



## **Heidi Adams**

President & CEO

Critical Mass: The Young Adult Cancer Alliance

Heidi Schultz Adams has been a tireless patient advocate since surviving Ewing's sarcoma in her mid-20s. Her career in advocacy began in 2000 when she founded a pioneering non-profit called Planet Cancer to create a community of support and advocacy for young adults with cancer, a first in the digital space, and to raise awareness about their unique medical and psychosocial needs. Her groundbreaking work on behalf of young adults with cancer continued as a volunteer leader of the

**LIVESTRONG** Young Adult Alliance, a unique international coalition of nearly 200 advocacy organizations and health care institutions, all working together to improve survival rates and quality of life for young adults with cancer.

Planet Cancer was acquired by the **LIVESTRONG** Foundation in 2009, which Heidi joined to assume a broader role overseeing grassroots advocacy and digital initiatives, eventually becoming Vice President of Strategic Partnerships. Last year, she returned to her passion of serving young adults with cancer by taking the role of the first President and CEO of Critical Mass, the new organization formed in the **LIVESTRONG** Foundation's spinoff of the Young Adult Alliance.

She has been widely recognized for her work on behalf of young adults over the years, including being named a Swiffer Amazing Woman of the Year and one of four national Health Heroes honored by WebMD magazine. In 2008, she was a national winner of the prestigious Lane Adams Award from the American Cancer Society, which recognizes exemplary cancer care. A writer by preference, Heidi is the co-author of two books in the cancer space: *Here and Now: Inspiring Stories of Cancer Survivors* and *Planet Cancer: (The Frequently Bizarre but Always Informative Experiences and Thoughts of Your Fellow Natives)*.

**Justin N. Baker, MD, FAAP, FAAHPM**

Chief, Division of Quality of Life and Palliative Care

Attending Physician, Quality of Life Service  
Director, Hematology/Oncology Fellowship Program

Associate Member

Departments of Oncology and Pediatric Medicine

St. Jude Children's Research Hospital



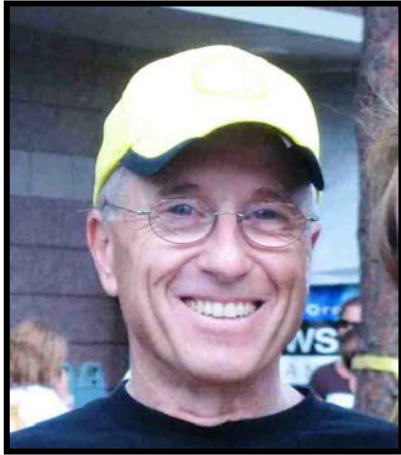
Dr. Justin Baker is Chief of the Division of Quality of Life and Palliative Care in the Departments of Pediatric Medicine and Oncology at St. Jude's Children Research Hospital. As a pediatric oncologist, palliative care physician, member of the ethics committee and Phase I and end-of-life care clinical investigator, Dr. Baker is intimately aware of the distress experienced by children and AYA with advanced cancer and the ethical and bereavement issues surrounding their disease progression. Dr. Baker currently serves as the Director of the Division of Quality of Life and Palliative Care at St. Jude as well as the medical director of their Quality of Life Service – the St. Jude palliative care team. Dr. Baker also serves as the Director of their Pediatric Hematology/Oncology fellowship program. His research interests include ethical considerations surrounding enrollment in Phase I clinical trials, integrating palliative care into the ongoing care of children with cancer, AYA palliative and end-of-life care as well as pain and symptom control in the context of pediatric oncology care. Dr. Baker has participated in more than 25 studies related to pediatric palliative care and has authored numerous manuscripts and book chapters on the topic of ethical decision making as well as other palliative care subjects within the context of pediatric oncology.



## **Lynda Beaupin, MD**

Assistant Professor of Oncology  
Roswell Park Cancer Institute

Lynda Beaupin, MD, currently serves as Staff Physician of Pediatric Hematology/Oncology, Director of the Adolescent and Young Adult Cancer Program, and Clinical Director of the Support for Life Survivorship Program at Roswell Park Cancer Institute. She also currently serves as Assistant Professor of Oncology at Roswell Park Cancer Institute and Assistant Professor of Pediatrics at the State University of New York at Buffalo. In addition, until October 2012, she served as an AYA Expert Consultant for CDC's project on Clinical Trials and Outcomes in Adolescents with Cancer. She has received numerous other committee appointments, including as a panel member of NCCN's AYA guidelines committee, co-chair of CDC's project entitled "Examining the Impact of Provider Specialty on Clinical Trial Enrollment and Subsequent Outcomes Among Adolescents with Cancer," co-investigator of Alliance Foundation's IRF4, A Novel Tumor Suppressor in BCR-ABL+B-ALL study, and principal investigator of Rally Foundation's Involvement and Awareness of Adolescents with cancer in the Decision Making Process study. She has completed various other research activities related to her interest in adolescent and young adult oncology and survivorship and oncofertility. Dr. Beaupin received her B.S. in Biology from York University of Canada, received her M.D. from Saba University School of Medicine, Netherland-Antilles, completed her residency at University at Buffalo – Women & Children's Hospital, and completed a fellowship in Pediatric Hematology/Oncology University at Buffalo – Roswell Park Cancer Institute and Women & Children's Hospital of Buffalo.



### **Archie Bleyer, MD, FRCP (Glasg)**

Originator, DEFEATcancer  
Clinical Research Professor, Knight Cancer Institute,  
Oregon Health & Science University  
Chair, Institutional Review Board,  
St. Charles Health System, Central & Eastern Oregon

Archie Bleyer, MD, became interested in Adolescent and Young Adult (AYA) Oncology in the mid 1990s when he became aware that the progress in cancer he had personally witnessed in children had not occurred in adolescents. As Chair of the Children's Cancer Group, he formed the CCG AYA Committee and in 1999, had the U.S. National Cancer Institute (NCI) conduct a workshop on the topic. Dr. Bleyer subsequently engaged the Children's

Oncology Group, NCI Cancer Therapy Evaluation Program, U.S. President's Cancer Panel, American Society of Clinical Oncology, University of Texas M.D. Anderson Cancer Center, Lance Armstrong Foundation and Aflac Foundation in a national AYA oncology initiative. The initiative has since been joined by the Teenage Cancer Trust, U.S. NCI Director's Office (Program Review Group), **LIVESTRONG**, Planet Cancer, CanTeen, Teen Impact, CancerCare, Enzon and Sigma-Tau Pharmaceuticals, and multiple cancer centers in the U.S., Australia, and Europe. All this was facilitated by what he learned from >\$75 million research grants over the years that he has had the privilege to administer as a Principal Investigator.



**Rebecca Block, PhD, MSW, LCSW**

AYA Psychosocial Research Leader  
Assistant Professor of Medicine  
Oregon Health and Science University  
Knight Cancer Institute

Dr. Rebecca Block is a licensed clinical social worker with a Ph.D. in social research. She is one of only a few Ph.D. prepared social workers engaging in research in adolescent and young adult oncology. Block is currently working on studies related to psychosocial

outcomes, mental health and fertility preservation decision-making. She is also an advisor to Critical Mass, providing her expertise in community organizing, systematic information gathering, and the psychosocial aspects of AYA cancer care. Dr. Block was the co-chair of the Standards of Care Task Force in the Lance Armstrong Foundation Young Adult Alliance, applying her skills to the important task of establishing and disseminating care standards for clinical treatment of adolescents and young adults with cancer. She is currently the mental health director for Camp Starlight and co-chair for the Camp Starlight Planning Commission and a member of the Board of Directors for Oncology Youth Connection. Camp Starlight is a camp for children infected and affected by HIV. Oncology Youth Connection is a community building organization inspiring resilient response in young adult cancer survivors.

Dr. Block developed expertise in research design and implementation in qualitative and quantitative methodologies. During a research assistantship, she conducted a project about adolescents with cancer and spirituality; it was an inspiration. Dr. Block has been engaged in psychosocial research with adolescents and young adults with cancer ever since. She taught clinical social work practice and research to graduate students in social work before shifting her primary focus to research in adolescents and young adults with cancer. The synergy of life experience, clinical and research skills and connection to social and professional community continues to inspire, motivate and move Dr. Block in all of the work that she does.



**Jacqueline (Jackie) Casillas, MD**

Director, UCLA Pediatric Cancer Survivorship Program  
Associate Professor, Pediatric Hematology/Oncology,  
Pediatrics

Associate Director, JCCC Patients and Survivors Program  
Area

Member, Endocrine Surgery Program  
UCLA Medical Center

Dr. Jacqueline Casillas, MD, MSHS, is a pediatric oncologist and Associate Professor of Pediatrics at the David Geffen School of Medicine at UCLA. She has earned her medical degree from the UCLA School of Medicine, completed her pediatric training at Harbor-UCLA, subspecialty training in pediatric hematology/oncology at UCLA, and earned her Master's of Science in Health Services at the UCLA

School of Public Health. She completed her postdoctoral research fellowship training in Cancer Prevention and Control Research at the UCLA's Jonsson Comprehensive Cancer Center. She is a health services researcher with a focus on pediatric, adolescent and young adult cancer survivorship with emphasis on underserved communities. She holds several leadership roles at UCLA including: the director of the Pediatric Cancer Survivorship Program at UCLA, Associate Director of the Patients and Survivors Program at UCLA's Jonsson Comprehensive Cancer Center's (JCCC) and the medical director for the UCLA Daltrey/Townshend Teen and Young Adult Cancer Program.



**Karen M. Emmons, PhD**

Professor, Department of Society, Human  
Development, and Health,  
Harvard School of Public Health  
Deputy Director,  
Center for Community Based Research  
Dana-Farber Cancer Institute

Dr. Karen Emmons is Deputy Director of the Center for Community-Based Research. She is Associate Dean for Research and Professor of Social and Behavioral Sciences at Harvard School of Public Health.

Dr. Emmons is a leader in research on community-based approaches to cancer prevention, particularly for underserved populations. Among her research interests are smoking cessation and development of policy interventions related to tobacco. Dr. Emmons has conducted seminal research on reducing environmental tobacco smoke among young children from low-income families. Her work includes a number of studies focused on reducing risk of preventable cancers among childhood cancer survivors and family members of cancer patients. Her work in this area targets prevention of lung cancer, colorectal cancer, and melanoma.

Dr. Emmons has received a number of awards and recognitions of her contributions. She is a Past-President of the Society of Behavioral Medicine. She received its Distinguished Research Mentor Award in 2004 and its Cancer SIG Outstanding Senior Scientist Award in 2009. She is an alum of the Hedwig van Ameringen Executive Leadership in Academic Medicine Program for Women (ELAM) and received the Harvard School of Public Health's Faculty Mentoring Award in 2013.

Dr. Emmons received her Bachelor's degree from University of Illinois and her M.S. and Ph.D. in Clinical Psychology from the State University of New York in Stony Brook. She completed an internship in Behavioral Medicine at Brown University School of Medicine.

## **Hollie Farrish**

Cancer Survivor

In 2005, diagnosed with what was originally thought to be Renal Cell Carcinoma with lung metastases, Hollie Farrish, at the age of 25, underwent a right nephrectomy and was entered into an Immunotherapy clinical trial. Pathology obtained from the nephrectomy revealed that it in fact was not Renal Cell Carcinoma, but Stage IV Wilms Tumor (Nephroblastoma), a kidney cancer common in children ages birth to five. Following the Children's Oncology Group Protocol, Hollie underwent six weeks of radiation and twenty-eight weeks of chemotherapy and has remained cancer free since 2006. 😊



Hollie remains active in the cancer community by participating in various “Life with Cancer” ([www.lifewithcancer.org](http://www.lifewithcancer.org)) educational forums and seminars, support groups and fundraising events. As a young cancer survivor, Hollie recognizes the importance of peer support and strives to be a positive influence and mentor to fellow patients, survivors and their families.

**Karen M. Fasciano, PsyD**

Psychologist at Dana-Farber Cancer Institute,  
Department of Psychosocial Oncology and  
Palliative Care  
Associate Psychologist,  
Brigham and Women's Hospital,  
Department of Psychiatry  
Instructor, Harvard Medical School



Dr. Karen Fasciano is a clinical psychologist and Director of Young Adult Mental Health at the Dana-Farber Cancer Institute. Dr. Fasciano has created a body of innovative clinical interventions for young adults coping with cancer, including an interactive educational website for the young adult patients at Dana-Farber/Brigham and Women's Cancer Center. In addition, Dr. Fasciano has participated in research publications on young adults coping with cancer. She has also developed patient educational materials, a clinical manual for the treatment of cancer-related anxiety in young adults, and a very successful local annual young adult patient conference.

Dr. Fasciano has been a member of the scientific program committee of the American Psychosocial Oncology Society for many years and co-chairs the Association of Oncology Social Work's SIG on Adolescent and Young Adults with Cancer. She has also appeared as an expert in several patient educational publications, videos, and podcasts and has also appeared as an expert on public television. Dr. Fasciano consults with other national and international cancer centers around the development of new clinical programs for young adults. Most importantly, Dr. Fasciano is an expert clinician whose clinical services help ease the emotional distress of many young adult patients coping with cancer.



**David Freyer, DO, MS**

Director, LIFE Cancer Survivorship & Transition Program  
Children's Center for Cancer and Blood Diseases  
Children's Hospital Los Angeles  
Professor of Clinical Pediatrics  
Keck School of Medicine, University of Southern California

Dr. David Freyer is Director of the LIFE Cancer Survivorship & Transition Program in the Children's Center for Cancer and Blood Diseases at Children's Hospital Los Angeles (CHLA), and is Professor of Clinical Pediatrics at the Keck School of Medicine, University of Southern California (USC). In these positions, Dr. Freyer is responsible for development and direction of clinical cancer survivorship services and related research at CHLA. Dr. Freyer is also a

Member of the Cancer Control Program at the USC Norris Comprehensive Cancer Center and of the Leukemia/Lymphoma Program at CHLA.

A Phi Beta Kappa scholar who graduated magna cum laude after three years at DePauw University, Dr. Freyer received his medical degree from the Des Moines University College of Osteopathic Medicine and Surgery. He took his general rotating internship at Chicago College of Osteopathic Medicine and Hospitals, pediatrics residency at Rush University Medical Center, and pediatric hematology/oncology fellowship at the University of Michigan Medical Center/CS Mott Children's Hospital. He is board-certified in pediatric hematology and oncology. In 2007, Dr. Freyer earned his M.S. in Clinical Research Design and Statistical Analysis at the University of Michigan School of Public Health.

Dr. Freyer's clinical and research activities have focused primarily on cancer control and survivorship, including the recognition, characterization, management and prevention of short- and long-term morbidity of treatment, as well as adolescent/young adult (AYA) oncology, health care transition, and patient reported outcomes. He is principal or co-investigator on several funded research grants. In the Children's Oncology Group (COG), he serves as Chair of the COG AYA Oncology Discipline Committee and on the Cancer Control & Supportive Care and Survivorship & Outcomes Steering Committees, as well as several protocol and administrative committees. For numerous consecutive years, his clinical expertise has been recognized with citations in "Best Doctors in America."



**Bernard Fuemmeler, PhD, MPH**

Associate Professor  
Community and Family Medicine,  
Psychiatry and Behavioral Science, and  
Psychology and Neuroscience  
Duke University Medical Center

Bernard Fuemmeler, PhD, MPH, is Associate Professor (with tenure) in Community and Family Medicine, Psychiatry and Behavioral Sciences, and Psychology and Neuroscience. He earned his doctorate from Oklahoma State University in clinical psychology and an M.P.H. in quantitative methods/epidemiology from Harvard

University. He completed postdoctoral training at the National Cancer Institute in the Division of Cancer Control and Populations Science's Cancer Prevention Fellowship Program. He is a licensed clinical psychologist with an emphasis in pediatric psychology. At Duke he directs the pediatric psychology and health promotion lab and is co-founder and director of the mHealth@Duke interdisciplinary interest group and colloquium series. Dr. Fuemmeler's research takes a lifespan epidemiologic approach toward understanding the determinants contributing to child and adolescent health behaviors, as well as seeks to develop innovative intervention strategies to promote health in children, adolescents and their families. Some of his recent work has examined diet, physical activity and weight management among adolescent survivors of childhood cancer. Novel intervention research in this area is evaluating the feasibility of using mobile phones apps for improving self-management of these behaviors among adolescent survivors. Dr. Fuemmeler has authored and co-authored numerous manuscripts in peer-reviewed journals and his work has received funding from the Lance Armstrong Foundation, National Cancer Institute, National Institute of Aging, National Institute of Environmental Health Sciences, Environmental Protection Agency, and the National Institute of Drug Abuse.



**Patricia A. Ganz, MD**

Distinguished University Professor  
UCLA Fielding School of Public Health  
David Geffen School of Medicine at UCLA  
Director, Cancer Prevention and Control  
Research  
Jonsson Comprehensive Cancer Center  
University of California, Los Angeles

Dr. Patricia A. Ganz is Professor of Medicine at the David Geffen School of Medicine and Professor of Health Policy & Management at the Jonathan and Karin Fielding School of Public Health at UCLA.

Dr. Ganz, a medical oncologist, has been a member of the faculty of the UCLA School of Medicine since 1978 and the UCLA School of Public Health since 1992. Since 1993, she has been the Director of Cancer Prevention and Control Research at the Jonsson Comprehensive Cancer Center. In 1999, she was awarded an American Cancer Society Clinical Research Professorship for “Enhancing Patient Outcomes across the Cancer Control Continuum.” Dr. Ganz was elected to the Institute of Medicine in 2007. She served on the National Cancer Institute Board of Scientific Advisors from 2002-2007 and on the American Society of Clinical Oncology (ASCO) Board of Directors from 2003-2006. She received the American Cancer Society Medal of Honor in 2010. Dr. Ganz is a pioneer in the assessment of quality of life in cancer patients and has focused much of her clinical and research efforts in the areas of breast cancer and its prevention. At the Jonsson Comprehensive Cancer Center, she leads the scientific program focused on patients and survivors. Her major areas of research include cancer survivorship and late effects of cancer treatment, cancer in the elderly, and quality of care for cancer patients. Dr. Ganz currently serves as Vice Chair of the Institute of Medicine National Cancer Policy Forum.

**Linda Harlan, PhD, MPH**

Epidemiologist  
Applied Research Program  
Division of Cancer Control and Population Sciences  
National Cancer Institute

Lynne Harlan is responsible for the National Cancer Institute's Patterns of Care/Quality of Care program. The program, which began with the collection of data in 1987, has examined the dissemination of state of the art therapy to adults and children diagnosed with cancer. Following the NCI/LAF report in 2006 that highlighted the lack of progress in AYA cancer, targeted studies of AYAs were initiated. Dr. Harlan serves as senior investigator for the Adolescent and

Young Adults Health Outcomes and Patient Experience Study (AYA HOPE), which is in response to the slow pace of improvement in survival in adolescent and young adults (AYA). This study examines 1) the feasibility of recruiting AYA cancer survivors, ages 15-39 years, from population based registries; 2) development and fielding a patient survey with a subsequent survey to examine changes over time; and 3) obtaining patient (or guardian) consent to review medical records. The program focuses on treatment and psychosocial and financial issues for AYA patients diagnosed with cancer.





**Brandon Hayes-Lattin, MD, FACP**

Associate Professor of Medicine  
Division of Hematology and Medical Oncology  
Medical Director, Adolescent and Young Adult  
Oncology Program  
OHSU Knight Cancer Institute

Dr. Brandon Hayes-Lattin serves as the Senior Medical Advisor to the **LIVESTRONG** Foundation, Associate Professor of Medicine in the Division of Hematology and Medical Oncology at Oregon Health and Science University, and the Director of the OHSU Knight Cancer Institute's Adolescent and Young Adult (AYA) Oncology Program. His clinical background is in the management of hematologic malignancies and the use of hematopoietic stem cell transplantation. However, as a young adult cancer survivor

himself, and a physician caring for many young adults with hematologic malignancies, Dr. Hayes-Lattin has taken a leadership role in the development of the discipline of AYA Oncology. He serves as the inaugural board chair for Critical Mass: The Young Adult Cancer Alliance, a coalition of over 150 member organizations leading efforts to research and serve AYA cancer patients. Dr. Hayes-Lattin also chairs the AYA Committee for SWOG, serves on the expert advisory panel to the Children's Oncology Group AYA Committee, and is a member of the CDC's Federal Advisory Committee on Breast Cancer in Young Women.



## **Melissa M. Hudson, MD**

Director, Cancer Survivorship Division  
St. Jude Children's Research Hospital

Melissa Hudson, MD, joined the St. Jude Children's Research Hospital faculty in 1989 after completing her fellowship in Pediatric Hematology-Oncology at the University of Texas M.D. Anderson Cancer Center. She is currently a Member and Director of the Cancer Survivorship Division in the Department of Oncology. In 1993, Dr. Hudson became the Director of the After Completion of Therapy (ACT) Clinic, which now monitors over 5000 long-term childhood cancer survivors treated on St. Jude trials. During her tenure as Director, the ACT Clinic evaluation evolved to include a series of focused educational interventions aiming to increase survivor knowledge about cancer and its associated health

risks and motivate the practice of health protective behaviors. The ACT Clinic has served as a paradigm of optimal risk-based survivor care, within a research setting, that provides a screening and prevention plan that integrates the cancer experience with health care needs. The ACT Clinic has also provided a forum for numerous research initiatives evaluating complications after childhood cancer and methods of health promotion. Dr. Hudson disseminated the St. Jude model of risk-based survivor care through her activities in the Children's Oncology Group (COG) as Co-Chair of the COG Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancer and Co-Chair of the International Late Effects of Childhood Cancer Guideline Harmonization Group. She is also the Chair of the Childhood Cancer Survivor Study (CCSS) Education Committee. Dr. Hudson has collaborated with CCSS and COG investigators in a variety of health promotion initiatives targeting childhood cancer survivors. She has published widely on her research initiatives in pediatric Hodgkin lymphoma, late treatment sequelae after childhood cancer, and health education of childhood cancer survivors.

**Tom Kean, MPH**  
President and CEO  
C-Change

Tom Kean has devoted more than 35 years of his career to chronic disease prevention and control. He has served government, not-for-profit and for profit institutions in progressively responsible positions as a health educator, evaluator and senior manager/administrator. His assignments have included the University of Texas System Cancer Center, the National Cancer Institute, and the AMC Cancer Research Center. In 1994, he co-founded Strategic Health Concepts, a Colorado based consulting company, to help health organizations better achieve their goals through sound planning and management combined with solid technical capacity. In 2006, Tom became the Executive

Director of C-Change, a coalition of leaders from organizations representing the public, private and voluntary sectors devoted to eliminating the burden of cancer on the U.S. population. In addition to his professional activities, Tom has been actively involved over the years in volunteer work with community groups for public school education, cancer control and tobacco use prevention. In 1986, he was awarded the NIH Award of Merit for his contributions in cancer prevention and control. In 1993, he received the National Cancer Institute's Marion Morra Award for his contributions in cancer communications. In 2009, he received the Distinguished Visionary Leader in Medicine award from the Life Beyond Cancer Foundation.





**Jennifer Levine, MSW, MD**

Assistant Professor of Clinical Pediatrics  
Director Center for Survivor Wellness  
Division of Pediatric Oncology  
Columbia University Medical Center

Jennifer Levine currently serves as the Medical Director of the Center for Comprehensive Wellness at Columbia University Medical Center. At Columbia, she is involved in the clinical care of pediatric and adolescent patients with leukemia and lymphoma by providing direct clinical care and by directing the long term follow-up clinic for survivors of pediatric and adolescent cancers. Her research interests include fertility preservation,

parental understanding of whole genome sequencing, and issues related to transitioning off of active therapy.

She also currently serves as the principal investigator of a Children's Oncology Group study evaluating surrogate markers of ovarian reserve before, during, and after treatment in adolescents with lymphoma, funded by the Leukemia & Lymphoma Society. Finally, she is also a charter member of the **LIVESTRONG** Fertility Advisory Council.



**Brenda Marion Nevidjon, RN, MSN, FAAN**

Professor, Nursing & Healthcare Leadership  
Duke University School of Nursing

Ms. Brenda Nevidjon has had an extraordinary nursing career of leadership in service and education. Through diverse clinical and administrative experiences in Canada, Switzerland and the United States, she has devoted her energy to bridging practice settings and academic environments to advance patient care, creating innovative work environments, promoting scholarship in practitioners, and developing leaders. She also has helped develop professional nursing organizations at the local, national, and international level and has made lasting contributions to the Oncology Nursing Society.

In addition to contributing extensively to the nursing literature, Ms. Nevidjon is regarded as a mentor for nurses to develop their power and voice through publication. Her diverse contributions include two volumes of oncology nurses' narratives as well as books, articles and chapters on oncology topics. She also has published articles and book chapters on cancer care topics and administrative topics, such as the role of advanced practice nurses and the nursing shortage.

Ms. Nevidjon is Professor and Coordinator of the Health Care Systems Instructional Area in the MSN Program at Duke University School of Nursing. She served as President of the Oncology Nursing Society from 2008 to 2010 and is president-elect of the International Society of Nurses in Cancer Care, a Trustee of the Association of Community Cancer Centers, and a member of the IOM's National Cancer Policy Forum. She was in the inaugural class of the Robert Wood Johnson Executive Nurse Fellows Program and completed the Johnson and Johnson/Wharton Fellows Program in Management for Nurse Executives. She is a Fellow of the American Academy of Nursing and received the American Nurses Association (ANA) 2012 ANA Honorary Recognition Award for her distinguished service to the nursing profession.



## **Kevin C. Oeffinger, MD**

Director

Adult Long-Term Follow-Up Program

Department of Pediatrics

Memorial Sloan-Kettering Cancer Center

Dr. Oeffinger is a family physician, a Full Member in the Departments of Medicine and Pediatrics at Memorial Sloan-Kettering Cancer Center (MSKCC), and Director of the MSKCC Adult Long-Term Follow-Up (LTFU) Program. The Adult LTFU Program, staffed by five physicians, three nurse practitioners, a nurse, a psychologist, and a social worker, provides risk-based survivor-focused health care for over 1000 adult survivors of childhood, adolescent and young adult cancer. Dr. Oeffinger is an NIH-funded investigator studying cardiovascular late effects of cancer therapy and

breast cancer following chest radiotherapy. He serves in a number of leadership roles for national organizations including: Chair, American Society of Clinical Oncology (ASCO) Cancer Survivorship Committee; Chair, Leukemia & Lymphoma Society Quality of Life Research Initiative; and Member of the American Cancer Society Board of Directors.



**Elyse Park, PhD, MPH**

Associate Professor of Psychiatry  
Harvard Medical School  
Mongan Institute for Health Policy  
Massachusetts General Hospital

Dr. Park is a clinical health psychologist and health services researcher who focuses on understanding and improving health-related behaviors, especially smoking cessation among vulnerable medical populations. Her research interests extend across physician and patient behavior change, telephone-delivered interventions, and the role of culture on cancer preventative behaviors and beliefs. For her translational research in cancer prevention counseling, Dr. Park has designed and evaluated motivational interviewing interventions and is certified as a trainer in this technique. She is

experienced in qualitative research development and uses qualitative research to inform quantitative survey design.

Dr. Park has led numerous externally-funded research projects, including a study examining risk perceptions of individuals undergoing lung cancer screening (American Cancer Society) and research assessing the feasibility of a pilot smoking cessation trial for lung and head and neck cancer patients (National Cancer Institute). She recently completed a Robert Wood Johnson Foundation grant examining how depression and anxiety affect postpartum relapse to smoking. Other interest areas include exploring cross cultural care issues with grants from The Commonwealth Fund. Dr. Park has published more than 40 original articles in a variety of peer reviewed journals. She has reviewed grant applications for the National Cancer Institute, the Lance Armstrong Foundation, and the American Legacy Foundation. She is currently co-chair of the American Cancer Society's peer review committee for Cancer Control and Prevention.

Dr. Park's clinical work focuses on oncology patients. In addition to MIHP roles, she is a founding member of the MGH behavioral medicine program and serves as Chief of Behavioral Health Research, Benson-Henry Institute for Mind Body Medicine.



## **Helen M. Parsons, PhD, MPH**

Assistant Professor

Department of Epidemiology and Biostatistics,  
School of Medicine

The University of Texas Health Science Center  
at San Antonio

Helen M. Parsons, PhD, MPH, is an Assistant Professor in the Department of Epidemiology and Biostatistics at the University of Texas Health Science Center at San Antonio. Her research interests focus on patterns and outcomes of cancer care in the US. She previously worked as a Public Health Advisor at the National Cancer Institute and has

expertise in the use of survey and administrative data to examine survivorship issues in cancer patients. Specifically, she worked with the Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) survey to examine the role of insurance and other socio-demographic factors on treatment, work and educational outcomes in this population. Additionally, she was responsible for supporting the Surveillance Epidemiology and End Results (SEER) cancer registry data linked to Medicare claims and developed a series of publications and online modules to aid researchers in the appropriate use, methodology and reporting requirements for this data. Dr. Parsons has a Ph.D. in health services research and M.P.H. in public health administration and policy, both from the University of Minnesota.

**Kavita Patel, MD, MS**

Fellow, Economic Studies Program  
Managing Director,  
Clinical Transformation and Delivery  
Engelberg Center for Health Care  
Reform  
Brookings Institution



Kavita Patel is a Fellow and Managing Director of Delivery System Reform and Clinical Transformation at the Engelberg Center for Health Care Reform at the Brookings Institution. She was previously Director of the Health Policy Program at the New America Foundation, a nonpartisan public policy institute in Washington, DC. Dr. Patel is a board-certified physician dedicated to bringing stories from the clinical world to the heart of policymaking. Her expertise spans delivery system reform, access, coverage and quality.

Dr. Patel was previously Director of Policy for the White House Office of Public Engagement and Intergovernmental Affairs and the Deputy Staff Director for the Senate HELP Committee, under the leadership of the late Senator Edward Kennedy.

Prior to Washington, Dr. Patel was a clinical instructor at UCLA and an Associate Scientist at the RAND Corporation. Dr. Patel completed a fellowship in the Robert Wood Johnson Clinical Scholars Program at UCLA and received her medical training at the University of Texas Health Science Center and Oregon Health and Sciences University where she served as Chief Resident in Internal Medicine.

## Chris Prestano

Chris Prestano is a 32 year old, native Washingtonian currently living in Utah. In 2008, when a large mass was discovered on her thyroid, physicians repeatedly told her not to worry because she was too young to have cancer. Yet, she convinced a reluctant surgeon to remove half her thyroid for her own peace of mind. When the pathology came back as papillary follicular variant thyroid cancer, she immediately underwent a second surgery and radioactive iodine treatment. Her treatment was not successful and a year later, Chris found herself living with a cancer she was too young to have.



That day marked the point when Chris began to advocate for young adult cancer survivors. In the past five years, she has been interviewed by Cure Magazine and The Cancer Warrior radio program. As a member of the DC Cancer Consortium, she has appeared in three of their 2012 Public Service Announcements that aired on WJLA. As a writer, her name appears on columns for Dear Thyroid, Everyday Health and Lifescript on the new normal of living with cancer. She tours the country as a public speaker for ThyCa: Thyroid Cancer Survivors' Association, Inc. conferences and at the Oncology Nursing Society.

Chris' experience as a co-leader and leader of Stupid Cancer's Washington, DC and Baltimore chapters led her to start up the only thyroid cancer support group in the state of Utah, where she is also a member of UCAN: Utah Cancer Action Network, a CDC funded program dedicated to reduce cancer incidence and mortality through educating on prevention, early detection, treatment, and enhancing quality of life.

Chris continues to advocate that there is no good cancer through social media, including her own website: [cancergirl730.com](http://cancergirl730.com)

**Ruth Rechis, PhD**

Director of Evaluation and Research  
The **LIVESTRONG** Foundation

During her eight year tenure, Dr. Rechis has worked to establish the office of Evaluation and Research and helped to design, implement, and evaluate numerous programs and resources for people affected by cancer. In her current role, Dr. Rechis and her team conduct intramural research, oversee extramural research projects, implement strategic yearly evaluation plans, and provide oversight to the **LIVESTRONG** Survivorship Center of Excellence Network. She is also the principal investigator on the **LIVESTRONG** Survey for People Affected by Cancer, a comprehensive survey assessing the experience of cancer survivors after treatment ends, and has published both reports on behalf of the Foundation and been published in peer-reviewed journals, such as the *Journal of Oncology Practice* and *Nature Reviews Clinical Oncology*. As an adolescent cancer survivor, she has a personal connection to the mission of the foundation. Dr. Rechis earned her doctorate in Educational Psychology from the University of Texas at Austin.





## **Ashley Wilder Smith, PhD, MPH**

Behavioral Scientist  
Outcomes Research Branch  
Applied Research Program  
National Cancer Institute

Ashley Wilder Smith is a Behavioral Scientist and Program Director in the Outcomes Research Branch of the Applied Research Program, Division of Cancer Control and Population Sciences at the National Cancer Institute (NCI). Her work focuses on developing, advancing and promoting research related to improving our understanding of patient reported outcomes and care for cancer patients and families. In particular, Dr. Smith oversees an NIH grant portfolio related to: (1) identifying and addressing gaps in cancer care and outcomes among adolescent and young adult (AYA) cancer survivors, (2) evaluating and improving patient reported outcomes/health-related quality of life measurement, and (3) addressing health and lifestyle behaviors (physical activity, weight status, energy balance) in healthcare delivery settings. Dr. Smith is currently the lead Program Director on an NIH Funding Opportunity Announcement Request for Applications to support the creation of a research infrastructure to support the use and enhancement of four NIH measurement information systems. Dr. Smith is co-chair of NCI's AYA Oncology Working Group, providing guidance and strategic planning to research activities focusing on this population, and is co-lead of the Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) Study.



## **Benjamin Rubenstein**

Author

"Twice: How I Became a Cancer-Slaying Super Man Before I Turned 21," "Secrets of the Cancer-Slaying Super Man (Q4 2013)," "cancerslayerblog"

Diagnosed with Ewing's sarcoma—aggressive bone cancer—when he was 16, Benjamin Rubenstein combated the disease in a unique way: by creating the delusion that he was superhuman. Instead of seeking support groups, he turned to humor; instead of fearing death, he gained a perspective on life. Just over a year after surviving Ewing's, Rubenstein was diagnosed with myelodysplasia—or, pre-leukemia—which was caused by the chemo that treated his

Ewing's. With his invisible superhero cape, Rubenstein survived two different cancers before turning 21.

Rubenstein's cancer memoir, "Twice: How I Became a Cancer-Slaying Super Man Before I Turned 21," was published in October 2010. Its upcoming children's version "Secrets of the Cancer-Slaying Super Man" is scheduled to release in late 2013. Rubenstein is also the author of *cancerslayerblog* and frequently contributes to *The Huffington Post*.

Rubenstein enjoys sharing his story about survival, positive attitude, setting and reaching goals, and healthy survivorship. His audience has included high school and college students, young patients and survivors, and health organizations.

**Eric Tai, MD, MS**

Medical Officer  
Comprehensive Cancer Control Branch  
Division of Cancer Prevention and Control  
National Center for Chronic Disease Prevention and  
Health Promotion  
Office of Noncommunicable Diseases, Injury and  
Environmental Health  
Centers for Disease Control and Prevention

Eric Tai is a Lieutenant Commander in the Commissioned Corps of the United States Public Health Service. He is a medical officer in the Comprehensive Cancer Control (CCC) Branch in CDC's Division of Cancer Prevention and Control. The National CCC Program funds states, tribes/tribal

organizations, and territories to establish coalitions, assess the burden of cancer, determine priorities, and develop and implement CCC programs.

His work focuses on children, adolescents, and young adults with cancer, evaluating quality of cancer care and improving infection control among cancer patients. Dr. Tai completed postgraduate training in Pediatrics and Preventive Medicine at the University of Maryland and the Epidemic Intelligence Service fellowship at CDC.



## **Robin Yabroff, PhD, MBA**

Epidemiologist  
Health Services and Economics Branch  
Division of Cancer Control and Population Sciences  
National Cancer Institute

K. Robin Yabroff, PhD, MBA, is an Epidemiologist in the Health Services and Economics Branch of the National Cancer Institute. She received her doctorate in epidemiology from The Johns Hopkins University School of Hygiene and Public Health. She also received an MBA in finance from the University of Rochester. Before joining NCI in 2002, she was a Research Assistant Professor in the Lombardi Cancer

Center at Georgetown University.

Dr. Yabroff's research is related to developing methods to estimate the economic burden of cancer and understanding the determinants of population trends, care, and disparities in the receipt of cancer screening, follow-up services, and cancer treatment. She is author or co-author of over 80 peer-reviewed journal articles on clinical epidemiology and health services research related to cancer. She serves as a reviewer for numerous clinical, health services research, and epidemiology journals, and is currently an associate editor for the *Journal of the National Cancer Institute* and on the editorial board of the *Journal of Cancer Survivorship*. She was a guest editor for a recent *Medical Care* journal supplement, Health Care Costing: Data, Methods, Future Directions and an upcoming *Journal of the National Cancer Institute* supplement, Comparing Cancer Care and Economic Outcomes across Health Systems: Challenges and Opportunities. Dr. Yabroff has received several NIH Merit Awards, including one for Economic Studies Related to Cancer Burden and Control and another for The Development and Dissemination of Innovative Statistical and Economic Methods Resulting in the Ability to Estimate the National Burden of Cancer. Dr. Yabroff is currently leading a collaborative effort to improve publicly available data for estimating the burden of cancer in the U.S., the Medical Expenditure Panel Survey (MEPS): Experiences with Cancer Survivorship Supplement.



## **Brad Zebrack, PhD, MSW, MPH**

Associate Professor,  
University of Michigan School of Social Work  
Member, University of Michigan Comprehensive  
Cancer Center, Division of Cancer Prevention and  
Control

Dr. Brad Zebrack is Associate Professor, University of Michigan School of Social Work, and a member of the University of Michigan Comprehensive Cancer Center, Socio-Behavioral Program. His teaching and research interests are in the area of health, medicine and quality of life. He is particularly interested in the effects of cancer on the psychosocial growth and development of adolescents and young adults, and his research has been funded over the past 15 years by the National Cancer Institute, American Cancer Society, Lymphoma Research Foundation, Lance Armstrong Foundation, Blue Cross/Blue Shield Foundation of Michigan, and HopeLab, Inc. Dr. Zebrack has clinical social work experience in both pediatric and adult oncology, and has been involved in the development of peer support/advocacy

programs for adolescent and young adult cancer survivors.

Dr. Zebrack is a medical advisory board member for First Descents, Imerman's Angels, and the Children's National Brain Tumor Foundation, all national organizations dedicated to providing support and information to adolescent and young adult cancer survivors. Dr. Zebrack currently chairs the Social Workers in Oncology Research Group for the Association of Oncology Social Workers (AOSW) and serves on the board of directors. He also has served on the boards of directors for the American Psychosocial Oncology Society (APOS), the National Coalition for Cancer Survivorship (NCCS), and the Candlelighters Childhood Cancer Foundation. Dr. Zebrack also was one of the first patient advocates to serve on the National Cancer Institute Director's Consumer Liaison Group (DCLG).

Dr. Zebrack is a 27-year survivor of Hodgkin's disease, diagnosed in 1985 at the age of 25. In 1989, Dr. Zebrack and his wife Joanne completed a one-year 11,000 mile bicycle trip around the United States to promote cancer survivorship. Brad and Joanne live in Ann Arbor, Michigan with their 10-year old daughter Sierra Grace, cat Cal, and guinea pig Poppy.