ADVOCATE LISTING

Nathan Begaye  
Huntsmans Cancer Institute  
*First-time participant*  
Email: Nathan.begaye@hci.uah.edu

Christine Hodgdon  
Independent Advocate  
*First-time participant*  
Email: chodgdon513@gmail.com

Howard Brown  
Colontown.org  
*First-time participant*  
Email: hsbrown36@gmail.com

Gretta Hutton  
The Canadian Cancer Clinical Trials Network  
*First-time participant*  
Email: teach.11hotmail.com

Vickie Buenger  
Coalition Against Childhood Cancer  
*First-time participant*  
Email: president@cac2.org

Anita Mitchell Isler  
Washington Colon Cancer Stars  
*First-time participant*  
Email: anita2141@yahoo.com

Howard Brown  
Colontown.org  
*First-time participant*  
Email: hsbrown36@gmail.com

Kathye D. Jenkins  
Cynthia Perry Ray Foundation  
*First-time participant*  
Email: info@giftofencouragement.org

Vickie Buenger  
Coalition Against Childhood Cancer  
*First-time participant*  
Email: president@cac2.org

Danielle Leach  
St. Baldrick’s Foundation  
*First-time participant*  
Email: danielle.leach@stbaldricks.org

Medha Deoras-Sutliff  
The US EFE Foundation  
*Past participant*  
Email: mesutliff@gmail.com

Stacie Lindsey  
Cholangiocarcinoma Foundation  
*First-time participant*  
Email: stacie@cholangiocarcinoma.org

Ivy Elkins  
EGFR Resisters  
*Past participant*  
Email: ivyelkins@yahoo.com

David Makumi  
Kenyan Network of Cancer Organizations  
*First-time participant*  
Email: dkmakumi@gmail.com

Jill Feldman  
CEO Oncology  
*First-time participant*  
Email: jfieldman4@sbcglobal.net

Renee Miles-Foster  
Independent Advocate  
*First-time participant*  
Email: rmilesfoster@sbcglobal.net

Victoria Geib  
Independent Advocate  
*First-time participant*  
Email: torigeib@gmail.com

Jill Hamer-Wilson  
Independent Advocate  
*First-time participant*  
Email: jill@cncf.ca

March 30 – April 2, 2019 | Georgia World Congress Center | Atlanta, GA
The Scientist↔Survivor Program®
at the Annual Meeting 2019

Nalisha Monroe
Caribbean Cancer Research Initiatives
First-time participant
Email: nalisha@live.com

William Rosvold
Pancreatic Cancer Action Network
Past participant
Email: wrosvold2@pancanvolunteer.org

Rudy Morgan
Georgia Prostate Cancer Coalition
First-time participant
Email: executedirector@georgiapcc.org

Seana Roubinek
Independent Advocate
Past participant
Email: skenibuor@gmail.com

Diane Nathaniel
Beat Stage 3
Past participant
Email: dianenathaniel@hotmail.com

Carlos Sandi
St. Baldrick's Foundation
First-time participant
Email: cjsandi@bellsouth.net

Katie Parker
Independent Advocate
First-time participant
Email: katie5271@gmail.com

Marilyn Sapsford
Ovarian Cancer Canada
First-time participant
Email: msapsford@ovariancanada.org

Denis Raymond
Independent Advocate
First-time participant
Email: denis.raymond13@gmail.com

Debra Stafford
ROAR
First-time participant
Email: debra.stafford@gmail.com

Kimberly Richardson
Independent Advocate
Past participant
Email: krichardson0924@gmail.com

Nicole Stromer
Breast Cancer Options
First-time participant
Email: mstromer1@gmail.com

Valencia Robinson
Independent Advocate
First-time participant
Email: robinsonvalencia01@gmail.com

Susan Strong
National Coalition for Cancer Survivorship
First-time participant
Email: stronglifenow@yahoo.com

Holly Rose
Don’t Be a Chump! Check for a Lump!
First-time participant
Email: hollyroses@checkforalump.com

Deborah Tobin
University of Wisconsin
First-time participant
Email: tobindeborah@gmail.com
Virgie Townsend
Independent advocate
Past participant
Email: vdtownsend@gmail.com

Lanette Veres
The Gray Matters Foundation
First-time participant
Email: lanette@graymattersfoundation.org
Nathan Begaye
Huntsman’s Cancer Institute

Nathan Begaye conducted a small-scale comparison study looking at cancer related disparities between urban and rural American Indian (AI) communities. During an environmental health research project with investigators from the University of Utah’s Department of Family Preventive Medicine’s division of Occupational & Environmental Health, he acted as a liaison between them and the Confederated Tribes of the Goshute Reservation. Facilitating and advocating equitable and culturally appropriate approaches to the radon testing before, during, and after the project.

Howard Brown
Colontown.org

Howard Brown is HBStrong! He has a huge worldwide movement and following on Facebook that is called “HBStrong!”. Brown is a stage 4 colon cancer survivor and Colontown.org empowered patient leader. He is a two-time Stage 4 cancer survivor, advocate, mentor, educator and motivational speaker. He is inspired to help others in their fight to be informed, stay positive and adopt a collaborative care approach with medical teams. Others before him have become his "cancer whisperers" and he intends to pay it forward.

Vickie Buenger
Coalition Against Childhood Cancer

Vickie Buenger serves as clinical professor at the Mays Business School with a joint appointment to the Professional Program for Biotechnology at Texas A&M University. She teaches competitive and cooperative business strategy and project management.

Buenger’s daughter, Erin, fought neuroblastoma for seven years. Since Erin’s death in 2009, Buenger has devoted time and energy to launching the Coalition Against Childhood Cancer (CAC2) on behalf of
the many dedicated organizations and individuals striving to make a difference for children with cancer. She currently serves as president of CAC2.

She combines her academic background with her interest in the science and policy of childhood cancer and has spoken before gatherings of scientists, clinicians, regulators, industry representatives, and advocates in the United States and Europe. Buenger also serves as the Board Chair of the Hospice Brazos Valley Living Endowment and on the Executive Committee of the Brazos County Democratic Party. She volunteers as an ordained elder in the Presbyterian Church-USA.

**Medha Deoras-Sutliff**
The US EFE Foundation

Medha Deoras-Sutliff is a two-time young breast cancer survivor--both diagnoses under the age of 40. She graduated from the Ohio State University with her master’s degree in preventive medicine/public health, and began her professional career at the Ohio Department of Health as a senior epidemiologist in disease surveillance. After her 2nd breast cancer diagnosis in 2005, her focus turned to the breast cancer world and she began training as an advocate volunteer with Komen, Young Survival Coalition (YSC), and the National Breast Cancer Coalition (NBCC). She is a graduate of the NBCC breast advocate training program, Project LEAD. In 2012, Deoras-Sutliff joined the staff of YSC as senior regional manager. In 2017 she moved to position with FORCE: Facing Our Risk of Cancer Empowered, as their director, education & research. In March of 2018, she joined the staff of NBCC as their director, scientific affairs. Deoras-Sutliff is a DOD BCRP consumer grants reviewer and a 2017 graduate of the AACR Scientist-Survivor program. She has also attended the San Antonio Breast Cancer Symposium and the NBCC Advocate Leadership Summit and Lobby Day. In January 2019, Deors-Sutliff moved into her new role as the executive director of the US EHE Foundation, a patient-driven and research-focused international organization for those diagnosed with the rare cancer, epithelioid hemangioendothelioma.

**Ivy Elkins**
EGFR Resisters

Soon after Ivy Elkin’s diagnosis in December 2013 with EGFR+ stage IV lung cancer that had metastasized to her bones and brain, Elkins became involved with the LUNGevity Foundation as a patient advocate. In addition to participating annually in Breathe Deep North Shore and National Hope Summit events, she served on the LUNGevity advocacy council, moderated a LUNGevity Facebook group for patients with EGFR lung cancer mutations and am a LUNGevity LifeLine Mentor for others. Elkins consider herself knowledgeable about scientific terminology and have increased
The Scientist↔Survivor Program® at the Annual Meeting 2019

this knowledge through attending conferences such as AACR, ASCO, IASLC and ESMO. Her primary focus is lung cancer research advocacy. She has been fortunate enough to serve in 2016, 2017 & 2018 as a consumer reviewer for the Department of Defense Lung Cancer Research Program and has completed two years of a five-year advocate faculty position in the ASCO/AACR Methods in Clinical Cancer Research Workshop. In the past year, Elkins has been appointed to the Patient Advocacy committee for IASLC and to the Cancer Patient Advisory Council at the University of Chicago. In August 2017, Elkins co-founded the EGFR Resisters, a patient-driven initiative to understand and improve treatments for EGFR+ lung cancer through collaborations with researchers, clinicians, industry, and other advocacy groups. The EGFR Resisters currently has over 800 patients and caregivers as members in 26 different countries. Elkins recently announced their first research project in collaboration with the Bonnie J. Addario Lung Cancer Foundation and Champions Oncology and expect to announce a future collaboration with LUNGevity as well. In addition, Elkins writes for Lungcancer.net and frequently shares her patient perspective with the media and with pharmaceutical companies involved in lung cancer treatments.

Jill Feldman
CEO Oncology

Jill Feldman served on the board of LUNGevity for nine years in various capacities, including Vice President, President, and Chair. Since her diagnosis in 2009, she has become more involved in patient support and research advocacy. Feldman writes blogs and shares her story at medical conferences, to pharma companies and community events and was featured on Pfizer’s Lung Cancer Profile stories. Feldman has been a peer reviewer for the DOD Lung Cancer Research Program since 2012 and serves on various patient advisory boards including LUNGevity, IASLC, SurviveIT and the Institute for Translational Medicine in Chicago. She was the patient co-author of the guidelines on SBRT in early-stage lung cancer in the November 2017 Journal of Clinical Oncology. In August of 2017, Feldman co-founded the EGFR Resisters. This provided the opportunity to attend and present at various conferences including Targeted Therapies, IASLC World Conference on Lung Cancer, MedImmune MEGO, and through a generous grant and help from CEC Oncology, organized their first Think Tank at ASCO 2018, which brought together top thought leaders in EGFR positive lung cancer to discuss gaps in practice and research.
Victoria Geib
Independent Advocate

Victoria Geib currently advocates through Living Beyond Breast Cancer as a Hear My Voice program volunteer, Ohio Partners of Cancer Control (Ohio Department of Health) as a member and Breast Cancer Committee project leader. Geib also serve as a MBC patient consultant and MBC advocacy ambassador for Eli Lilly’s More For MBC campaign, training coordinator and event partner for the annual Ohio MBC Day of Action Day (which was recognized this year by the Franklin County Commissioners Office as well as Governor John Kasich of Ohio). Geib has also accepted the position as Honorary Chair of the 2019 Columbus Komen Race for the Cure. She previously served as the chair and founder of the Ohio Metsquerade Gala, social networking, press, and media director; contributing writer for The Underbelly Magazine (breast cancer blog), and patient advocate and group founder for Cancer Support Community Columbus. Geib has been featured in multiple media outlets to promote awareness of metastatic breast cancer and advocacy including People.com, Everyday Health, AllRecipes Magazine, Our American Stories, Good Morning America, and various other publications and news outlets (both local and regional). She continues to volunteer and speak at various events throughout her local community and around the state of Ohio.

Jill Hamer-Wilson
Independent Advocate

Jill Hamer-Wilson is a member of a new support group, the first of its kind in Ottawa, Canada for women with lung cancer. The program, Sharing Air Together, helps those living with cancer to tell their stories, share information and lean on each other. She is actively involved as a trailblazer in her local community and a community of support for lung cancer patients and caregivers. Hamer-Wilson started outreach days at cancer centers. She is also a patient representative for the CCTG (Canadian Cancer Trials Group), Lung Site and serves as Canadian National Co-coordinator, ALK Positive, who cares about all people affected by lung cancer, or any kind of cancer, anywhere on earth.
Christine Hodgdon
Independent Advocate

Christine Hodgdon has worked with several organizations in various capacities including Metavivor, Living Beyond Breast Cancer (LBBC), Young Survival Coalition (YSC), and Tigerlily Foundation. She graduated from the National Breast Cancer Coalition’s 2018 Project LEAD® Institute, the Alamo Breast Cancer Foundation's Scholarship Program at the San Antonio Breast Cancer Symposium (SABCS18), and LBBC’s Hear My Voice training to become a better MBC advocate in her community. She currently serves as a helpline volunteer for LBBC & YSC, a grant reviewer for Metavivor’s Metastatic Breast Cancer (MBC) Research Award, and as a consumer reviewer for the Depart of Defense’s Breast Cancer Research Program. She launched a website, TheStormRiders.org, as a resource for the MBC community.

Gretta Hutton
Canadian Cancer Clinical Trials Network

Gretta Hutton is a community social worker for Closing the Gap Healthcare Group. Patient advocacy has played a major role in her work life and as a cancer patient. She is now happily in remission due to participation in a clinical trial for Mantle Cell Lymphoma. She has taken advantage of her return to good health to support cancer clinical trial advocacy. Hutton has taken advantage of her unique perspective as a health care social worker & cancer patient through participating as a lay representative on the Canadian Cancer Clinical Trials Network since 2015. She has also assisted in the development of the Cancer Trials Hamilton website in promotion of trial participation and have contributed to trial promotion through the Academic Hospitals of Ontario and Hamilton Health Sciences.
The Scientist↔Survivor Program®
at the Annual Meeting 2019

Anita Mitchell Isler
Washington Colon Cancer Stars

Anita Mitchell Isler started a 501(c)(3) Washington Colon Cancer Stars for the state of Washington, which focuses on educating everyone to know the symptoms, family history, and risk factors. As founder and executive director, she speaks to medical students, high school students and works with high-risk populations in her area doing health fairs with the inflatable colon. Isler runs two peer-to-peer in-person colorectal cancer support groups at two hospitals and has trained other leaders. She helps on the online community and sits on various committees locally and national providing a patients voice. She also attends patients appointments on request and helps connect researchers to patients for focus groups.

Kathye D. Jenkins
Cynthia Perry Ray Foundation

Kathye Jenkins is the Founder and President of Witness2Fitness which was organized in January 2000. The organization’s overall theme “Providing Support for Education, Encouragement, and Empowerment to and from Black Churches for a Healthier Community.” Witness2Fitness focuses on health issues, in particular, cancer that are impacting our communities by providing health resources, community health forums, advocates training and awareness of research participation. She is currently a candidate for a Master of Public Health in Urban Health Disparities at Charles R. Drew University of Medicine and Science to gain additional knowledge in her cancer work to address disparities and research engagement.

Danielle Leach
St. Baldrick’s Foundation

Danielle Leach came to St. Baldrick’s with over 20 years of experience in the health nonprofit industry. Danielle has worked in leadership positions at the American Cancer Society, Ovarian Cancer National Alliance and Strang Cancer Prevention Center in cancer control program development and implementation. While living for six years in Latin America, she served as an international development consultant for American Cancer Society, CARE, Catholic Relief Services, United...
The Scientist↔Survivor Program® at the Annual Meeting 2019

States Agency for International Development (USAID) and PLAN International, working on cancer and AIDS-related programming and resource development training. Leach is a dedicated volunteer and advocate for cancer and children's issues. She is the founder of the Mason Leach Superstar Fund at the American Childhood Cancer Organization, in memory of her son, Mason, who died of pediatric brain cancer in 2007.

Leach serves on several boards and committees related to children's issues and health in the community. She currently serves as the co-chair of the Alliance for Childhood Cancer, a national coalition tackling childhood cancer policy issues. Leach is a member of the National Cancer Institute’s National Council of Research Advocates, as well as a member of the Pediatric and Adolescent Solid Tumor Steering Committee. She served Vice President Biden’s Cancer Moonshot, as part of the Pediatric Cancer Working Group. Leach was recognized in 2018 with the ASCO Partners in Progress award and the Rare Disease Legislative Advocates Rare Voice Award.

She holds a master of public administration degree in health policy and management from New York University.

Stacie Lindsey
Cholangiocarcinoma Foundation

Stacie Lindsey served as an advocate for CCA patients for the past 12 years. She attended conferences seeking to educate community oncologists and oncology nurses about current treatment opportunities which are rapidly emerging for CCA patients. Lindsey has also worked with community researchers to form a research network to streamline clinical trial access and opportunities for patients. She meets with industry groups regularly who are interested in the patient voice being part of the clinical trial process and facilitate these meetings. Lindsey is always seeking to improve communication and educational materials to help patients understand all the options they have available to them.

David Makumi
Kenyan Network of Cancer Organizations

David Makumi started as a nurse working in an oncology unit of a private university hospital and volunteering with cancer civil society groups during his free time and now involved in cancer advocacy on a full-time basis. He is currently the chairman of the Kenya Network of Cancer Organizations which is the umbrella body of over 25
cancer civil society (CSO) and patients groups who work as a united front in different aspects of cancer control from prevention to patient support. As chair, he advocates for inclusion and representation of CSOs and patients groups in different policy forums, oncology professional forums and change processes using a leave no one behind mantra. Makumi has been involved in cancer-related advocacy for over ten years at clinical, policy, legislation and access to care. The focus of his advocacy work is on evidence-based policies and legislation that support resource allocation to cancer programs and research and equitable access to quality, affordable cancer care.

Renee Miles-Foster
Independent Advocate

Renee Miles-Foster’s involvement in advocacy comes as a caregiver. Her husband was first diagnosed with kidney cancer in 1996. In 2007 he was diagnosed with metastases in his lung, liver, and brain. They both became advocates in the Kidney Cancer Association, the AACR and the Cancer Center Patient and Family Council at the University of Chicago. She has tried to reach as many cancer survivors as possible through projects on radio, television, magazines, panels; online documentaries live speaking engagements, musical performances, and person-to-person talks.

Nalisha Monroe
Caribbean Cancer Research Initiatives

Nalisha Monroe studied radiation therapy in Canada and returned to Trinidad to care for her father who was diagnosed with metastatic prostate cancer. She then became an advocate for the many patients that came through the doors of the cancer treatment centers where she worked. In 2007, the country saw the first linear accelerator which, meant that cancer patients could now experience a better standard of care. Monroe advocates for these patients to receive the ideal standards of practice using this radiation therapy equipment by assisting in training radiation therapists to treat and care for these patients. In August 2018, the first Cancer Navigation Training Program was launched in Trinidad, and she now works as a cancer navigator in assisting patients and their families.
Rudy Morgan
Georgia Prostate Cancer Coalition

Rudy Morgan is the former executive director of Georgia Cancer Foundation. He has 35+ years executive leadership experience in the health care industry, serving as the CEO of three non-profit organ donor recovery programs and bone and soft tissue recovery agencies. Additionally, Morgan has served as vice president of Donor Services for AlloSource in Centennial, Colorado; one of the nation’s largest non-profit providers of human bone and soft tissue materials for use in medical treatments and procedures.

He has served on several boards, including Association of Organ Procurement Agencies; United Network for Organ Sharing; North American Transplant Coordinators Association; Georgia Transplant Foundation and American and the Society of Multicultural Health & Transplant Professionals where he was one of its founding Board Members and Past President.

He is a prostate cancer survivor and is now currently serving as the acting executive and vice president of the Georgia Prostate Cancer Coalition, an organization who vision is “To eliminate cancer death due to Prostate Cancer. And mission is “To build awareness, provide education and prevention of the advance stages of Prostate Cancer for the men of Georgia.

Diane Nathaniel
Beat Stage 3

As a Stage 3 colon cancer survivor, Diane Nathaniel participates in cancer advocacy as a survivor/patient advocate. Nathaniel is an Ambassador Team LEAD with American Cancer Society Cancer Action Network; the legislative arm of American Cancer Society. In this role, she meets with members of Congress, engages in policy development, and advocates for quality healthcare for people who have been affected by cancer. Nathaniel is an inspirational speaker on cancer health with A-Speakers International Speakers Bureau. She is the co-founder of Beat Stage 3, Inc., a non-profit organization dedicated to raising community awareness about cancer health, screening and prevention. Her organization promotes image consciousness and renewed self-love for those who have suffered the ravages of cancer treatments. She aims to highlight and implement health, beauty, and fashion makeovers to influence positive lifestyle changes and improve self-confidence that often disappears during and after treatment. Having a personal experience with cancer has afforded Nathaniel the opportunity to partner with research scientists from S.U.N.Y. Downstate and S.U.N.Y. Stony Brook Medical Center that researches the disparities of GI Cancer
in African-Americans. Nathaniel serves as their community liaison. Nathaniel continues to volunteer by speaking/tabling at various health fairs and community events in NYC and other states.

Katie Parker
Independent Advocate

Katie Parker became involved with Young Survival Coalition as a State Leader, Face2Face Coordinator, Survivor Link Mentor, and Council of Advisors Member; also, with Bright Pink as an Education Ambassador and a 2017-2018 Young Advocate for Living Beyond Breast Cancer. In 2016, she was selected to be the Honorary Bat Girl for the Colorado Rockies and was able to be a consumer reviewer for the Department of Defense, Breast Cancer Research Program of the Congressionally Directed Medical Research Programs. Parker hopes she's always able to encourage others to give themselves the best chance against breast cancer and prove that cancer isn't always the end, but a beginning.

Denis Raymond
Independent Advocate

In the early summer of 2013, at the age of 26 years old, Denis Raymond was aggressively thrown against the wall of mortality with a terminal diagnosis of glioblastoma multiforme (GBM), the most invasive and fast-growing of the brain cancers. As a young adult, he found myself having to re-prioritize the activities in her life: filling out power of attorney forms instead of getting married, moving back in with my parents instead of continuing my pursuits of adventure and travel, and preparation for saying more goodbyes than hellos, to name a few. Though Raymond was faced with a dismal prognosis, he decided to adapt to his new situation in order to do as much meaningful work as possible. As a child youth worker and teacher, Raymond always sought to empower and embolden those around his, and cancer had provided him a new tool for this task. Participating in a clinical trial unlocked a capacity to talk about the cancer research process to both affected populations and researchers, allowing him to act as a bridge between the two worlds. Raymond jumped towards building a new skillset by completing a Masters of Social Work at the University of Ottawa in Canada. He became involved with numerous organizations over the years, which have allowed him to access the people who most need hope, and taken to becoming a leader in AYA and Brain Tumour/Cancer groups, and, more recently, have become a specialist in support services with the Brain Tumour Foundation of Canada.
In November of 2017, Raymond was fortunate to become involved in a patient-advocacy-training program at the bi-annual Canadian Cancer Research Conference (CCRC), much like the Scientist-Survivor Program, which has opened an entirely new avenue to becoming a better patient advocate and patient collaborator in new and innovative cancer research. Raymond now sits on two committees for this event so that he might bring forward the patient voice in future cancer research efforts.

Kimberly Richardson
Independent Advocate

For the last three years, Kimberly Richardson has participated in legislative advocacy to increase Department of Defense funding for ovarian cancer research as an advocate leader for the Ovarian Cancer Research Alliance. Locally, she has shared her story with community-based hospitals in conjunction with political officials and the health care initiatives. Richardson will continue her legislative advocacy work with the Alliance but I have also established connections with other national cancer advocacy organizations such as the National Comprehensive Cancer Network and the National Coalition for Cancer Survivorship to broaden her understanding of legislative advocacy on all rare forms of cancer.

Valencia Robinson
Independent Advocate

Valencia Robinson, Ed.S was diagnosed with triple negative breast cancer in October 2006. She continued teaching during chemotherapy, and this ignited in her a passion to be an advocate for others as she saw many women suffering and dying after their diagnosis. As a board member of the Florida Breast Cancer Foundation, she serves on various committees where she visits the state capitol in Tallahassee advocating for legislation that would make life easier for cancer patients and funds to continue research and treatment for patients. She has also advocated for similar legislation in Washington DC working along with the National Breast Cancer Coalition and Metavivor. She serves on the triple negative patient advisory board of the pharmaceutical company Astra Zeneca where she advises the company on clinical study design and planning efforts to optimize patient experience. She also works with the Department of Defense, Congressional Directed Medical Research Programs, specifically the Breast Cancer Research Program which challenges the scientific community to design research that will address the urgency of ending breast cancer. In her local community, she has sponsored a Wellness Retreat for eight years where breast cancer patients and survivors come for a free

March 30 – April 2, 2019 | Georgia World Congress Center | Atlanta, GA
three day weekend of rest and relaxation. In 2013 she was selected as a National Teacher of the Year by People Magazine. She is an author and speaker who uses her personal testimony which is life-affirming and encourages all to change their outlook on the miracle of daily life.

Holly Rose
Don’t be a Chump! Check for a Lump!

Holly Rose is the founder and CEO of the Arizona based non-profit Don’t be a Chump! Check for a Lump! They strongly advocate for women to be empowered with the facts regarding breast cancer to help save lives through early detection and are committed to educating women, men, and young girls on the many ways one can lower their risk of breast cancer to help decrease the incidence of breast cancer and many other diseases. Rose provides support to women battling breast cancer through their free wig program. Also, they break down the financial barrier that often prevents a woman from receiving a diagnostic mammogram, ultrasound or biopsy through a free mammogram program. If something suspicious is found in a free mammogram, they provide pay for the additional testing needed to confirm a diagnosis.

William Rosvold
Pancreatic Cancer Action Network

William (Bill) Rosvold have served as advocacy chair for the Pancreatic Cancer Action Network [PanCAN] affiliate in the New York City area, ongoing from 2012. He have worked to build a presence in Congress advocating for improved funding for cancer research; building teams of survivors, caregivers, doctors, and scientists; and balancing facts and statistics with personal stories to put a human face on advocacy. Rosvold has worked to establish recognition as an established presence by legislators and staff. He is also a survivor and a caregiver and spoken as a survivor for PanCAN’s Purple stride fundraiser, and served on grant review boards for the National Cancer Institute, the Dept of Defense, and PanCAN. He has represented PanCAN for outreach and education at scientific and medical conferences in NYC at Columbia University, Mt. Sinai, Weill-Cornell, SUNY Downstate; and in Philadelphia at University of Pennsylvania and Thomas Jefferson University. Rosvold has attended numerous other conferences to improve his knowledge of cancer, including AACR Science↔Survivor Program, AACR Pancreatic Cancer Conferences, and the National Comprehensive Cancer Network Annual Conference.
Seana Roubinek
Independent Advocate

Seana Roubinek is a survivor of recurrent ovarian cancer. She is a research advocate with the Ovarian Cancer Research Alliance (OCRA) as well as a presenter with Survivors Teaching Students® which is a signature program of OCRA. She has served as a consumer reviewer with the CDMRP Ovarian Cancer Research Program and is currently a research advocate with the Ovarian Cancer Academy. She is a CPAT (Cancer Policy & Advocacy Team) member with the National Coalition for Cancer Survivorship (NCCS). She is a previous participant in the ACR Survivor↔Scientist Program (2015).

Carlos Sandi
St. Baldrick’s Foundation

Carlos Sandi is a healthcare information systems professional and childhood cancer parent who volunteers extensively with the St. Baldrick’s Foundation.

Sandi’s daughter, Althea, was diagnosed with acute myeloid leukemia when she was 16 months old. Althea died from her disease shortly after her second birthday. Six years later, Sandi’s son, Phineas, developed treatment resistant acute lymphoblastic leukemia. Phineas was saved by an early CAR-T cell trial at the National Cancer Institutes in Bethesda Maryland and since then, his family has become deeply involved in advocating for pediatric cancer research. The entire Sandi family is deeply grateful for the incredible and timely scientific progress that saved their son’s life and for the countless researchers, donors, volunteers and advocates who have made that progress possible.

Marilyn Sapsford
Ovarian Cancer Canada

Marilyn Sapsford was diagnosed with stage 1 clear cell ovarian cancer in 2002. Fortunately, found early, she is now cancer free! As regional director for the Province of Ontario, the largest province in Canada, she is responsible for the implementation of support programs for women with ovarian cancer, raising awareness of the disease with health care providers and the general public and building relationships with treatment center staff and community organizations. Sapsford participates as a co-investigator in a research study through the Odette Cancer Centre in Toronto, seeking to
understand the experiences of family members caring for a loved one with advanced ovarian cancer. This research was published in the Journal of Hospice and Palliative Nursing in October 2018. She is the manager of Ovarian Cancer Canada’s National programs. In this role, she manages and develop support programs, resources and information for women with ovarian cancer across the country as well as provide pertinent disease information and updates to constituents and organize national webinars on relevant topics like clinical trials and fear of recurrence.

**Debra Stafford**

**ROAR: Reclaiming Ourselves After Recovery (from cancer)**

Debra Stafford is a 4-year breast cancer survivor and serving as a peer navigator/mentor at two cancer centers, as well as in the community. She branched out to other cancer types including pediatric cancers, ovarian cancer, GI cancers, and head and neck cancers. Stafford developed a Pilates-based exercise program for cancer patients which she teaches at a physical therapy clinic, a local cancer center, and an integrative medicine clinic. She is also the founder of nonprofit (501(c)3 pending, ROAR: Reclaiming Ourselves After Recovery (from cancer). Through ROAR Survivorship, Stafford helps individuals affected by cancer to build a life they love whatever their new normal. Through ROAR Legacies, she provides metastivors with tools and support to leave behind their legacy in this world. ROAR Access Wellness offers affordable access to and education about complementary therapies. Stafford serves as a Reiki practitioner and workshop leader at Hoag Cancer Center. She and her dog provide pet therapy to pediatric cancer patients and their families at Open Mind Modalities, an outpatient integrative medicine clinic associated with Children’s Hospital Orange County. In 2019, Stafford began collaborating with City of Hope, Claremont Graduate University, Open Mind Modalities, St. Joseph’s Hospital and Breastlink to conduct two breast cancer epidemiological studies.

**Nicole Stromer**

**Breast Cancer Options**

Nicole Stromer has worked for SHARE cancer hotline and taught art at Dubin Breast Cancer Hospital in NYC. Also, works in breast cancer support groups at Memorial Sloan Kettering in NYC.
Susan Strong
National Coalition for Cancer Survivorship

As a long-term (35 year) survivor of pediatric cancer, Susan Strong is a passionate advocate for cancer survivors. She is particularly interested in Quality of Life measures and effective interventions to improve QOL for cancer survivors and education and early diagnosis of late effects impacting long-term cancer survivors. I serve as a member of the NCCS Cancer Policy & Advocacy Team (CPAT) and as an as a long-term (35-year) survivor of pediatric cancer, Susan Strong is a passionate advocate for cancer survivors.

Focused on Quality of Life measures and effective interventions to improve QOL for cancer survivors and education and early diagnosis of late effects impacting long-term cancer survivors. She serves as a member of the NCCS Cancer Policy & Advocacy Team (CPAT), as an NCCS representative on the NQF Cardiology Standing Committee and a patient stakeholder in clinical research through PCORI, both as a research team member/patient reviewer, and a PCORI Ambassador.

Deborah Tobin
University of Wisconsin

Deborah Tobin has been an active member/participant of the University of Wisconsin Carbone Cancer Center (UWCCC) Breast Cancer Research Advisory Network (BCRAN) since September 2015. She has served as a member of both a research team and a grant review committee for internal UWCCC awards. Deborah has also participated as a member of a subcommittee addressing broad consent for tissue donation. She is also a member of the National Breast Cancer Coalition (NBCC) and the Wisconsin Breast Cancer Coalition (WBCC).
Virgie Townsend  
Independent Advocate

I am involved with UAB Medicine PFAC, Interacts with other patients to empower them to advocate for themselves and others. Also active with NCCS Survivorship. Involved with Joint Community Action Roundtable.

Lanette Veres  
The Gray Matters Foundation

Lanette Veres has used her personal experience as a caregiver then as a patient to become actively involved in the lives of others dealing with the same disease. Many families on the brain tumor journey are looking for someone who understands someone who has walked the walk— that personal connection. When Veres started this journey, she felt there was a real lack of support and that pushed me to start Gray Matters Foundation. Over time it has evolved into many forms of advocacy. This is a huge part of our mission: sharing support not statistics! Veres felt the mission was about the emotional connection with the family.