

Taking the Lead

A new breed of patient advocate is reshaping the future of cancer research.

March 18, 2019 By Bryn Nelson

Liz Salmi and Adam Hayden found each other on Twitter and bonded over the fact that both had been in punk rock bands and both had been diagnosed with brain cancer.

On Facebook, biochemist Corrie Painter met an instant friend who had been diagnosed with rare angiosarcoma of the breast—just like her.

And over drinks at a national summit for cancer survivors, former rocket scientist Janet Freeman-Daily connected with four other lung cancer patients who shared the same uncommon tumor gene mutation.

Finding others who share a specific diagnosis can be an invaluable source of support and information. Beyond that, these allies went on to launch ambitious efforts that could help reshape the future of cancer research.

Patient-led research is growing in both size and sophistication. What's more, these projects are attracting the attention of academic institutions and funding agencies with their focus on largely unaddressed scientific questions and unmet medical needs.

Diving into the research was “so scary but also so exciting,” says Salmi, who helped start a project that could lead to better care for people with brain cancer.

Advocates Find Their Voice

The new patient advocates are going beyond Twitter and Facebook. They're meeting leading researchers at major scientific conferences as well as patient-centered gatherings, like the Stanford Medicine X|ED Conference and the LUNGeivity Foundation's HOPE Summit.

Two main trends have fueled the growth of these research partnerships, according to Aime Franco, PhD, associate professor of physiology and biophysics at the University of Arkansas for Medical Sciences in Little Rock. First, the internet has enabled patients to find one another more easily, even those with exceedingly rare cancers. Second, people living with cancer are now able to quickly access detailed scientific information.

“Patient advocates have become so much more motivated but also more educated about their

own disease, and I think that's really pushed the needle forward," says Franco, a thyroid cancer survivor.

Patients can help drive research questions and suggest new lines of inquiry because they understand the day-to-day realities of living with cancer. They can also point out where existing research isn't well aligned with priorities such as quality of life.

Collaborating researchers bring their scientific training and understanding of how to ask and answer questions in a laboratory or clinic. "They understand the limitations of what can or can't be done," Franco says.

Researchers increasingly recognize that understanding how cancer develops in individual patients will be critical for advancing the science, offering a compelling rationale for closer interaction between the two communities.

"When you involve patients in the research from the get-go, you not only end up asking the right questions but also asking them in a way that the community understands," says Stacey Tinianov, who leads outreach and engagement for Count Me In, a nonprofit that brings patients and researchers together. "When people are part of the process, they know they can trust the process."

A New Model

The group formed by Janet Freeman-Daily and fellow lung cancer patients, dubbed the ROS1ders after the mutated ROS1 gene responsible for their shared malignancy, is already helping to expand the scientific tool kit.

In 2011, the retired aerospace engineer from suburban Seattle, now 62, was diagnosed with advanced non-small-cell lung cancer in her left lung. Despite chemotherapy and radiation, the cancer eventually spread to her right lung, and a genetic test revealed that her cancer cells had an extensive ROS1 gene rearrangement. She enrolled in a clinical trial in late 2012 to test the then-experimental ROS1-targeted drug Xalkori (crizotinib). "I've had no evidence of disease ever since," she says.

After they met during the 2015 HOPE Summit, Freeman-Daily and other ROS1ders decided to form a Facebook group that has since grown to include more than 300 patients in 22 countries. "It was a great comfort for us to talk to other people who were experiencing the same things we were," she says.

Janet Freeman-Daily Courtesy of Janet Freeman-Daily

But that wasn't enough. "We were all on crizotinib; there was no next treatment. We all had kids at home, and we knew that everybody on this drug eventually progresses," Freeman-Daily says. "We asked, 'What can we do to accelerate research?'"

And so the ROS1ders became one of the first oncogene-specific patient groups to seek out research partnerships—a move that others soon followed. Representatives from similar groups that sprung up around other gene mutations now meet regularly to share best practices.

In 2017, the ROS1ders launched the ROS1 Cancer Model Project in partnership with researchers, including Robert Doebele, MD, PhD, associate professor of medical oncology at the University of Colorado at Denver. To date, Doebele says, the collaboration has allowed his lab to collect donated

tissue and fluid samples from 10 patient volunteers and to grow four much-needed ROS1-driven cancer cell lines for his research.

Most of those cell lines are from people who have stopped responding to Xalkori. By sequencing the cells' genome, researchers can determine which secondary mutations might have helped the cancer develop resistance, offering potential new targets for treatment. All the resulting data will be made publicly available.

While in Denver on a recent trip, Freeman-Daily visited Doebele's lab to see the new cancer cell lines for herself. "I'm a science geek, so it was really cool," she says. "I think the researchers appreciate knowing that they're making a difference for real people."

Joining the Band

Liz Salmi and Adam Hayden have pursued a different kind of patient-led research initiative focused on palliative care, which aims to provide symptom relief and improve quality of life for people with late-stage disease.

After Hayden, 36, was diagnosed with glioblastoma, an aggressive type of brain cancer, in 2016, he completed his master's degree in philosophy while undergoing treatment (see [Diary](#)). He learned everything he could about his disease and carved out a niche as a blogger, describing both his personal battle and the science behind his illness.

Salmi, 39, who lives in Sacramento with her husband, was diagnosed with a related form of brain cancer called astrocytoma in 2008. A digital communications specialist and self-taught computer coder, she is the senior strategist for outreach and communications for OpenNotes, a research project housed at Beth Israel Deaconess Medical Center in Boston. The project is studying the benefits of giving patients full access to their medical records and clinical notes.

Adam Hayden Courtesy of Adam Hayden

Liz Salmi Courtesy of Liz Salmi

Before her two brain surgeries, two years of chemotherapy and months of learning how to walk again, Salmi knew nothing about brain cancer or medical research. “It was never on my radar,” she recalls. But viewing and sharing her own records on a blog for friends and family of cancer patients piqued her curiosity. She also began volunteering for online patient communities and research advisory boards.

Salmi became the director of communications for the Coalition for Compassionate Care of

California, a nonprofit focused on palliative care education and advocacy. She realized that many other people with cancer don't even know what palliative care is, much less how to ask for it. She began attending scientific conferences and met Bethany Kwan, PhD, MSPH, a social psychologist at the University of Colorado whose own mother had died from glioblastoma without receiving proper palliative care.

Together, Salmi, Kwan, Hayden and a band of likeminded supporters won a \$50,000 grant from the Patient-Centered Outcomes Research Institute's Pipeline to Proposal program. The initiative provides seed money to help patient communities form partnerships, formulate a scientific agenda and build the infrastructure to ask research questions that are important to them.

In 2017, the newly funded Brain Cancer Quality of Life Collaborative took its first big steps toward its goal of improving patients' lives through palliative care. One research priority is designing a multisite study to examine the benefits of offering such care to people with brain cancer immediately after diagnosis.

People living with brain cancer often face a constellation of challenges, including epilepsy and short-term memory loss. "Palliative care could help not only with pain management but also with psychosocial support and other unmet needs," Hayden says.

The group's other research priority is exploring how best to educate doctors and people living with cancer about palliative care and help them talk about it more openly. "Educating one patient is only going to go so far," Salmi says, but educating and training neuro-oncologists could have a much larger and longer-lasting impact.

Count Her In

Corrie Painter, PhD, associate director of operations and scientific outreach for the Broad Institute Cancer Program in Cambridge, Massachusetts, was diagnosed with angiosarcoma in 2010, while pursuing a doctoral degree in biochemistry. At the time, she didn't think she would live more than three to six months.

Too few people had been diagnosed with the rare and aggressive cancer—which results from the out-of-control growth of blood-vessel-derived cells—to help researchers develop useful data, tools or guidance.

"It was very challenging to be a scientist and know the stark reality that there was just nothing I could do to try and make a change," Painter says.

Corrie Painter
Courtesy of Broad Institute

Then she stumbled upon a Facebook group for people with angiosarcoma and found Lauren Ryan, another patient like her. “I can’t overemphasize the importance of having a connection with somebody else who truly understands what it’s like to walk in your shoes,” Painter says.

Together they started a nonprofit called Angiosarcoma Awareness. To date, the group has raised around \$1 million for research into the orphan disease. “It’s really exciting to think that we’ve made a difference,” says Painter.

But that wasn’t enough. As a scientist, Painter realized that a few medical publications wouldn’t cure angiosarcoma on their own. Instead, she says, “I felt that to make an impact, we have to fundamentally change the system.”

An opportunity to do just that came in the form of Count Me In, a newly launched patient-led program backed by the Broad Institute and partner organizations. As associate director since 2015, Painter has helped lead the charge to reinvent cancer research by working closely with patients throughout every phase of a study, from designing and naming it to shaping its survey questions to deciding how to release the data.

Starting with its initial effort, the Metastatic Breast Cancer Project, Count Me In aims to deliver high-quality, extensively annotated and freely available genetic and clinical data for all major cancers and many rare ones.

Along with its three other projects launched so far—the Metastatic Prostate Cancer Project, the Esophageal & Stomach Cancer Project and the Brain Cancer Project—Count Me In recently took a major step toward changing the future of angiosarcoma research by releasing data from the first 36 patients in its Angiosarcoma Project.

After completing an intake survey about their cancer experience, patient volunteers receive a consent form via email. They can opt in or out of allowing researchers to retrieve copies of their medical records—uploaded into an encrypted folder to protect privacy—and collect saliva, blood and leftover tumor biopsy tissue samples. The project's researchers sequence DNA from the saliva samples, which provides a record of an individual's germline genome, or entire set of inherited DNA. By comparison, DNA from a blood or tumor sample can reveal subsequent mutations that occur in evolving cancer cells.

So far, the Metastatic Breast Cancer Project has released three batches of detailed clinical and genetic information that include more than 200 samples from 130 patients, stripped of identifying details. Over the past year, the project website has logged more than 80,000 hits. At the 2018 San Antonio Breast Cancer Conference, Painter saw that multiple talks and posters included data from the project. "It was fascinating," she says. "It is being used by the biomedical community."

A New Way Forward

Amid the progress, one challenge has been protecting patient-led projects from the disruptive nature of cancer itself. "On the one hand, being driven by patients, we are very motivated, and we are putting a lot of time and effort into this. But we do get sick, and that gets in the way sometimes," Freeman-Daily says.

Other obstacles include mistrust and researchers who fear being told how to do their jobs. The American Association for Cancer Research Scientist Survivor Program aims to forge partnerships and build trust among scientists, cancer survivors and patient advocates. Each year, the program accepts about 40 applicants, who attend scientific symposia and special sessions at AACR meetings. "People go away with a lot of knowledge but also a lot of motivation," says program chair Anna Barker, PhD. "It's transformational—it creates a whole new advocate."

As a highly motivated advocate, Salmi knows that her cancer is projected to eventually become glioblastoma, and it could be a long time before her group's research project delivers any solid

results. “That could take years, but someone needs to do it,” she says.

Maybe the palliative care questions they’re working to answer will someday benefit her. Maybe they will benefit Hayden or another friend or others yet to be diagnosed. Already, though, Salmi has seen health care providers who have benefited from their participation in the project, learned to trust patients and begun to change how they approach palliative care as a result. It’s a start, and it makes her happy.

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