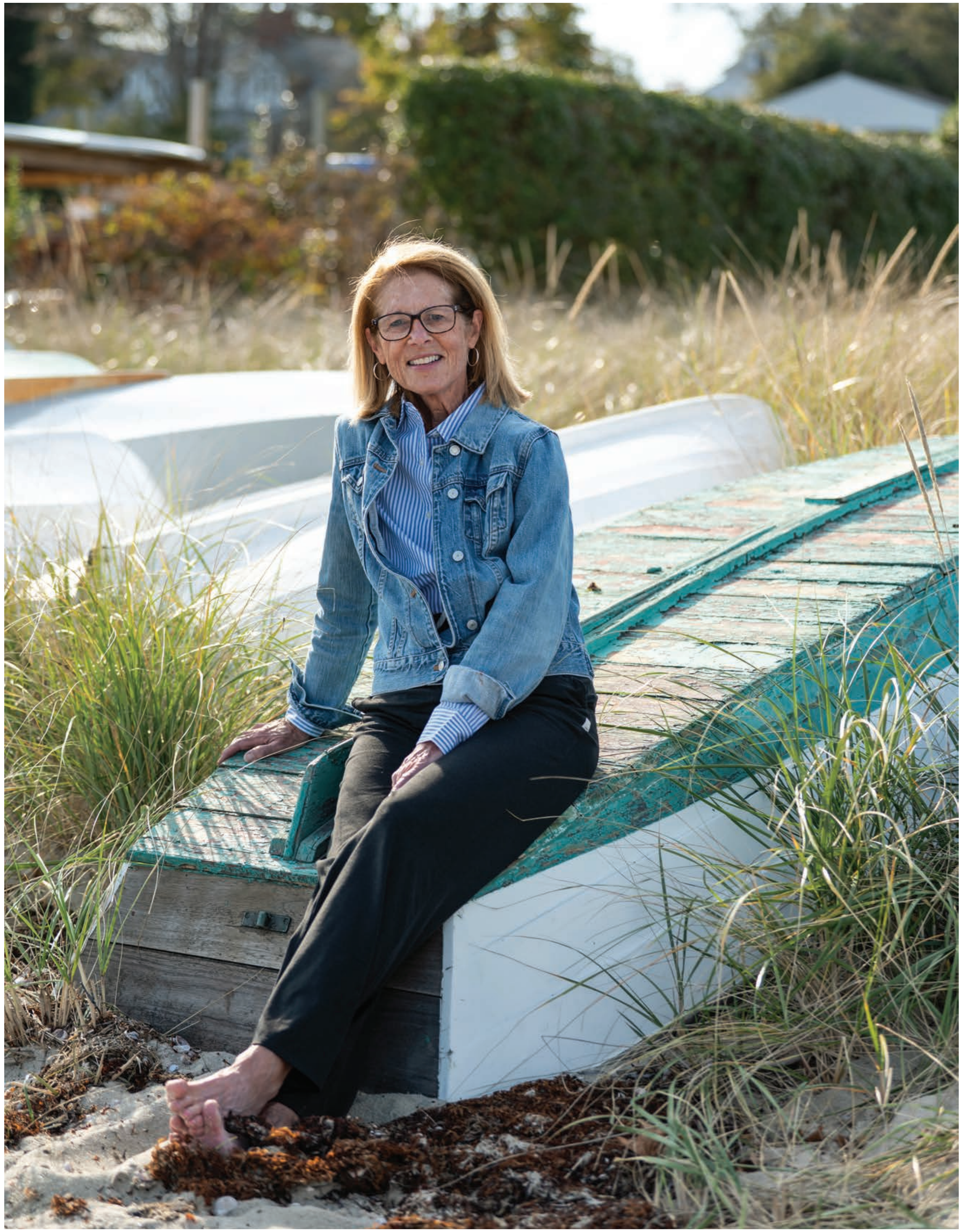
She discovered lumps that later would be diagnosed as Hodgkin in April 1972, while a high school freshman in **Summit, New Jersey**. “I kept them a secret,” she says. “I was in the middle of trying out for **cheerleading** and finishing up ninth grade. I didn’t want to miss out on anything.”

That summer, Cummings, one of seven children, was vacationing with family and sharing a room with her younger sister **Eileen**. While Cummings was undressing, her sister noticed lumps protruding noticeably from Cummings’ skin. “Eileen ran down and told my mother,” Cummings recalls. “At the time I was furious, but in reality, she saved my life.”

Cummings endured four surgeries over five weeks and returned to school bearing the ravages of her disease and treatment. “You know, the goal as a teenager is to fit in,” she says. “But that fall, I looked like hell. I had lost 20 pounds, I lost my hair, and my skin was a sickly yellow tinged with green. I was often nauseous. Kids stayed away from me because in those days many thought cancer might be contagious.”

Surviving subsequent tumors and treatments, Cummings finished high school and followed her sister **Cathleen G. McDonough ’78** to Holy Cross, intending to become a **surgeon**, a plan influenced by her cancer experience. “I thought I would be really good at it,” she says. “I would know to treat patients like people and not like they were a medical case. I had a surgeon who treated me that way, and I wanted to be the kind of doctor that my surgeon was.”

In her senior year, Cummings, a **chemistry major**, took a **medical sociology** course with **Edward Thompson**, today professor emeritus of sociology. “That put a little bug in my ear about other careers in medicine that didn’t necessarily mean eight more years of schooling followed by an internship,” she recalls. “I did a project with another student at **UMass Medical School** in Worcester, called **The Doctor-Patient Interaction**. We followed surgeons



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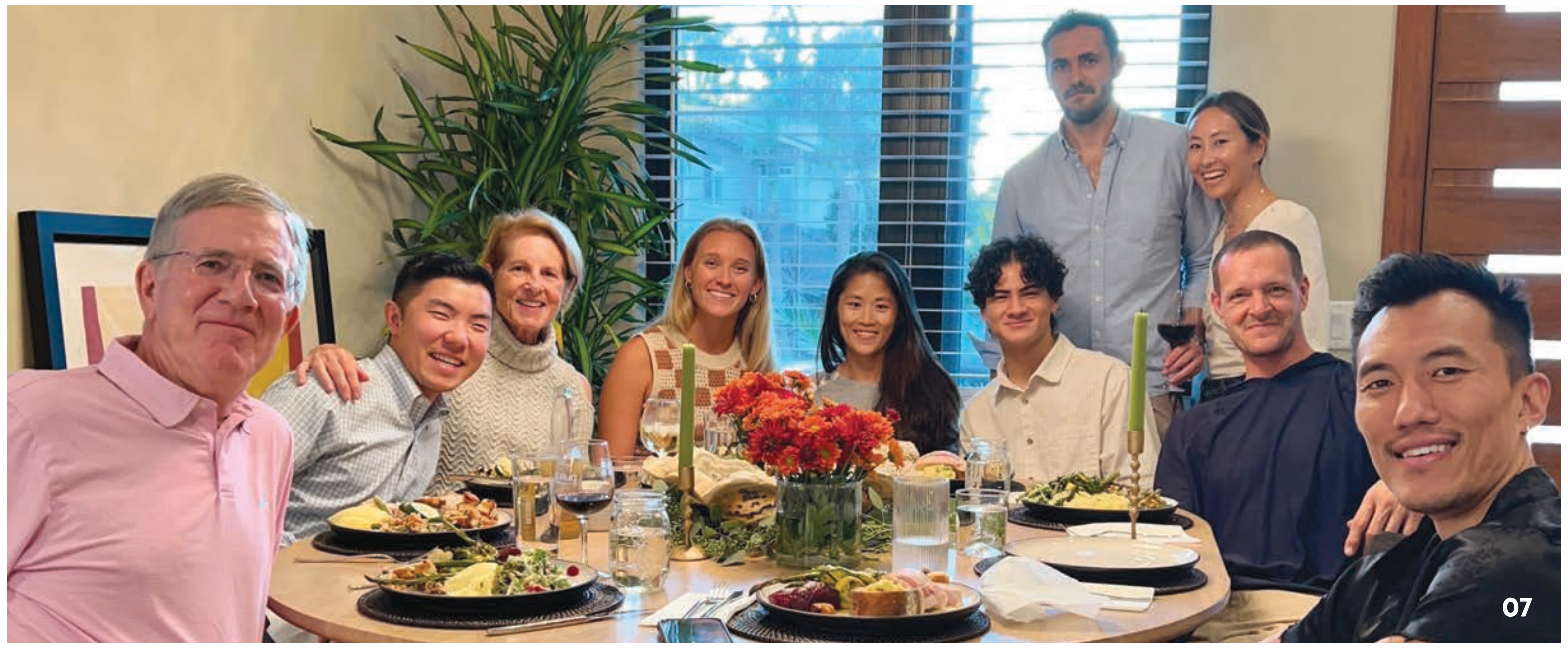
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01 Cummings as a high school cheerleader in Summit, New Jersey. **02** With her sisters and mother, *(left to right)*: Deidre, mom Susan, Cummings, Eileen and McDonough. **03** Running the Boston Marathon in 1982. **04** Running the 1998 New York City Marathon with Eileen. **05** At her 1983 wedding to Rich Cummings '76. **06** With Rich and their children as youngsters … **07** … and all grown up.

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and looked at their bedside manner and how well their patients did depending on whether or not they sat down on the bed or held their hand or stood in the doorway. It got me thinking about what I was good at – really listening to what people had to say. That's why I went into **medical social work**."

After college, Cummings worked at **Beth Israel Hospital** in Boston and earned a master's in social work. "I feel like the gift that Holy Cross gave to me from the Jesuits was to be in the service of others," she says. "I would say that is a profession that never disappoints."

She met her husband, **Rich Cummings '76**, at a fundraiser a year after graduating Holy Cross; they married in 1983. "Erin never hid anything from me," he says, "so it was there from Day 1, including what she'd been through and the risks for the future."

In her mid-20s, Cummings experienced her first of what would be many long-term effects of her teenage cancer battle: **infertility**. A procedure gave her hope, but resulted in an **ectopic pregnancy** that had a dangerous ending at about nine weeks.

Already considering **adoption**, the couple moved forward and over 13 years added four children from **South Korea** to their family. Their children bore witness to many of the medical effects of their mother's early cancer treatments, including **thyroid cancer**, **bilateral mastectomies**, and **open heart** and **lung surgeries**.

"I have guilt sometimes about what my kids have had to put up with," Cummings says. "There was a fair amount of disruption. At the same time, I think they became, as I did, so much more resilient."

Even after 14 surgeries, Cummings insists she is healthier in person than what appears on her medical charts. She began running after she reached five years in remission and ran the **Boston Marathon in 1982**. She's run eight marathons in total, six in New York, raising more than $100,000 for **pediatric cancer research** at the **Memorial Sloan Kettering Cancer Center**, where she was treated.

"Kettering happens to be right at the 16-mile mark," she recalls of her **1998 New York City Marathon**. "I had not been to the hospital in over 25 years. When I spotted patients cheering us on from the sidewalk, wrapped up in their blankets, holding on to their IVs, I completely lost it. I burst into tears, remembering the kid that I was all those years ago. My sister Eileen, who was running with me, had to literally pull me together and get me going again. That story is a fitting metaphor for a lifetime of dealing with late effects. We are dealt one blow after another, and yet we somehow scrape ourselves off the sidewalk and get going again."

GATHERING SURVIVORS

The late effects Cummings experienced over the years led her to co-found **Hodgkin's International** in 2016. As a teen going through cancer treatment, she wished she could meet an adult who had dealt with cancer when they were young, but that opportunity never came. The desire to connect with others who had similar experiences only intensified as she got older and dealt with additional cancer diagnoses.

Cummings was hospitalized to have suspicious **lung nodules** removed in 2007 when she met a patient who was being treated for **esophageal cancer**. She, too, had previously survived Hodgkin lymphoma. As the women talked, they realized how similar their stories were. "That convinced me to find other people," Cummings says.

She discovered online groups through the **American Cancer Society** and, eventually, a **Facebook group**, where survivors talked about their experiences and supported each other. It was there she realized how common late effects, such as other cancers and heart issues, were.

Cummings and Facebook group member **Dolly Griffin** talked about hosting a party for Hodgkin survivors, "sort of like a wedding reception, but with no one getting married," she notes. Cummings flew to Texas to meet with Griffin to plan a party and ended up founding an organization – Hodgkin's International – instead.

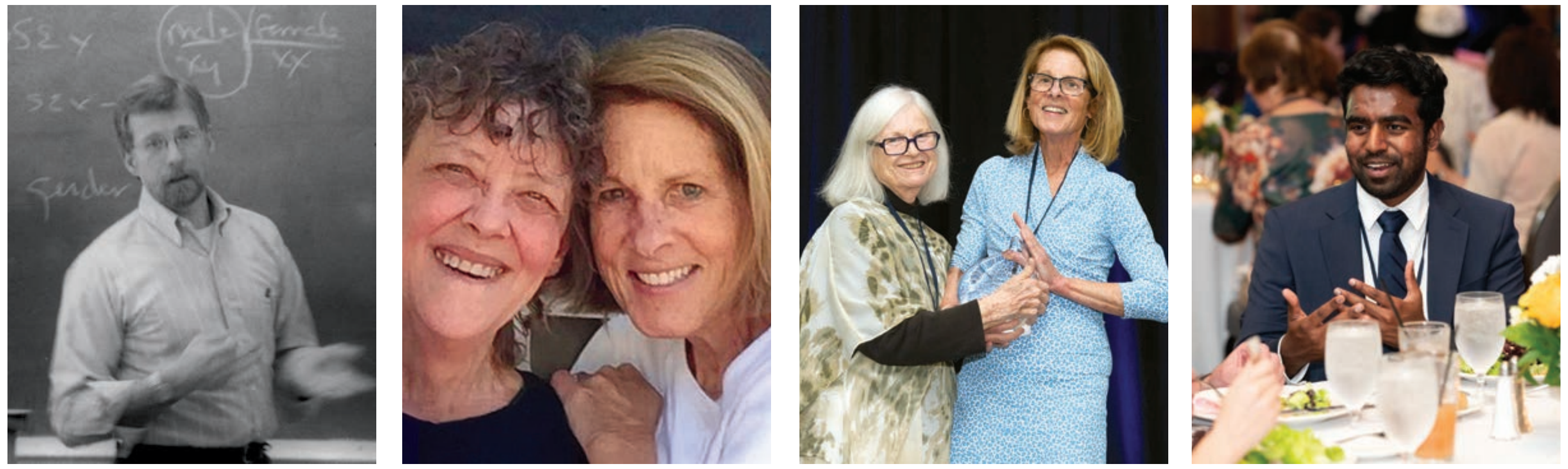
"We discussed how often in the Facebook group people shared about the symptoms they weren't getting answers to, about doctors who pooh-poohed their concerns," Cummings says. They decided they needed an organization to not just support survivors, but also to educate them because they weren't getting information elsewhere.

"Erin instinctively knew what survivors needed," Rich Cummings says. "Starting Hodgkin's International was clearly a passion and a calling."

According to the organization **Children's Cancer Cause**, more than 95% of childhood cancer survivors will have a significant health-related issue by the time they are 45, yet many patients, their parents and doctors have no idea of the future risks they face.

"Doctors are not necessarily being taught," Cummings notes. "They are learning about oncology, but the concentration is on finding a cure, not on what happens after the cure. The information is often available, but held in the clinical sphere and not getting out to the general medical community."

When **Gloria Gene Moore** was diagnosed with bilateral breast cancer 23 years after Hodgkin lymphoma, her oncologist told her



"it had absolutely nothing to do with my Hodgkin disease." Twelve years later, she dealt with **angiosarcoma**, a rare cancer.

"Through the Facebook groups I realized all of my cancers had been brought on by earlier treatment. And without the Hodgkin's International screening guidelines Erin developed, I wouldn't have known to go for **heart screenings**," she says. "They discovered that I had an artery that was 100% blocked."

Part of the mission of Hodgkin's International is to get this information out not only to survivors, but also to physicians. The group's website offers care plan documents for survivors and links to the **National Comprehensive Cancer Network** guide specifically for doctors. Cummings hopes those resources will be used not only by Hodgkin survivors, but also by any cancer survivor. "I want to remind people: Don't be afraid to talk about your cancer," she says. "Make sure you understand you can be part of the decision-making process."

The organization continues to share information through its website, the Facebook group, a **monthly newsletter** and **Zoom meetings**, which are later available on **YouTube**. Cummings also attends the yearly meeting sponsored by the **National Coalition for Cancer Survivorship** and spends time with other survivors on **Capitol Hill**, advocating for bills that impact cancer survivors.

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A LONG-PLANNED GATHERING

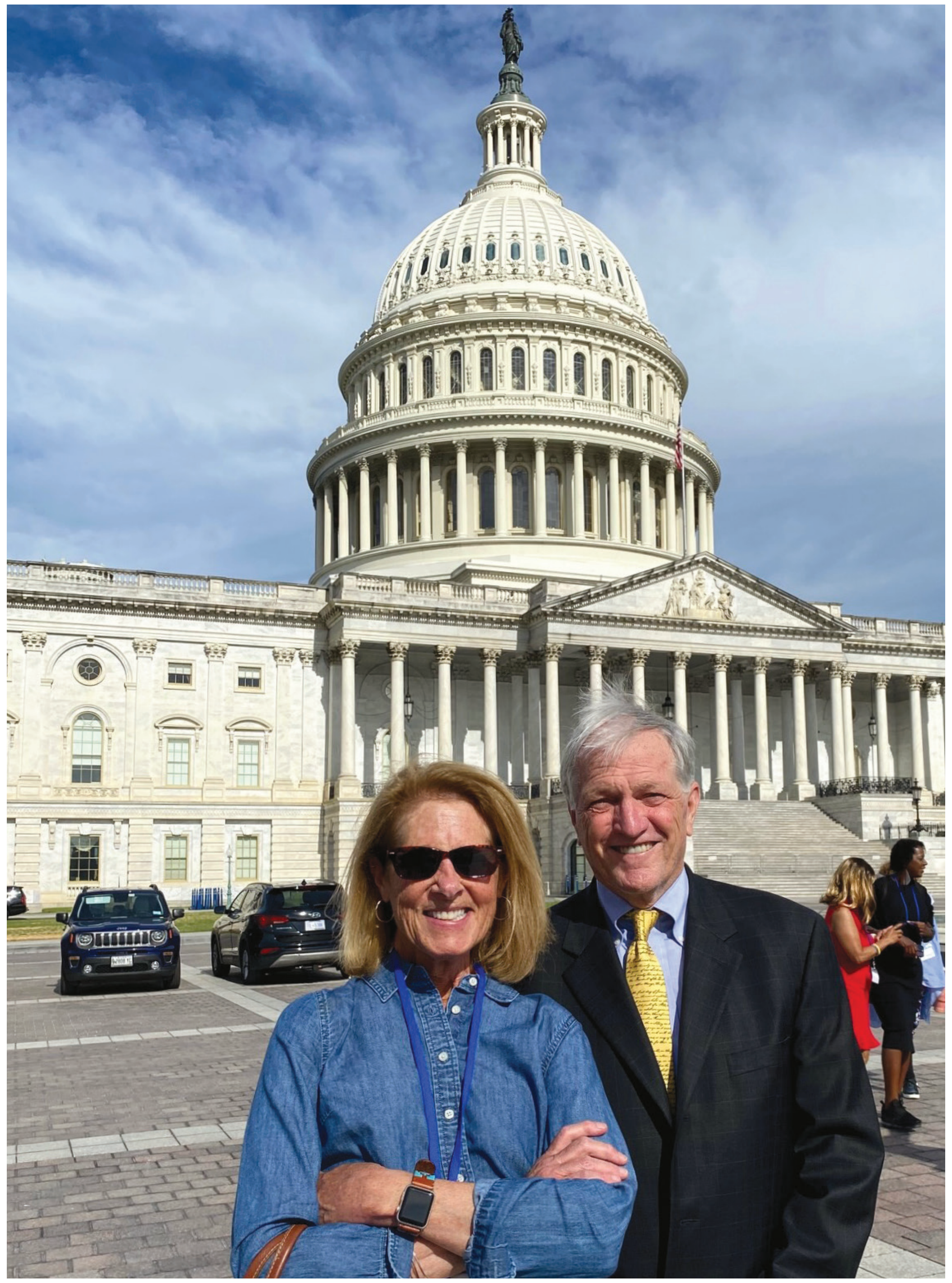
Hodgkin's International co-founder Griffin passed away not long after she and Cummings launched the nonprofit. It was another blow, but one that inspired Cummings to host that big party they originally envisioned. Postponed by **COVID-19**, the first Hodgkin's International Symposium was held over a June 2024 weekend in Boston. Survivors traveled from across the **United States** and three **European countries** for the opportunity to meet Facebook friends and confidants in real life.

"For Erin to get the quality of speakers that she did for our very first Hodgkin symposium was absolutely amazing," says **Susan Leigh**, a Hodgkin survivor and a retired oncology nurse. "She successfully procured respected researchers and clinicians from both the **National Cancer Institute** and other major academic centers, all having a major focus on survivorship education and care. And, more importantly, Erin made sure that survivors themselves were equally represented along with the medical experts during panel discussions."

"Long-term survivor care is not something that's in every textbook or in the media," says **Kiran Manisubbu**, a second-year medical student at **St. George's University** in **Grenada**, who found information about the symposium online and drove seven hours to attend. "There are probably papers published on it, but information doesn't find its way to the patient. The conference was so patient-focused, patient-centric."

"Thousands of people were treated long ago and have managed to stay alive, but do not know they are at risk because no one's looking for them to tell them so," Cummings says. "And when they do show up at a doctor's office, they are often misunderstood by the person that's standing in front of them."

ABOVE Thomas, who affected Cummings' career path; the late Griffin, who co-founded Hodgkin's International with Cummings; Leigh, symposium attendee, Hodgkin survivor and retired oncology nurse; and second-year medical student Manisubbu, who drove seven hours to attend the inaugural symposium. **OPPOSITE** "As a survivor of a non-curable but treatable blood cancer, I know firsthand the importance of ensuring cancer survivors have access to the support and resources they need to be healthy and happy in all facets of life through a seamless continuum of care," says Rep. DeSaulnier, with Cummings on Capitol Hill *(top);* speakers and attendees of the Hodgkin's International Symposium on Long-Term Survivorship, held in Boston in June 2024.



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Cummings even ran into **U.S. Rep. Mark DeSaulnier** '74, of California, a fellow cancer survivor. DeSaulnier founded the **Congressional Cancer Survivors Caucus** and co-authored the **Comprehensive Cancer Survivorship Act**, introduced in the **U.S. House of Representatives** in 2023, which aims to ensure a continuum of care for cancer survivors. Cummings was on Capitol Hill to advocate for this bill.

Through community and its educational and advocacy work, Cummings hopes that Hodgkin's International will bridge that information gap and be part of the solution. "There may be no such thing as a good cancer," Cummings told attendees at the symposium, "but let's make sure that what we all have been through is worth something." ■