Anne Willis
MA, Director of Survivorship Programs for the National Coalition for Cancer Survivorship

Anne Willis, a 14-year Ewing’s Sarcoma survivor, Anne oversees the organization’s education resources, including the award-winning Cancer Survival Toolbox®. Her focus is on developing programs and resources to empower survivors to be more involved in the decision-making process throughout the cancer experience, from diagnosis through end of life. Previous to her NCCS position she worked in the National Cancer Institute’s Office of Advocacy Relations and planned, promoted, and executed the Institute’s first-ever summit for the patient advocate community. In 2005, Anne received her MA in communication from Auburn University after graduating summa cum laude with a bachelor’s degree in radio/tv/film from the University of Texas.

Amy Sales, MSW, LCSW-C
Clinical social worker for over 20 years in Oncology at Johns Hopkins Hospital

I have devoted much of my career to teaching caregivers and professionals about adjustment, survivorship, loss and grief. As I lecture and teach, I am struck by the common threads for which caregivers speak: feeling lost, alone, isolated in worry, unable to plan for what is unknown. In response to these repeated themes, I took the time to put them to paper and wrote Walking on Eggshells (available at Amazon.com). The response from caregivers has been overwhelmingly positive: “Wonderful, it made me feel like I was normal, like we could beat this. I felt like I wasn’t in a black hole anymore. I didn’t feel like I was crazy anymore” — Tina Steffey, caregiver.” Walking on Eggshells has received endorsements from Benjamin Carson, Sr., MD, neurosurgeon at Johns Hopkins Hospital and author of Gifted Hands, Laurie Singer, award winning network television news producer, and countless others. You can view portions of the book by going to www.youtube.com/johnshopkinskimmel where you will find a 10 part video series titled Walking on Eggshells.

Education Bachelor of Science in Psychology, Graduated 1987, Frostburg State University Masters in Social Work, Graduated 1990, School of Social Work, Clinical Tract

Achievements
Through the years I have advanced in rank and am now at a supervisory level at John’s Hopkins Hospital. My primary achievement has been gaining the trust and respect of the Oncologist that I work side by side with each day. A patient’s care plan and end-of-life needs are more often than not, driven by my clinical expertise and ability to advocate.
Description of the Book

Walking on Eggshells is a practical guide for caregivers and families who are assisting a loved one through the journey of a life threatening disease. Common themes that occur for caregivers and their loved one are provided, along with helpful and therapeutic ways to cope with them. Addressed throughout are topics such as loss of control, life after diagnosis, preparing for medical appointments, financial issues, receiving and giving bad news, hope, grief and loss, accepting help and seeking support, and preparing for end of life. Sensitivity, humor, and wisdom are woven throughout the chapters. Most importantly, the goal of the book is to allow the reader to know that despite the emotional pain that they are experiencing, which is unique to their situation, they are not alone. The moment that someone is diagnosed with a terminal illness their world often shatters around them, and knowing when and how to say things can become scary, i.e. Walking on Eggshells. It is my hope that this book provides insight and examples that are useful to making their journey a bit easier.

Drucilla Brethwaite
MSW, LCSW, OSW-C, Oncology Counselor

Drucilla is an oncology certified and licensed clinical social worker at Life with Cancer, a community supported organization, whose mission is to enhance the quality of life of individuals and families facing cancer by providing information, education and support. Her work at Life with Cancer includes individual and family counseling to promote adjustment to illness and improved quality of life and group facilitation with an interest in caregivers, couples, stem cell transplant, leukemia, end of life and bereavement. She has also helped to create psychoeducational programming on Exploring Mind-Body Techniques, Couples Facing Cancer as a Team and Creating a Legacy. Drucilla sits on the program review and research committees and was a co-author on recently submitted articles looking at inpatient distress and caregiver bereavement. Drucilla is an adjunct faculty member at George Mason University, teaching in the Social Work Department and a field instructor for graduate students from local universities. She earned a master’s in social work from Virginia Commonwealth University and is a member of the Honor Society of Phi Kappa Phi.

Laurel Gregory
Case Manager/Interim Director, LIVESTRONG Program, Patient Services
Patient Advocate Foundation

Laurel came to PAF in December 2006 as a Benefit Specialist in the Co-Pay Relief Program. Laurel has 20 years of experience in various healthcare settings which include, Medicare outpatient billing, hospital patient accounts follow-up, insurance coordinator, treatment plan coordinator; financial administrator, business manager and 15 years as office manager in a 2 doctor dental practice. While in this position, Laurel was honored by the Old Dominion Dental Society with the President’s Award for Outstanding Service, an honor that had only previously been awarded to dentists.
Laurel has worked as an adjunct instructor in the Workforce Training and Development Program at Thomas Nelson Community College; instructing adult students in Dental Office Procedures, Dental Coding and Billing and Dental Bookkeeping. Laurel was honored to be selected as a guest speaker for the commencement ceremony of the first graduating class from the program.

While working in the Co-Pay Relief Program at PAF, Laurel was given the opportunity to take on the Kidney silo as the solo benefit specialist. In the first full month assigned to this silo Laurel was successful in achieving 150% of the silo’s goal; an accomplishment that had not previously been met. The following month Laurel was recognized by the director of the program for record breaking numbers in the Sarcoma silo.

In June of 2008, Laurel was promoted to Case Manager in Patient Services and has served on the LAF team for the past two years. She currently serves as the Interim Director of the LAF, LIVESTRONG Program here at Patient Advocate Foundation and is an active member of the National African American Outreach Program.

Laurel has recently completed her undergraduate degree in Business Administration after a 30 year absence from higher education. She is currently pursuing her master’s degree in Human Services with a focus on Health and Wellness.

Reason to Hope – The Survivor’s Panel

Jacquie Britt: I retired in 2007 after 30 years in advertising. That was the year my clival chordoma metastasized to my heart, and I thought it may be time to drop the stress of a life in advertising! I was originally diagnosed in 1987, and thanks to a trial in highly-charged particle radiation at Lawrence Berkeley Lab, my tumor did not grow for the next four years. In those years, neurosurgeons had been working in skull-based surgery and had learned a lot. I’ve since had 8 craniotomies, open-heart surgery, and several corrective surgeries. Also four more rounds of radiation, including Cyberknife three times. I’ve had no recurrence since 2008. I have been blessed to be in front of the curve for 23 years. The next huge jump in fighting chordoma is being done here and now - with help from the Chordoma Foundation - in cell micro-biology and the search for the final cure. Thanks to each and every one of you for all you contribute to the fight.

Judy Carter: I am a 66 year-old mother of two with two grandsons. I love music, reading, gardening and my job as a financial aid director (until I retired on December 31). Now I hope to love retirement and spend more time with my family. My cervical chordoma was discovered 8 years ago in the same month as I was diagnosed with breast cancer, and was the third of four primary cancers diagnosed in less than two years. Given all of the surgeries and treatments for the other cancers, I opted for Proton Beam radiation as my only treatment for chordoma. So far, there has been little or no growth of the tumor. The physicians thought my MRI of about 2 1/2 years ago might have shown slight growth, but none of my recent tests have suggested any increase. Many thanks to my husband, Joe, who has been wonderfully helpful and supportive throughout.

Ed Lawson: I’m a sacral chordoma survivor, having become symptomatic in the Spring of 1990 and being diagnosed in October 1990. I’ve experienced extensive medical surgeries; radiation treatment and
numerous radiological tests used to manage and monitor my circumstances. I've been using something called Erlotinib since mid-2005 to control the growth of the existing tumor and amazingly, it has worked quite well. I say prayers daily due to my survivability and manage my future one day at a time. I'm quite sure my strong positive attitude and faith coupled with the faith and strength of my wife, family and friends has all contributed to my longevity and I'm grateful to say so.

Bill Monahan: I am a 46 year old married father of two daughters, one a recent college grad and one getting ready to enter college. I was diagnosed with a sacral chordoma in September of 1998 when I was a 34 year old sergeant in the NYPD. At the time, a surgical biopsy was done and I believe this was a good thing instead of a needle biopsy, making an incision wide enough as to not leave any of the tumor behind as might happen with a needle and on 12/1/98 I had a sacral resection from S2 down which forced an early retirement from NYPD. I had no further treatment such as radiation or chemotherapy. Since then, I have once per year follow-ups and all MRI scans have been negative. While I gave up sports for the most part due to a weakened leg, I still am active with golf, hunting and traveling. I strive to survive every day for my wife and family!

Bill Victor: A tumor at L-4 was diagnosed in October of 2002 at age 53. L-4 was removed March 2003 and replaced with rods and a cage. Since then, I have had 8 surgeries to remove multiple tumors, two series of IMRT photon radiation treatments, two radiosurgeries, and drug therapy with Gleevec, Hydrea, Avastin, Torisel, and Doxil in various combinations with no effect. Heart issues (left ventricle failure) diagnosed in October 2008. Unending tests and scans have consumed countless hours. My wife and children (one in college and two in high school) have enabled me to survive this chaotic existence with some semblance of sanity. The Chordoma Foundation did not exist when I was diagnosed. The Foundation has provided a point of focus for patient support, medical treatment and scientific research that benefits us all. Thank you to the Foundation for these doctor's and community conferences which have changed our outlook for the future.

Erin M. Dunbar, MD
Co-Director of the Preston A. Wells, Jr., Center for Brain Tumor Therapy and Neuro-Oncology Program

Special Interests:
Novel Therapeutic and Supportive-care Clinical Trials
http://www.neurosurgery.ufl.edu/research/clinical-trials.shtml
Patient and Caregiver Advocacy
Comprehensive Brain & Spine Tumor Care for Floridians
http://www.neurosurgery.ufl.edu/research/preston-wells-center.shtml
Medical Education

Erin M. Dunbar, MD completed medical school, Internal Medicine Residency, and Medical Oncology Fellowship at the University of Florida, in Gainesville. She completed a dedicated Neuro-Oncology Fellowship at Johns Hopkins University in Baltimore, Maryland. Service, professional, and academic awards kindly bestowed upon her during her training include election into the Phi Beta Kappa and Alpha Omega Alpha academic honors societies.

In July 2007, she joined the faculty in the Department of Neurosurgery, as Assistant Professor, and is
honored to serve as Co-Director of the Preston A. Wells, Jr., Center for Brain Tumor Therapy and Neuro-Oncology Program, where she directs the Neuro-Oncology clinical-research, administers the medical Neuro-Oncology service, facilitates the multi-disciplinary tumor board, and leads a variety of interdisciplinary neuro-oncology training initiatives.

Dr. Dunbar is an active member the academic societies involved in the care of primary and metastatic brain and spinal tumors, including the Society of Neuro-Oncology, American Society of Clinical Oncologists, the American Academy of Neurology, and the American Association of Neurological Surgeons. She is involved in numerous translational and clinical research initiatives at both UF and in collaborations with other institutions, consortia, and industry. She is a member of the state legislature-mandated Florida Center for Brain Tumor Research.

Dr. Dunbar is committed to providing patients with the highest level of comprehensive and compassionate care. Accordingly, she spearheads educational and support services as well as clinical trials in the areas of novel treatments, symptom management, quality of life, educational, and outcome measurements. This commitment has also led to her positions in Government Relations Committee for the American Society of Clinical Oncology and as Legislative Chairwoman and Executive Board Member for the Florida Society of Clinic Oncology (http://www.flasco.org/Flasco_Website/Home/), organizations dedicated to advocacy of cancer patients and the clinicians who serve them.

Micheline Toussaint, LCSW, RYT
Oncology Counselor at Life with Cancer

A social worker for over 20 years, Micheline developed an interest in complementary mind-body approaches to healing while growing up in Asia. In addition to being a licensed clinical social worker, she is a registered Yoga teacher and a certified End-of-Life Counselor. At Life with Cancer she provides individual, couples and family counseling for cancer patients and their loved ones. She helped develop a 6-week Mind-Body education series, leads yoga and meditation classes for patients and caregivers, facilitates support groups, and speaks to community groups about issues related to cancer. Micheline has a particular interest in using mind-body practices to strengthen resiliency in cancer patients and their caregivers.