Life with Cancer at Inova Schar Cancer Institute
Life with Cancer is the psychosocial and educational arm of the Inova Schar Cancer Institute within the Inova Health System in northern Virginia. For nearly 30 years, Life with Cancer has transformed community cancer care by turning evidence-based research into unique and innovative services. Conceived from one man’s vision, Life with Cancer has become a leading cancer care education and support program in the metropolitan Washington, D.C., area. (For more about the birth of this program, see “The Power of a Single Seed,” page 53. Every day, our team works together to improve the psychological and physical health of people affected by cancer. We also continually explore ways to expand our services through programs on information, education, healthy living, yoga and exercise, stress management, and support groups, as well as programs for our special populations—children and adolescents, young adults, and Spanish-speaking families.

The Dewberry Life with Cancer Family Center, also known as “Carolyn’s House,” is a 17,000-square-foot home-like setting in the heart of Fairfax, Va. Opened in 2009, it serves as the hub for Life with Cancer services. The main campus of the Inova Schar Cancer Institute is nearby, which makes the Life with Cancer Family Center convenient to access for patients and families.

The Family Center was created with the inspiration (and perspiration) of many caring individuals in the community, including Milt and Carolyn Peterson and Sid Dewberry. Designed to have a residential look, the Family Center provides a serene and healing environment where people gather to receive support services, attend programs and classes, and address needs and concerns with highly skilled clinical staff.

Of note is the Great Room, which can accommodate up to 100 participants; a beautiful library; and the children and adolescent areas with both play and art therapy rooms. The lower
level garden room looks out on a healing garden with a stone pond. This area offers space for a variety of exercise classes, as well as yoga, Reiki, and relaxation.

**Competence, Creativity, Community: Keys to Success**

Life with Cancer includes a multidisciplinary team of more than 40 staff, including a psychiatrist/psycho-oncologist, oncology nurse navigators, licensed clinical social workers, licensed professional counselors, licensed art therapists, fitness instructors, and administrative staff. Oncology therapists and oncology nurse navigators possess diverse skill sets and specialized training that enables them to meet patients’ needs throughout the care spectrum—time of diagnosis, active treatment, advanced disease, survivorship, end-of-life experiences, and bereavement. These staff members can provide guidance and intervention strategies, including cognitive behavioral therapy, art therapy, mindfulness training, trauma care, techniques and resources to promote sexual health, and strategies to manage insomnia and cognitive impairment.

Oncology nurse navigators and oncology therapists work together and cofacilitate networking and support groups, as well as collaborate on psychoeducational programming on topics like sexual health and treatment side effects. According to Drucilla Brethwaite, MSW, LCSW, OSW-C, Director for Life with Cancer, this co-facilitator model ensures both educational and psychosocial needs are met. “When a patient is distressed in a group, it may stem from a lack of medical information or a psychosocial issue. Having an oncology nurse navigator and oncology therapist in our groups can help to quickly identify what’s causing the emotional distress and provide appropriate information and/or intervention strategies to help better manage the situation.”

Life with Cancer programs are research informed, and we collaborate with the Inova Schar Cancer Institute research team to keep our practices current. We offer an adolescent and children’s program, disease-specific support groups, and groups for caregivers and young adults. We also provide general wellness classes, such as exercise therapy, and integrative approaches, including mindfulness training, meditation, Healing Touch, and yoga. Currently,
we offer more than 200 classes for adults, young adults, adolescents, and children each month.

From its earliest days, Life with Cancer staff built an innovative foundation of collaboration with the Inova Health System, community leaders, the public school system, area organizations, and healthcare providers that continues to support our work today. Life with Cancer programming is provided at the Family Center, as well as at Inova’s five area hospitals alongside a pediatric oncology center, three infusion centers, and five radiation oncology departments. However, cancer patients and their families can use Life with Cancer services regardless of where patients receive treatment. All programs, services, and classes are free of charge, except for massage and psychiatry services.

**Leadership Buy-In**

Another key to Life with Cancer’s continued success is the enthusiastic support from Inova leadership, led by J. Knox Singleton, CEO, Inova Health System, and Donald “Skip” Trump, MD, CEO, and executive director, Inova Schar Cancer Institute. “Every cancer program provides some form of psychosocial support, and most recognize how important these services are,” says Dr. Trump. “What is unique in my experience about Life with Cancer is its start as a philanthropic project; its growth into a comprehensive, self-directed program; and its relationship to Inova. Life with Cancer’s leadership recognizes the importance of community links. It reaches beyond philanthropy to advocate for and improve understanding and support for cancer patients and families in the community.” With cancer as the leading cause of death in Northern Virginia—according to the Northern Virginia Health Foundation—this role is more important now than ever before.

**Programmatic Benefits**

Our Life with Cancer program has been instrumental in helping the Inova Schar Cancer Institute meet Commission on Cancer (CoC) standards for distress screening and community outreach and education. For example, Life with Cancer staff collaborate with staff at Inova Schar Cancer Institute to complete and deliver survivorship care plans. Data gained from distress screenings and problem checklists have helped support the value of psychosocial support for patients and drive future programming needs. Meeting CoC standards improves clinical practice, patient care, and patient outcomes. Distress screening enables staff to quickly identify
With more than 200 classes a month, Life with Cancer includes options for adults, young adults, adolescents, and children. Clockwise from top left: Restorative yoga for children, adult exercise, educational class and the sand tray for child therapy.

patients who will benefit from various Life with Cancer programs and decreases patient and family distress, which can improve quality of life, increase adherence to treatment, and decrease physical and psychological symptoms.

Life with Cancer also supports Inova oncology staff with in-services, processing groups designed to enhance quality care and decrease compassion fatigue, and assistance with system-wide initiatives. A Life with Cancer staff member is trained as a Schwartz Rounds facilitator, a national program to promote compassionate healthcare between patients and healthcare providers. With the collaboration of Inova leadership, Life with Cancer programs make a significant difference in the lives of patients, families, and Inova’s oncology staff.

Expanding and Sustaining an Integrated Team

Life with Cancer’s success derives from providing evidence-based, integrated, coordinated psychosocial support. “Cancer care support can be disconnected and uncoordinated in some communities,” says Thomas Graves, vice president for Cancer Services and associate director for Administration, Inova Schar Cancer Institute. “For example, athletic clubs without a cancer identity may offer an exercise support program for cancer patients. Family support services may be offered somewhere else. Here, we have a central facility, the Family Center, which is outside the stressful environment called ‘healthcare’ that is so familiar to cancer patients and their families.”

The Executive Director of Life with Cancer is part of the Inova Schar Cancer Institute leadership team and meets with Cancer Institute administrators weekly. “We look to Life with Cancer leadership to learn what our patients are experiencing as they go through our healthcare system,” says Graves.

Life with Cancer oncology nurse navigators and therapists in each of our five community hospitals have broadened our point of contact with cancer patients in the Washington, D.C., region. Nurse navigators educate patients about their diagnosis and treatment plans and answer questions. Together with psychiatrist Sermstak Lolak, MD, navigators triage cancer patients and families, identify those who may benefit from Life with Cancer support, and explain the program and services available. Dr. Lolak was hired by Life with Cancer and the Inova Schar Cancer Institute
Life with Cancer Fundraising Activities—Something for Everyone

• Joan Hisaoka Annual “Make a Difference Gala.” 2017 marked the 10th anniversary of the “Make a Difference Gala,” in memory of Joan Hisaoka, to assist those living with cancer. Last year’s event raised $919,000; Life with Cancer was the primary beneficiary of the event.

• Annual Lobster Extravaganza. More than 1,000 community members eat lobster and steak during this casual event, which has been a community favorite for 19 years. Members of the Fairfax Fraternal Order of Police set up tables and chairs, and Life with Cancer volunteers work as wait staff with Foster’s of Maine to serve food. A silent and live auction, as well as live music, is part of the festivities.

• The Annual Clifton Lions Labor Day Car Show. Life with Cancer is a beneficiary of the Annual Clifton Virginia Lions this event, which last year raised $141,968 for Life with Cancer programs.

• Fairfax Fraternal Order of Police. Cancer is personal. Several years ago, five members of one precinct in the Fairfax Fraternal Order of Police developed cancer in a short period. Three died. Life with Cancer supported the precinct during its cancer struggles. Dr. Trump spoke at a precinct meeting and arranged for special cancer education presentations by Inova Schar Cancer Institute experts. The Fairfax Fraternal Order of Police made a $500 donation in recognition of this support at the time and continues its support every year. In addition to volunteering for the annual Lobster Extravaganza (see above), they collect bicycles and boxes of toys for children at the Family Center. In 2016, the Fairfax Fraternal Order of Police presented Life with Cancer with a $20,000 donation.

• We Will Survive Cancer. Members of We Will Survive Cancer raise money throughout the year to bring holiday cheer to families not able to participate in holiday gift-giving. In 2016, this group fulfilled holiday wish lists for nearly 20 families.

• Virginia Run Turkey Trot. Life with Cancer is now the exclusive beneficiary of an annual Turkey Trot 5K held in Centreville, Va. Community members started a small race locally; Life with Cancer did not benefit from the first few races, but eventually, more community members and major sponsors got on board. Now, in its 29th year, the race attracts approximately 4,000 participants. At one point, it was one of the top five largest races of its kind. Over the past 25 years, the race raised $1.3 million; the 2016 race’s net was $80,000.

• Community-Based Restaurants. Restaurants and other commercial establishments hold Life with Cancer fundraisers regularly that support our programs. “It’s important to work at finding the right philanthropic relationships in your community. These are committed relationships that will continue to donate, support, and help you organize your philanthropic programs. These donors are the ones who recognize that their contributions make lives better,” says Amy Richards, Leadership Giving Director for Life with Cancer.

Always Evolving, Always Responsive
Life with Cancer has been nominated as “Best Practice” by the CoC and the National Accreditation Program for Breast Centers for its diverse programming. Our range of services fulfills some of the 2016 recommendations by the American Society of Clinical Oncology related to providing distress screening, psychosocial support, community resources, and nurse navigation. We are continually mindful of program size and the benefits and risks of larger versus smaller groups and programs. Some of our programs are intentionally limited to fewer than 15 patients to encourage greater connectivity and a more therapeutic space. We also support educational presentations and symposia that are designed to reach larger audiences. Life with Cancer programs include the following:

• Disease-specific support groups.
• Counseling for adults, children, and teens with cancer; children and teens with a loved one with cancer; couples and families.
• Supportive events for children and teens with cancer and for children and teens with a loved one with cancer.
• Classes on how to interpret laboratory tests and other diagnostic procedures; presurgical classes for breast cancer patients;

(continued on page 53)
Inova Health System

Inova is the Washington, D.C., region’s leading not-for-profit healthcare system and serves more than 2 million people annually. The Inova Schar Cancer Institute provides expert cancer care at all Inova facilities, including the following:

- Inova Alexandria Hospital
- Inova Fair Oaks Medical Campus
- Inova Fairfax Medical Campus
- Inova Loudoun Hospital
- Inova Mount Vernon Hospital

Opening in June 2018, the Inova Schar Cancer Institute’s new building will provide patient-centered care, expertise from national and internationally recognized cancer specialists, and translational research and clinical trials to patients at one central location. The collaborative approach to cancer care will provide seamless, coordinated treatment—translating to better outcomes.

Life with Cancer oncology nurse navigators and therapists in each of Inova’s five community hospitals help reach cancer patients in the Washington, D.C., region.
chemotherapy education; communication strategies for individuals and couples facing cancer, including sexual health and intimacy-related issues; insomnia and fatigue management; how to improve physical activity; and strategies for managing treatment-associated complications such as peripheral neuropathy and chronic pain, cognitive impairment, fatigue, body image concerns, depression, distress, and anxiety.

- Fitness and nutrition classes, including healthy cooking programs.
- Mind-body integrative-focused classes, such as Mind over Matter, Compassion Cultivation Training, Mindfulness-Based Cancer Recovery, meditation, yoga, Reiki, qi gong, tai chi, guided imagery, spirituality, and Healing Touch.
- Life with Cancer Connect, a triage line created as a critical touch point for patients and families looking for support. This central point of contact has streamlined access and care. 703-206-LIFE (5433).
- “Walking the Labyrinth,” an ancient meditation and mindfulness practice to promote healing and reduce stress. Our portable, indoor canvas labyrinth allows us to offer this ritual on a regular basis.
- Compassionate cultivation training is a unique curriculum implemented by Dr. Lolak that combines traditional contemplative practices, such as mindfulness-based stress reduction, with contemporary psychology and scientific research. This eight-week course helps participants develop compassion, empathy, and kindness for oneself and for others.
- Expressive therapeutic arts: art therapy, therapeutic dance, music, and journal therapy.
- Survivorship education and survivorship care planning.
- End-of-life and bereavement programs.
- Community outreach and engagement for underserved populations, including bilingual services and collaboration with community free health and mental health clinics.

Child, Adolescent, and Family Services
The child and adolescent program is a cornerstone of Life with Cancer and has been an integral part of programming from the start. Coping with a cancer diagnosis and treatment can be especially difficult for children and adolescents, whether they are coping with their own diagnosis or confronting a cancer diagnosis for someone they love. Life with Cancer’s experienced oncology therapists provide support to children, teens, and their families from diagnosis, during active treatment, and through survivorship or end of life and bereavement. Through counseling, art therapy, play therapy, and sand tray therapy, as well as education and discussion, our oncology therapists assist children and teens in gaining a deeper understanding of themselves and how cancer is affecting their lives. Relaxation techniques and other therapeutic interventions are integrated into the support provided to help children and teens manage anxiety and stress. Counseling support is also available to parents and caregivers who are navigating both the impact cancer is having on their family and on themselves.

“Life with Cancer provides a safe space for children, teens, and their families to express how they are feeling when a loved one is diagnosed with cancer or they are navigating grief,” says Jean McCaw, MA, ATR-BC, LCPAT, children and adolescent program coordinator. “Children will often share what they don’t talk about with anyone else. Our child and adolescent programs are designed to facilitate expression of feelings, provide a sense of release and relief, and decrease anxiety and general distress. These modalities lead to improved communication between a parent and child, as well as within the family system.”

Therapeutic support for children, teens, and parents addresses a range of psychological, emotional, spiritual, and social challenges that can result from illness, treatment, and hospital admissions. This support is available in outpatient clinics (including the long-
term survivorship clinic), where treatment is most often provided, and during inpatient hospital stays. Additional outpatient support for children, teens, parents, and other family members is available throughout the care continuum at the Life with Cancer Family Center.

The oncology therapists at Life with Cancer who work with children, teens, and their parents also create specialized programs for families with a child or teen in treatment and for families with an adult family member in treatment. These programs also include supporting families in survivorship or in their bereavement. Direct support for children is provided through the Curious About Cancer Support Group and Touchstone Grief Support Group. The Parenting Alone Grief Support group is for parents who have lost a spouse or partner and are raising children or teens alone.

Programs for children and adolescents in treatment and their families include a monthly parent oncology meeting, which provides opportunities for connection for both children and parents who share similar experiences and feelings. These meetings provide education and at times are more social and fun, focused on relaxation, rejuvenation, and connection. Programs include the following:
• Mother–Daughter Spa Night
• Father–Son Activity Night
• Specially crafted Halloween and holiday parties
• Kid & Sib Day for children in treatment and their siblings
• Surviving Cancer Competently Intervention Program, focused on teaching parents coping skills to better manage their child’s or teen’s cancer journey.

Of note, Life with Cancer’s “I’m Cured, Now What?” conference for teens and young adult survivors of childhood cancers has provided more than $100,000 in college scholarships in 10 years.

Additional resources are available to parents and families through our website, including a resource called “Touching Grief: Frequently Asked Questions About Child and Adolescent Grief” for parents who are navigating the terminal illness or death of a loved one and supporting their child or teen through that process.

Life with Cancer partners with and connects families to a variety of supportive community foundations for practical supportive needs. Our services are also extended through a partnership with Fairfax County Public schools that makes Life with Cancer resources available to social workers, counselors, and teachers to provide additional support for children in treatment and those who have a family member with cancer. Among the support services we offer are cofacilitating grief support groups, providing information and support by phone, and meeting with school personnel to help plan ways to best support students who are impacted by cancer. This partnership provides a clear path for the school personnel to refer families to Life with Cancer for support.

**Exercise is Everything**

Many staff contribute to growing our innovative, evidence-based programming. In 2004, Susan Gilmore, MS, ACSM-CET, joined Life with Cancer to help meet the specialized exercise needs of patients. Susan, an American College of Sports Medicine-certified Cancer Exercise Trainer, developed classes with adapted movements to address balance issues, chemotherapy-related fatigue, weakness, muscle atrophy, and neuropathy-associated numbness and pain, among other conditions. She created patient assessment instruments and offers various levels of exercise to meet the changing physical capacities of patients. Susan also assesses and guides instructors on how to create and adapt classes such as Cross-Train Challenge, Functional Circuit Training, Barre Tone, and Barre-Pilates-Fuze for cancer patients and survivors and oversees our physical activity classes, including yoga (gentle, restorative, and Yin), tai chi, belly dancing, and Zumba. Research on the health benefits of exercise for those with cancer is well established, and our exercise program meets this critical need.

**Mind-Body Connection**

Through education and evidence-based practices, Life with Cancer helps patients and families disrupt the negative cycle of anxiety and uncertainty associated with a cancer diagnosis. Clinical interventions, such as the 5-week Mind over Matter series and the 6-week Mindfulness-Based Cancer Recovery program, use traditional cognitive behavioral strategies. Mindfulness-based stress reduction practices help participants learn how to manage anxious thoughts and reach a more relaxed, calm state. Group members engage in practices that promote a greater understanding of the mind–body connection and are guided through exercises that empower them to use their bodies and minds to induce the relaxation response and achieve equanimity and an overall sense of well-being.

Research consistently supports that mindfulness-based practices can significantly improve psychological and physical functioning in cancer patients by lowering depression and anxiety and reducing symptomatology such as fatigue, pain, and insomnia. These practices also enhance positive biological outcomes, including lowering levels of stress hormones and inflammatory markers, thereby improving immune function. Controlling stress and anxiety permits participants to become actively involved in their own healing and recovery, thus facilitating a sense of mastery and promoting healthier functioning.

**Planning Ahead—Help with Tough Conversations**

This series on death and dying covers information about how the body dies, how to create and leave a legacy, estate and funeral planning, and writing wills. It prepares patients and families for many end-of-life considerations. The emotional benefits of discussing death are now well established by research and better accepted by most patients.
Research Contributions

Life with Cancer staff have been involved in research studies in such areas as distress screening, effectiveness of mind–body techniques, sexual health, insomnia, and understanding grief. Currently, Inova and Life with Cancer, in collaboration with The James at Ohio State University, are engaged in a biobehavioral study based upon the work of Barbara Andersen, PhD, around biobehavioral interventions that decrease psychological symptoms and improve health to reduce the burden of cancer in patients, their families, and the healthcare system. In addition, many staff members have written articles on a variety of psychosocial issues in oncology. Going forward, Life with Cancer intends to substantially expand its research capabilities.

Philanthropy: Fundraising Traditions Set Cornerstones for Success

Seventy percent of Life with Cancer’s operating budget is supported through philanthropy, primarily from community contributions; 30 percent of the operating budget is supported by the Inova Health System. Longstanding community support enables Life with Cancer to offer and sustain free services. “Our fundraising model hasn’t changed drastically. We couldn’t exist without our strong community support and our dedicated volunteers,” explains Amy Richards, Leadership Giving Director for Life with Cancer. Though a handful of large Life with Cancer fundraisers are enormously successful from year to year, Amy emphasizes that all donations make a difference and are always 100 percent donor driven. “All funds, whether from galas, golf outings, or 5K runs, go directly to whichever program or general fund the donor wants to support within Life with Cancer,” says Richards. “Life with Cancer supports our neighbors and in turn our community supports us. We are grateful for all their support.” Turn to page 45 for a look at some of Life with Cancer’s many fundraising activities.

Volunteers: Place Them Where They Enjoy Working

“One outstanding characteristic of Life with Cancer’s volunteers is the remarkable expertise they contribute,” explains Catherine Intartaglia, community affairs and volunteer coordinator for Life with Cancer. Volunteers make our unique and numerous programming options possible. For example, 60 community Reiki masters, who receive training specific to cancer patients, volunteer their time to offer this healing, stress reduction, and relaxation technique to Life with Cancer patients and family members. Two sessions are held each month at the Family Center, and 30 patients now participate in monthly sessions at the Inova Fair Oaks Medical Campus. One patient, who had received Reiki at Life with Cancer, became a Reiki master and returned to Life with Cancer to volunteer. “Our patients really respond to this program,” says Intartaglia. Women recovering from breast cancer surgery reported having better range of motion and less pain. At the Inova Fairfax Medical Campus and Inova Loudon Hospital, nurse volunteers trained in Healing Touch offer this energy therapy to interested patients.

Intartaglia creates job descriptions with clear expectations for her volunteer pool and then hires and trains these individuals. Some of Life with Cancer’s 150 volunteers help with logistics for fitness programs, including setting up the room, checking in participants, managing paperwork and waivers, and assisting the instructors. Others provide the many hands that are needed for Life with Cancer’s fundraising events. One volunteer distributes the distress screening on the oncology inpatient unit at the Inova Fairfax Medical Campus, helping Life with Cancer staff identify patients who could benefit from psychosocial intervention or education. Catherine would like to train more volunteers to perform this task, which requires someone with objectivity and good boundaries. Help with community outreach for health fairs and other events for which less training is necessary is another opportunity for volunteers. “I pay attention to the reasons why people volunteer and what they find fulfilling, so we can keep them for a long time,” says Intartaglia.

Looking Ahead: More Programs, More Innovation

Moving forward, we are developing new programs to meet the educational and support needs of our population in a rapidly changing oncology care environment. We hope to attract more men to our psychosocial services, build a nutrition program, and develop additional innovative programs for teens. We plan to offer more intentionally structured, evidence-based programs—those with a defined beginning, middle, and end, which enables participants to learn information, practice skills, manage symptoms, and feel empowered to get back to engaging in life.

As the Inova Schar Cancer Institute grows, it will be important that directors, managers, or staff of psychosocial support programs continue to have a seat at every table. Participation and collaboration in committees and meetings, such as the ethics committees, tumor boards, cancer committees, patient experience meetings, development meetings, executive council meetings, and clinical operation meetings, are critical to assure the biopsychosocial–spiritual needs of patients remain at the forefront. Our observations, knowledge, and experience as clinicians are critical as we flesh out and define best practices for integrative oncology care, a key component in the personalized medicine approach that ensures the best outcomes for our patients.

Though it is daunting to consider creating a psychosocial services support program for cancer care, it is possible for most community cancer care centers. Salaries are a big part of the initial expenditure. With $250,000, two staff can get a program started. A philanthropic gift of approximately $1 million is needed for a larger program. You will need office space and equipment, a website, and marketing materials to promote services. Start small, with a few services offered once a month and a newsletter or announcement offering resources. And grow your base. “Having an engaged group of volunteers and board members is essential,” says Amy Richards, Leadership Giving Director for Life with Cancer.

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