Nobody could say no to Sophie Steiner—especially after her departure, as UNC Hospitals filled the void with a new kind of advocate for teen and young adult cancer patients.

by Mark Derewicz
Teens can feel trapped

Authenticity. That’s what cancer can strip from a young life. Sophie Steiner never let cancer take it. She fought to make sure her disease didn’t define her. Yet she couldn’t have gotten through that moment, Sophie was not a cancer patient. She was, simply, Sophie.

Sophie Steiner, age 15, looked up. The light in her eye returned. "Sophie, I’m breaking you out of here,” the nurse whispered. “You ready?"

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"We’re in uncharted waters,” said Dr. Ned Sharpless ’88 (’93 MD), Lineberger’s director, who has known the Steiners since he and Lucy were Morehead Scholars together as undergraduates. "Lucy is a force of nature,” Sharpless said. "I haven’t been at all surprised by her incredible progress in getting the message out about adolescent and young adult cancers and in raising funds."

"Explode with light Have no fear” Sophie Steiner from a poem she wrote before her diagnosis

"Keeping your normal existence going while getting treated for cancer is very challenging for anyone and particularly hard for adolescents and young adults, some of whom might not have much support from parents or might not want much support from parents. So our belief is that more people working in Dr. Doss’s group to help these patients will improve their quality of life during therapy and their outcomes from therapy." said Dr. Fedoriw who has been the adolescent and young adult liaison wouldn’t completely solve this problem, Rosenberg said, but he believes the person in this position could help families figure out the logistics so more kids could participate.

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"But let’s forget about calling it the ‘procedure chair,’ and laugh and just love to be around her.”

"And, honestly, she was known in the family to be a bit of a whiner. But from the moment she was diagnosed, she never complained about it. She just took it on. She showed real spirit. And she was brave.”

"Be Loud"

In early October 2012, about halfway through the field hockey season at East Chapel Hill High School, Sophie felt strange aches and pains in her shoulders. Her belly was distended. Clothes didn’t fit right.

The Steiners took her to Dr. Kelly Fedoriw at UNC Family Medicine. A general examination offered no clues. X-rays showed nothing. Fedoriw ordered a CAT scan.

It was cancer. Sophie’s stomach and liver were stuffed with tumors.

At the same time Fedoriw was telling the Steiners the bad news, Ian Davis was poring over Sophie’s CT scans. The next day, after a biopsy, Davis suspected germ cell cancer, but the cells didn’t respond to the chemotherapy. Davis suspected germ cell cancer, but the cells didn’t respond to the chemotherapy. The only other possibility was that the cells had broken down the social barriers that too often keep younger patients from participating in potentially lifesaving clinical trials. This would be no small accomplishment. Cancer survival rates for teens and young adults have not improved in the past 25 years, in part because it’s more difficult to enroll them in clinical trials. An adolescent and young adult liaison wouldn’t completely solve this problem, Rosenberg said, but he believes the person in this position could help families figure out the logistics so more kids could participate. There was no clinical trial to help Sophie. Her cancer was too rare and too far along. But her attitude — positive but blunt — has inspired nurses, doctors, administra-

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researchers across the country. In the end, everyone agreed Sophie had a rare and aggressive kind of germ cell cancer.

After four rounds of chemo, the tumors shrank. After another two rounds, the tumors no longer responded to therapy. This was early in 2013.

On her blog, she wrote: “I don’t want you to feel sorry for me. I want you to encourage me to keep going. Just to be there when I need you. You can feel bad for me; just don’t show it. Because that’s not gonna help me feel any better. I need people to be strong with me because for me, that is the only way that we are all going to fight this battle together.”

Sophie sensed she might die. She resolved to do everything she could to live as full on as she always had, as a poem she penned a year before her diagnosis suggested. It read, in part:

Be Loud
And move with grace
Explode with light
Have no fear

When Sophie wasn’t feeling great, she refused to abandon ballet practice. When she was too sick to leave the hospital, her dance teacher brought ballet shoes so Sophie could go up on pointe and dance. It was an achievement that took years to accomplish. Cancer couldn’t take that from her.

When there was one kind of food Sophie could stomach, she didn’t hesitate to tell someone. Usually, her parents would grab it. On occasion, Dr. Stuart Gold, head of pediatric oncology, would make sure the special food made it to Sophie’s room.

Sophie loved photography, and she taped dozens of photos to her hospital room wall. Doctors would notice, and Sophie would wryly say, “You haven’t been there, have you, doc?”

On her 15th birthday, thanks to one of Niklaus’ former students, Mackenzie Thomas ’13, a bunch of UNC field hockey players surprised Sophie with home and away jerseys with her name on the backs. Sophie was floored. Not long after this, she realized not many kids in the cancer ward experienced visits like that. And her question was simple: “Why not?”

Cancer is always horrible, but being a teenager with cancer is a particular kind of horribleness. It’s an awkward time. Hormones are raging. You’re trying to figure out who you are, and then, all of a sudden, a life-threatening disease tries to decide that for you. Your parents are heartbroken right there in front of you. And they are your parents; sometimes you don’t want them around. The walls can close in. But there’s nowhere to go.

Caroline Braswell ’03 (’08 BSN), one of Sophie’s nurses, noticed this happening with Sophie. Between shifts, Braswell volunteered to take her for a walk to Starbucks in the N.C. Cancer Hospital. “By this time, she was really sick, and she looked it,” Braswell said. “I noticed people staring at her. I asked, ‘Does that bother you?’ I expected her to be a little introspective. But instead Sophie said: ‘Nah, it doesn’t bother me. They all have their own problems probably worse than mine. And most of them are more ugly than me anyway.’”

Braswell belly-laughed; the people were now staring at her.

Not long after that walk, on Aug. 29, Stuart Gold noticed that Sophie had taken a dramatic turn for the worse. That day and night, a stream of visitors, including surgeons and doctors and nurses who had befriended Sophie, paid their respects to her. The next morning, Sophie died at home surrounded by family.

A week later, at a memorial service nearly 1,000 people strong, family friend Paul Youngman ’95 (MA, ’03 PhD) said, without a trace of sentimentality, “Sophie’s life was too short, but it was a success.”

As fate would have it, Sophie’s life would continue to be a success.

A fund, but what kind?

At the end of the obituary was the sentence: “In lieu of flowers, please consider making a donation to the Sophie Steiner Fund.” But the Steiner family didn’t really know what that fund would be.

“We figured we would raise maybe $5,000 or $10,000 and buy gas cards for parents. Down East who had to travel so far to the hospital,” Niklaus said. “We honestly didn’t know.”

Within a few weeks, donations topped $10,000. By the end of 2013, the Sophie Fund neared $70,000. “That’s when we thought this wouldn’t be just a little fund,” Niklaus said. “We decided to start a foundation that could make systemic changes to the way we support teen and young adult cancer patients.”

The family named it the Be Loud! Portfolio

S
ophie Steiner enjoyed taking photos that were subtle and narrow in focus. She taped dozens of them to her hospital room wall. She took the self-portrait on pages 38 and 39.

To see more of Sophie’s photos go to beloudsophie.org/sophie-photos.

From Her Portfolio

Sophie Steiner and Caroline Women in Focus

Francie Chapman Mangan ’83, Latta Chapman ’87

Francie Mangan and her sister Latta Chapman have been involved in the Carolina Women’s Leadership Council since its inception. “Being on the Council has both reinforced our relationship to Carolina and deepened it,” Francie said.

“Each of us had our own Carolina experience, but being on the Council is something we have done together, and that has made it really special,” Latta added.

The Chapman siblings — Francie, Latta and their brother John, ’91 (MDA) — focus their support at the Learning Center, because it has the resources to help all Carolina students maximize their academic performance while at Carolina.

“We want to make sure that all students have everything they need to succeed in their studies,” Francie said. “The Learning Center has one-on-one academic coaching, peer tutoring and study groups. They also have classes for students interested in pursuing graduate study.”

Francie and her husband John are the parents of two Carolina students, Francie ’15 and Caroline ’19, and another daughter, Elizabeth, at the University of Georgia.

Francie said they have seen how college is different from high school. “High school is a highly structured environment, and college requires time management skills,” she said. “The Learning Center has workshops on time management and study strategies, and these can help every student.”

The Chapmans and the Mangas hope that others will help support the Learning Center. A portion of its budget comes from private gifts, and the more funds it has, the more resources it can provide to both undergraduates and graduate students.”

This is why we give,” Francie said. “We want all Carolina students to succeed.”

Carolina Women are leaders in their fields, and they volunteer their time, energy and expertise serving on University boards and championing Carolina in their home regions. The Carolina Women’s Leadership Council is a network of women committed to supporting the University. In addition to members’ individual gifts, the council funds the Faculty Mentoring Awards, the Eve Carillon Memorial Lecture and the Carolina Women’s Leadership Council Scholarship Honoring Lady Brown May. For more information, contact Lady Brown May at lady_brown_may@email.unc.edu or 919-843-5883.
Sophie Foundation, as if Sophie were the first hint of her poems. The foundation’s first event was showing her favorite documentary, Hana Nagla, which was co-produced by her namesake and family friend Sophie Sartain ’88. The night at the Varsity Theatre raised $5,000.

Soon, the Be Loud! Sophie Foundation had raised nearly $100,000.

“We thought about what Sophie would want us to do with this money,” Niklaus said. “And that’s when we realized we could create an advocate position at the hospital, someone who could befriend teens and young adults and help them navigate these incredibly difficult situations.”

Lucy said, “We looked at other hospitals to find a model for this position. But we couldn’t find anything like it, nothing for this particular age group of 13 to 26.”

They learned of the Teen Cancer Research Center at Duke University and the Center for Childhood and Family Health, a collaboration among Duke, UNC and N.C. Central University.

“When a friend showed me the job description, I couldn’t believe it because this position was exactly what I wanted to be doing with my life,” Lux said. “At a time when teens and young adults are becoming who they are, this very traumatic, horrible thing happens, and it gets folded into their narrative. I love this age group.”

Part of her job will be to figure out how to balance the medical needs with other needs the patient might have. For instance, if there’s a teen who’s been isolated because she held a stem cell transplant, developmentally that isolation might not be appropriate.

Lucy said some hospital personnel are natural at working with different groups of patients. Others might require training to work better with adolescent and young adult patients. “Not everyone has to be great with teens or young adults, but I’ve found that this patient population can be a real question mark for health care providers, and we need to address that.”

Lucy and Niklaus Stein are in awe of the work of the UNC Lineberger Health Care and the Chapel Hill community have rallied to their aid.

Niklaus said “One reason why we care so much about this is that Sophie’s care at UNC was absolutely phenomenal. We’re so grateful for all that the hospital did. For some reason, what we’re trying to bring to light — what’s happened within this community.

“They have said to me that they don’t know if they’ll be able to handle living in the same place where something so traumatic, losing a child had happened. I understand that. I really do. But nothing would seem more alien to me than moving away and starting all over again. Because a big part of what’s sustained us is this community and all the ties we have here, I couldn’t dream of not being part of it.”

Mark Dorrizzi is a freelance writer and the science communications manager for UNC’s School of Medicine.