Cancer Health™

The Cancer Health 25: Change Makers

These remarkable individuals make a difference every day.

June 15, 2020 By Cancer Health Staff

Let us celebrate these change makers. They have each experienced cancer, either personally or through someone they love. And it has changed them, made them want to give back and given them a mission to make a difference for others living with cancer.

Change makers, we honor you.

Melinda Bachini

Billings, MT

Melinda BachiniCourtey of Melinda Bachini

In 2009, Melinda Bachini was working as a paramedic when she was diagnosed with cholangiocarcinoma, a rare cancer of the bile ducts, which soon spread to her lungs. Two years later, she decided that chemotherapy was too detrimental to her quality of life, but she remained determined to see her six children grow up. Melinda, 51, joined a clinical trial of adoptive cell therapy at the National Cancer Institute and experienced a remarkable response. Though not cured, her cancer remains at bay. Today, she is a public speaker, legislative advocate and advocacy coordinator for the Cholangiocarcinoma Foundation.

Amy Berman

New York, NY

Amy BermanCourtesy of Amy Berman

How do you live well with serious illness? Amy Berman, RN, 60, offers two words of advice: palliative care. Since being diagnosed with Stage IV inflammatory breast cancer nearly a decade ago (she’s still living with cancer), Amy enlisted palliative specialists to manage pain and symptoms. Judging by her adventures in world traveling, reindeer sledding and camel riding, which she chronicled in the Winter 2020 issue of Cancer Health, it works. She promotes palliative care through lectures, social media, blogs and her work as senior program officer at The John A. Hartford Foundation, which invests in better care for older adults. In 2015, the online platform Disruptive Women in Healthcare named her one of “15 Disruptive Women to Watch.” She recently testified before the Senate Committee on Aging.

Justin Birckbichler

Fredericksburg, VA

Justin BirckbichlerCourtesy of Justin Birckbichler

The founder of the award-winning blog ABallsySenseofTumor.com (ABSOT), Justin Birckbichler, 28, became a men’s health activist shortly after being diagnosed with Stage II testicular cancer in 2016. His goal is to use humor to help men overcome their fear of opening up and thus help promote discussions about testicular cancer. A prolific and passionate advocate, Justin has written more than 160 articles for online and print magazines. In 2019, he was named one of “40 Under 40 in Cancer” by a team of global health care advisers. A highlight of his advocacy includes giving a TEDx Talk on men’s testicular health in November 2019.

Jamie Ennis Bloyd

Lexington, KY

Jamie Ennis BloydCourtesy of Jamie Ennis Bloyd

When Jamie Ennis Bloyd’s 5-year-old son was diagnosed with Stage IV Burkitt’s lymphoma in 2014, she used her years of public policy, political and advocacy experience to get Kentucky’s first-ever pediatric cancer legislation passed. The governor then appointed her to the board of the state’s Pediatric Cancer Research Trust Fund. Jamie, 39, is currently director of government affairs and external relations at the American Childhood Cancer Organization, the nation’s oldest and largest grassroots organization dedicated to childhood cancer. In 2017, she secured corporate support from Amazon to launch a historical campaign to raise awareness of childhood cancer, and in 2019, the Foundation for a Healthy Kentucky named Jamie a “Healthy Kentucky Policy Champion.”

Anne Boyer

Kansas City, MO

Anne BoyerCourtesy of Anne Boyer/Cassandra Gillig

Sometimes, the tools society hands people with cancer don’t really help, and it takes an artist to show us why. “We are expected to keep our unhappiness to ourselves but donate our courage to everyone,” wrote poet and essayist Anne Boyer, 46, about her harrowing experience with triple-negative breast cancer in her 2019 memoir, The Undying. She rebelled against the pink ribbon world of breast cancer awareness, which often asks women to stay “positive.” Instead, she demonstrated that openness and honesty about uncertainty, fear and pain can be liberating.

Mike Dubron

Los Angeles, CA

Mike DubronCourtesy of Mike Dubron

Los Angeles County firefighter-paramedic Mike Dubron, 57, was 39 when he was diagnosed with Stage IV colorectal cancer. He found other firefighters with cancer to lean on during his nine-month battle. After discovering the horrors cancer wreaks among firefighters, Mike founded the Firefighter Cancer Support Network (FCSN), which assists newly diagnosed firefighters and connects them with fellow firefighters who have survived cancer. The nationally recognized organization also educates members of fire services about the health hazards associated with fighting fires and advocates for improved equipment, tactics and wellness exams. FCSN (FirefighterCancerSupport.org) leads the charge to proactively fight cancer in fire services around the world.

Dan Engel

Los Angeles, CA

Dan Engel Ari Michelson

As a melanoma survivor, Dan Engel, 58, has overcome a lot to finally be able to say he is cured. His cancer recurred five times following his initial diagnosis 22 years ago. Dan underwent 10 operations and participated in six clinical trials to get where he is today. “You don’t get six chances at life unless it’s for a good reason,” he told Cancer Health in the Summer 2019 feature about his life. Now Dan is dedicated to helping others with cancer. Two years ago, he started PatientTrueTalk.com, a free online platform that connects people living with cancer as well as survivors based on their cancer type and treatment plans.

Janet Freeman-Daily

Seattle, WA

Janet Freeman-Daily Courtey of Janet Freeman-Daily

Janet Freeman-Daily, 63, a retired aerospace engineer, was diagnosed with advanced non-small-cell lung cancer in 2001. She cofounded a global group of over 300 lung cancer patients who share the same uncommon genetic mutation, the ROS1ders. She says she is alive today thanks to clinical trials of treatments that target ROS1. Janet is a blogger (GrayConnections.net), public speaker and consultant advocating for patient-led research. She is a cofounder and moderator for #LCSM (Lung Cancer Social Media) chat, a social media forum for lung cancer survivors and researchers, and she participates in lung cancer communities on Inspire.com, SmartPatients.com and CancerGRACE.com.

Robert Ginyard

Baltimore, MD

Robert Ginyard, MDCourtesy of Robert Ginyard, MD

After entrepreneur Robert Ginyard, 58, was treated for prostate cancer in 2010, his life’s mission changed. He now educates men and their partners about intimacy, sharing his own experience to help them tackle major issues such as sex, love and life after prostate cancer. As an African-American man, he is particularly engaged in raising awareness in the Black community, where prostate cancer rates are alarmingly high. Robert, who lives with his wife and two children, is now chair of the board for ZERO—The End of Prostate Cancer.

Jamie Troil Goldfarb

Takoma Park, MD

Jamie Troil Goldfarb, MDCoutesy of Jamie Troil Goldfarb, MD

Jamie Troil Goldfarb, 42, was diagnosed with Stage II melanoma in 2007. She and her husband happened to work in clinical trial recruitment, and after the cancer spread to her liver and pancreas, she joined a study of tumor-infiltrating lymphocytes, a new type of immunotherapy, at the National Cancer Institute (NCI). She credits the trial with saving her life. She now helps drug companies find study participants and is a research advocate for the NCI. She works with the Melanoma Research Alliance, the Melanoma Research Foundation, the Melanoma International

Foundation, the Alliance for Regenerative Medicine, the Center for Information and Study on Clinical Research Participation and Imerman Angels, a one-on-one cancer support community.

Patricia J. Goldsmith

New York, NY

Patricia J. Goldsmith Courtesy of CancerCare

Since 2014, Patricia Goldsmith, a colorectal cancer survivor, has served as CEO of CancerCare, a national organization that provides free and professional support services for people living with cancer. She oversees the vision and direction of the organization, bringing more than 20 years of nonprofit, management and strategic planning experience to her role. Patricia has held senior-level positions at the Moffitt Cancer Center and the National Comprehensive Cancer Network, where she oversaw operations with the goal of improving the quality and effectiveness of care for cancer patients. Most recently, she started CancerCare’s Pet Assistance and Wellness Program, which addresses the unique needs of people with cancer who share their home with a cat or dog.

Adam Hayden, MA

Greenwood, IN

Adam Hayden, MACourtey of Adam Hayden, MA

Since his 2016 diagnosis with the brain cancer glioblastoma, Adam Hayden, 38, has used his academic training as a philosopher, writer and speaker to engage audiences through articles, speaking engagements and his blog, Glioblastology. His focus on living and dying well with cancer has resonated with many audiences, including the End Well Symposium in San Francisco.

Recently, Adam tackled COVID-19 in an online article about how those with serious illnesses could help the public more readily accept mitigation guidelines and personal responsibility. “My wife is a health care worker,” he says. “I’m so proud of her and thankful for other health care workers during this public health crisis.”

Karen Hoyt

Tulsa, OK

Karen HoytCoutesy of Karen Hoyt

A former public school teacher and adjunct professor, Karen Hoyt, 63, was diagnosed with liver cancer in June 2014. She had been living with hepatitis C for years after initially being misdiagnosed. After undergoing chemotherapy and a liver transplant in April 2015, the inveterate educator transitioned into life as an author, blogger, yoga teacher and mindful meditation guide. She serves on several boards and committees that advocate for transplant candidates. Karen shares her experiences and insights about living her best life, including building good relationships with herself and others and “honoring the extra days and hours I’ve been given,” she says.

Florence Kurttila

Citrus Heights, CA

Florence KurttilaAlanna Hale

Florence Kurttila, diagnosed with colon cancer in 2001, is a longtime patient advocate. As profiled in Cancer Health (Spring 2019), she was successfully treated with surgery and chemotherapy but lost her husband to cancer five years later. She then began sharing her experiences and supporting others living with the disease. Since retiring from her human resources career in 2018, Florence, now 67, has become even more active, speaking at conferences, lobbying legislators and reviewing research grants from a patient’s perspective. She works with the American Cancer Society, the American Society of Clinical Oncology, the Colorectal Cancer Coalition, Fight Colorectal Cancer and the SWOG Cancer Research Network.

Corrie Painter, PhD

Cambridge, MA

Corrie Painter, PhDCourtesy of The Broad Institute

Corrie Painter was diagnosed with angiosarcoma in 2010 while studying for her doctoral degree in biochemistry. She cofounded Angiosarcoma Awareness, which raises money to study the rare malignancy. Corrie, 46, is associate director of operations and scientific outreach for the Cancer Program of the Broad Institute of MIT and Harvard. She is also associate director of Count Me In, a nonprofit that enables patients to participate as partners in cancer research by making their genetic and clinical data freely available. Current initiatives include the Metastatic Breast Cancer Project, the Metastatic Prostate Cancer Project, the Angiosarcoma Project, the Brain Cancer Project and the Osteosarcoma Project. Corrie is also on the steering committee of the new COVID-19 & Cancer Consortium.

Daniel G. Petereit, MD

Rapid City, SD

Daniel G. Petereit, MDCourtesy of Daniel G. Petereit, MD

When radiation oncologist Daniel G. Petereit, 57, was growing up, he loved fishing for walleyed pike on South Dakota’s Missouri River with his physician dad. His own medical career took him to the Midwest, but in 1999, he decided to move back West to raise his family and work at a community cancer center in Pine Ridge. It primarily serves Northern Plains American Indians, who have the highest cancer rates and lowest life expectancy of any ethnic group in the country. In 2002, with a National Cancer Institute grant, he started the Walking Forward program. Building trust took time, as did overcoming a sense of fatalism about cancer in the community. The program has helped more than 4,500 American Indians through patient navigation, community education and access to clinical trials. As a result, those with screening-detectable cancers (breast, cervix, prostate, colorectal, lung) now get treated at earlier stages and experience higher cure rates.

Amelie Ramirez, DPH

San Antonio, TX

Amelie RamirezCourtesy of the UT Health Science Center at San Antonio

Amelie Ramirez has worked for over 30 years to investigate the causes of cancer disparities among Latinos—and to find solutions. She was influential in proving that patient navigation improves the quality of life for Latino cancer patients and survivors. She directs the University of Texas Health Science Center at San Antonio’s Institute for Health Promotion and Research as well as Salud America!, a national Latino-focused organization that promotes health equity. Amelie hosts the annual Advancing the Science of Cancer in Latinos conference, which unites health professionals in tackling cancer among Latinos. She also leads the Éxito! Latino Cancer Research Leadership Training program, which supports Latinos who want to earn doctoral degrees and pursue careers in cancer research.

Steve Schwarze

Missoula, MT

Steve SchwarzeCourtesy of Steve Schwarze

As Steve Schwarze puts it, he’s a dad, mountain biker, hockey player, professor of communication studies and the director of climate change studies at the University of Montana—and for the last four years, he’s been doing it all with Stage IV colorectal cancer. He also serves as interim mayor for Colontown, a Facebook community of colorectal cancer survivors and caregivers, where he helps lead 10 “neighborhoods” focused on clinical trials. Steve, 49, describes his job on the sites as helping “patients learn about clinical trials and navigate the process of making decisions and enrolling in those trials.” After his own diagnosis, Steve found community and solace online. Now he’s giving back. You could say it’s the neighborly thing to do.

Mary “Dicey” Jackson Scroggins

Washington, DC

Mary (Dicey) Jackson Scroggins Courtesy of Mary (Dicey) Jackson Scroggins

Dicey Jackson Scroggins, 70, is a 23-year ovarian cancer survivor, health activist and writer. She is the cofounder of In My Sister’s Care, an organization focused on eliminating health disparities and improving gynecologic cancer awareness and care for medically underserved women. As director of global outreach and engagement at the International Gynecologic Cancer Society, Dicey is responsible for establishing and maintaining relationships with gynecologic cancer advocacy communities globally on the society’s behalf. She and her daughter are founding partners of the writing and film production firm Pinkie Hugs, which specializes in documentaries about social justice, such as the short film People Will Carry Your Story, coproduced with the documentary production company Spark Media, about raising awareness of gynecologic cancers among the Navajo people.

Kelly Shanahan, MD

South Lake Tahoe, CA

Kelly Shanahan, MD Courtesy of Kelly Shanahan, MD

Kelly Shanahan, 60, had a successful practice as an obstetrician-gynecologist when she was diagnosed with Stage II breast cancer in 2008. She underwent surgery and chemotherapy, but five years later, she was diagnosed with metastatic cancer. After treatment side effects forced her to give up her career as a surgeon, she devoted herself to advocacy. She is a board member of

METAvivor, which is dedicated to the fight against metastatic breast cancer in women and men, and a member of the Metastatic Breast Cancer Alliance and the Advanced Breast Cancer Global Alliance. She speaks at conferences, is an active advocate on social media and has participated in legislative advocacy for more research funding for metastatic cancer—but she says her most important job is being a mom.

Aki Smith

Los Angeles, CA

Aki SmithCourtesy of Aki Smith

“Inspire hope.” The phrase greets visitors on the Hope for Stomach Cancer website. And inspire hope is exactly what the nonprofit’s cofounder, Aki Smith, excels at. After her father, Shigeo Tsuroka, was diagnosed with advanced-stage stomach cancer in 2013, Aki helped him navigate the daunting cancer landscape—medical decisions, health care staff, paperwork, insurance, financial help, all of it. Her dad had a gastrectomy (removal of the stomach) and recovered but still deals with permanent toxicity from his treatment. Today, Aki, 39, and the nonprofit provide support, guidance and resources for others on similar journeys; she also collaborates with many other organizations. Whether on social media, at a podium or behind the scenes, Aki is raising awareness, working for a cure and, yes, inspiring hope.

Jeff Taylor

Palm Springs, CA

Jeff TaylorAri Michelson

After contracting HIV in the 1980s—long before effective treatment was available—Jeff Taylor, now

58, relied on clinical trials and advocacy to keep himself alive. A decade later, those lessons of self-empowerment served him well when he was diagnosed with anal cancer. His doctor said the labs, which regularly handled Pap smears for women, wouldn't even process anal Pap smears for men. Plus, doctors believed his cancer would progress very slowly, so they wouldn't operate, which led Jeff to find a more proactive surgeon. Then he got to work changing the standard of care for anal cancer prevention to, among other things, include Pap smears so insurance would cover them. Clinical trials are currently underway. As the executive director of HIV+Aging Research Project—Palm Springs, he's devoted to working with HIV providers, researchers and long-term HIV survivors, a population at higher risk for some cancers, to promote living well with chronic disease.

Willie Underwood III, MD, MSc, MPH

Buffalo, NY

Willie Underwood III, MD, MSc, MPH Luke Copping

Urologist Willie Underwood, 55, a prostate cancer survivor first diagnosed in 2012, has studied racial disparities in prostate cancer his entire professional life. Black men diagnosed with more aggressive cancer are the least likely to get treatment, his studies show. But when Black men get equal care, including early detection, appropriate treatment and access to quality insurance, most outcome disparities disappear. Willie’s own cancer experience, profiled in Cancer Health (Winter 2020), has also changed the way he practices medicine, prompting him to share his story with patients, loved ones and the public to help men overcome both the emotional and medical challenges of prostate cancer.

Milli Wilson

Albuquerque, NM

Millie Wilson Courtesy of The American Lung Association

A singer with a beautiful voice, Milli Wilson, 62, never thought she would get lung cancer, despite her family history and being a smoker for 45 years. But one day, an American Lung Association (ALA) commercial about risk and early detection prompted her to get screened for the disease. That screening saved Milli’s life. She was diagnosed with Stage II non-small-cell lung cancer. She got treated for her cancer, quit smoking and became an ALA advocate, promoting lung cancer screening. Although she was afraid her cancer would hurt her singing voice—her favorite song is “At Last” by Etta James—Milli says it actually gave her a new sound. And everyone in her extended family who had been a smoker has quit.

Matthew Zachary

New York, NY

Matthew Zachary Courtey of Matthew Zachary

While a college senior, Matthew Zachary, a concert pianist and composer, was diagnosed with pediatric brain cancer. Today, 25 years later, Matthew, now 46, has turned that experience and his health care advocacy into a digital media empire. From 2007 to 2018, he hosted and produced the wildly popular podcast The Stupid Cancer Show. In 2020, he launched not just a new podcast—Out of Patients with Matthew Zachary—but an entire podcast production company, Offscrip Media. Its mission? “Through raw, unapologetic podcasts about advocacy, heroism and the audacity of health,” he promises, “we’re going to build community, end isolation, amplify voices and improve quality of life for patients and caregivers around the world.” You know we’re tuning in!
