Letter From the Director

The Nemours Center for Cancer and Blood Disorders (NCCBD) at Nemours/Alfred I. duPont Hospital for Children has a multifaceted mission that includes excellence in service delivery and patient/family satisfaction, participation in clinical and laboratory research, patient/public education and advocacy.

Through participation in the Children’s Oncology Group (COG) and other research consortia, Nemours is able to offer our patients the most up-to-date cancer treatment available. In 2014, the center received a $4.65 million award from the National Cancer Institute’s Community Oncology Research Program (NCORP), a project of the National Institutes of Health. This award makes Nemours only the second designated pediatric NCORP in the U.S. NCORP’s goals are to increase community engagement in the care of patients with cancer and to improve delivery of high quality care in the community setting, particularly for underserved populations.

Nemours research scientists are focused on increasing understanding of the molecular basis of cancer and finding new therapies, which will ultimately result in improved pediatric care and treatment. Most importantly, the NCCBD is dedicated to making the difficult experience of patients and their families as successful and comfortable as possible. In 2014, oncology and hematology patients moved into the newly expanded Alfred I. duPont Hospital for Children, where all children have private rooms with overnight sleeping accommodations for parents, storage and in-room dining. The new unit provides a healing environment and supports Nemours’ commitment to family-centered care.

The children Nemours cares for are heroes — and an inspiration to all of us.

E. ANDERS KOLB, MD
Director, Nemours Center for Cancer and Blood Disorders
Introduction

The Nemours Center for Cancer and Blood Disorders (NCCBD) at Alfred I. duPont Hospital for Children is the patient care site for the Division of Pediatric Hematology/Oncology. Collectively, the program is responsible for the diagnosis and management of children with cancer and disorders involving the blood. The NCCBD is involved in clinical, translational and laboratory research and carries out multiple missions related to education and advocacy while maintaining excellence in service delivery and patient satisfaction. The efforts of the hematology-oncology physicians are supported on an integral basis by an outstanding staff of clinical and advanced practice nurses, physician assistants, child life associates, psychosocial staff and research personnel. In addition, collaboration with other medical and surgical specialties helps support activities of the NCCBD to ensure that the program is among the very best in the nation.

The mission of the Nemours Center for Cancer and Blood Disorders is to improve outcomes and quality of life of children with cancer and blood disorders through individualized, expert and compassionate care and research. Central to this mission are:

- an expert multidisciplinary, family-centered approach to care with optimum psychosocial support
- continued innovation through clinical, translational and basic research
- educational programs for health care personnel, patients, family and the community
- effective, flexible and efficient stewards of resources
Hospital Expansion Marks a New Era of Care

- Nemours/Alfred I. duPont Hospital for Children is ranked by *U.S. News & World Report* as one of the best children’s hospitals in the nation in cancer, cardiology & heart surgery, diabetes & endocrinology, gastroenterology, neurology & neurosurgery, nephrology, orthopedics and pulmonology.

- To support our nationally ranked clinical care, our newly expanded facility, opened in 2014, has technologically advanced single patient rooms with sleeping accommodations and amenities for families. Team stations with eight beds maximize patient contact with staff and support family-centered care. After months of preparation, hematology/oncology moved patients to the new building in November 2014.

- A new 44-bed Emergency Department nearly doubled the treatment capacity to support the hospital as the state’s only Level I Pediatric Trauma Center.

- An expanded Pediatric Intensive Care Unit, including an eight-bed stepdown unit for patients requiring ventilators, has large private rooms to accommodate bedside technologies and space for families to stay with their child 24/7. A centralized rooftop helipad provides easy access to operating rooms, critical care units and the Emergency Department.

- Family-centered spaces outside the patient rooms, such as lounges, solariums, Child Life playrooms, pocket parks and other amenities contribute to comfort and healing for our patients and their families.

- A soaring atrium entrance provides easy access to all services and a welcome center for families and visitors.

- The 450,000-square-foot expansion was designed with the help of families and creates an environment that promotes healing while advancing quality of care.
Screening and Prevention Programs

Testicular Screening

In 2014, the NCCBD initiated a prevention program to screen for testicular cancer. The cancer prevention program is designed to meet the needs of our community and to reduce the incidence of a specific cancer.

Male patients with acute lymphoblastic leukemia (ALL) were screened in order to detect the presence of testicular cancer in the early stages. Our goal is to decrease the number of patients with late-stage disease.

Nemours implements screening and prevention programs consistent with evidence-based national guidelines and best practices.

- Total number of male patients with a documented baseline screening were compared to the total number of male patients with ALL
- 100 percent of target reached

Skin Cancer Awareness

According to the Children’s Oncology Group (COG) survivorship guidelines, very few people realize that the skin is the largest organ in the body. The skin is the body’s first line of defense against outside invaders. It also regulates body temperature and stores water, fat and vitamin D. Such an important organ requires care and monitoring. Treatments for childhood cancer sometimes cause damage to the skin. Survivors who received radiation as part of their therapy, or experienced graft versus host disease (GVHD) post transplant are at a greater risk of developing skin cancers. Many late effects can be found on the skin ager receiving cancer therapies.

Our program focused on reducing the risk of skin cancer among our patient population through education on the importance of using sunscreen. The Nemours Center for Cancer and Blood Disorders focused on new patients seen in survivorship clinic. All patients received skin cancer educational material during the initial visit to the survivorship clinic. This tool includes helpful tips for patients and families on the prevention of skin cancers.

In addition to materials, we also distributed more than 2,500 sunscreen packets at community events including:
- Brain Tumor Awareness Walk
- B+ Foundation 5K Run at Salesianum School
- Leukemia Research Foundation Delaware (LRFD) Junior Mud Run
- D.O. Believe 5K Event
- LRFD Mud Run
- Cure Search Walk
- Cure for Cam/Chester County Turkey Trot

The prevention program got underway early in 2014. Educational materials were not only given out at community events but also in our survivorship clinic. No patients seen in our survivorship clinic in 2014 had positive findings of skin cancer. Should the need arise, we would refer such patients to dermatology.

Our plan is to continue providing educational tools to all families visiting survivorship clinic in 2015. We will also continue to distribute sunscreen at local events to emphasize skin cancer prevention in our community.
Given our commitment to improving patient care we developed a quality improvement project focusing on compliance with medications. National guidelines and studies such as the MEMS Cap ACCL 1033 study demonstrated high rates of noncompliance among patients and caregivers taking oral chemotherapy at home.

The 2014 quality improvement project was developed to assess caregiver understanding of the oral chemotherapy administration instructions provided by the prescriber during an outpatient visit. The prescriber utilized a standard approach to teaching oral chemotherapy administration, including dose, method of administration, side effects and reportable toxicities.

The assessment of understanding was determined through follow-up phone calls with the caregiver made by a registered nurse knowledgeable in the patient’s treatment plan and the safe administration of oral chemotherapy.

Caregivers who were not able to verbalize the correct administration instructions were provided with corrective information and guidance by the registered nurse.

The data reflected an overall assessment call connect rate of 64 percent, meaning the call was answered and the registered nurse spoke with a caregiver 64 percent of the time. Of those who were contacted, the overall accuracy of caregiver understanding is 92 percent. This indicates that a majority of caregivers were able to accurately describe the oral chemotherapy administration instructions that were provided.

We will continue to monitor this quality improvement and strive to make sure all caregivers are able to accurately describe the oral chemotherapy instructions.
Clinical Trial Accruals

In 2014 there were 135 enrollments to clinical trials at Nemours/Alfred I. duPont Hospital for Children. These studies help to reduce cancer risks and mortality and to enhance quality of care and quality of life for our patients.

2014 Clinical Trial Accruals

Definitions of Clinical Trial Studies:

Cancer Control Study: The study of symptom management and preventive maintenance.

Biology Study: Studies the behavior of cancer cells and involves the collection of specimen (tissue/blood) samples.

Registry Study: The collection of data to study outcomes.

Treatment Study: Research studies to determine the safety and effectiveness of a treatment for a particular disease.

Other: Quality of life studies, transplant specific trials, survivorship trials, blood bank studies and any other studies that are being offered at Nemours/Alfred I. duPont Hospital for Children.

Multidisciplinary Cancer Conferences

Nemours/Alfred I. duPont Hospital for Children is dedicated to improving patient outcomes. We have a multidisciplinary team whose goal is to improve cancer outcomes and patient satisfaction. A team of oncologists, surgeons, radiation oncologists, pathologists, orthopedists, radiologists, genetic counselors, nurses, clinical research staff, quality managers and others meets weekly. The weekly meeting is categorized as a tumor board conference and is a certified continuing medical education activity for physicians and nurses.
### Programs and Services

| Dedicated outpatient hematology/oncology Infusion clinics |
| Dedicated inpatient hematology/oncology units |
| Blood and bone marrow transplantation program |
| Blood disorders, e.g., sickle cell anemia, hemophilia |
| Bleeding disorder program |
| Psychosocial and social work services |
| Pain management |
| Palliative care |
| Integrative care (healing touch, pediatric massage, music and art therapy) |
| Cancer survivorship |
| Long-term care |
| Transition of care program |
| Neuro-oncology program |
| Hereditary cancer predisposition program |
| Child Life |
| National Cancer Institute funded Research Program (NCORP) patient navigation |
| Cancer care coordinator |
Corinna L. Schultz, MD, joined Nemours/Alfred I. duPont Hospital for Children as a staff hematologist/oncologist in 2014. A graduate of Jefferson Medical College, Dr. Schultz completed pediatric residency training at Brown University, Hasbro Children’s Hospital and a pediatric hematology/oncology fellowship at the Children’s Hospital of Philadelphia. Additionally, she earned a Master of Science Degree in health policy research at the University of Pennsylvania. She is board-certified in pediatrics.

Dr. Schultz concentrates primarily on pediatric hematologic disorders. She sees patients at Alfred I. duPont Hospital for Children and at our partner facilities in Philadelphia and southern New Jersey.

In 2014, we welcomed Renee Gresh, DO, as hematology/oncology’s first fellow. Dr. Gresh is one of our own having served her pediatric residency and chief residency in the Thomas Jefferson University/duPont Hospital for Children program. She is a graduate of the New Jersey School of Osteopathic Medicine and is certified by the National Board of Osteopathic Medical Examiners.

Survivorship Program

Survivor. What a beautiful word. When a child or teen has completed treatment and made it to the other side, the journey is just beginning. Now that they are disease-free, it’s time to focus on overall health and wellness for the rest of their lives.

We want our “graduates” to stay well and in order to do that, they have to be aware of what their bodies have been through. At Nemours, once patients have been off treatment for one month, they come to see us and talk about life and health after cancer. We provide a treatment summary that captures their diagnosis, past medical history, radiation, chemotherapy and other treatments throughout the patient’s experience with us. We want to empower the patient and family as well as the patient’s primary care physician with information that is useful and important now and into adulthood.

Along with the summary, we explain the implications of treatment on the body. For example, patients who have had a certain class of chemotherapy drugs are at higher risk for heart problems. They need to be aware of the risk factor, to take care of their heart by eating well and exercising and by letting us know if they have symptoms such as palpitations. It’s not uncommon for kids and teens to ignore symptoms because they’re tired of doctors and hospitals and they want to be well! We understand. Our goal is to empower families with knowledge so that they can help their children take ownership of their health, recognize red flags and be their own best advocates.

Nemours Survivorship Clinic Profile

- Clinic involves approximately 250 patients per year.
- Clinic is led by advanced practice nurse with more than 25 years’ experience in pediatric oncology.
- Offers psychology support for survivors and family.
- Relevant educational information and books are distributed to patients and parents.

Nemours Survivorship Facebook Page

A closed Facebook page is available to all patients/parents treated at Nemours/duPont Hospital for Children who attend the survivorship clinic. The page offers a safe place to chat, pose questions to the nurse and physicians, and share medical/social information relevant to the group.

Survivorship Research

Two research studies got underway in 2014.

- A Daisy Grant was awarded to survivorship nurse practitioner Joanne Quillen to identify barriers among young adults transitioning to adult health care.
- A research study is underway in conjunction with the Children’s Hospital of Philadelphia’s survivorship program, the purpose of which is to assess knowledge of disease/potential late effects among survivors (16–21 years) and parents. Knowledge gained will help improve education going forward.
Continuing the Journey

The Wellness Road in Pediatric Cancer Survivorship workshop took place in May 2014. The goal of the program was for survivors to learn more about the importance of wellness and preventive care after treatment is finished. Topics included use of alternative therapies, physical therapy and caring for one’s emotional well-being. A panel of long-term survivors spoke at the conclusion of the program. The interactive day was calming and life-affirming as participants found hope in hearing from those who were healthy and well years after treatment.

Monthly Oncology Scrapbooking

An evening of scrapbooking acts as a therapeutic avenue for expression and healing among children with cancer and their families. The Department of Hematology/Oncology at duPont Hospital for Children holds the scrapbooking night on a monthly basis. Families receive all supplies and sessions free of charge thanks to the generosity of sponsoring partner Delaware Dreams, Inc.

Cosmetology Day of Beauty

We encourage patients and families to take time out from the rigors of dealing with illness to relax and rejuvenate. The Hodgson Vocational Technical High School provides beauty services for patients and families served by the Nemours Center for Cancer and Blood Disorders at duPont Hospital for Children. Cosmetology students get needed practice while our families receive haircuts, facials, massage, manicures and pedicures free of charge.
Community Outreach (continued)

Cure4Cam

In 2014, the Nemours Center for Cancer and Blood Disorders at duPont Hospital was the beneficiary of a $20,000 donation from the Cure4Cam Childhood Cancer Foundation. Cure4Cam was started by the family and friends of Cameron Evans of Downingtown, Pa., who lost his battle with cancer in 2012 at age 13. The foundation’s twofold mission is to raise awareness about pediatric cancer, its effects and current treatments, and to raise funds to support the development of new, less toxic therapies for children fighting these diseases. Cameron’s mother Regina Evans said, “We relive his story every day because, although we didn’t choose this cause to fight, we do choose every day to fight for this cause.”

When Cameron was diagnosed with acute lymphoblastic leukemia, his initial reaction was to worry about how everyone around him would take the news, including his family and his cross-country running teammates. Physically isolated during treatment, Cam stayed in touch by email, phone, text, Facebook and Facetime. Once he felt up to it, he started posting his journey on his website, never failing to include something inspiring about his challenges, his “hills” as he called them, using running as a metaphor.

When Cameron needed a bone marrow transplant and was matched with a donor, he encouraged everyone he knew to sign up for the bone marrow registry. His friends and classmates then came up with the idea of selling “Cure4Cam” bracelets, which touched him, knowing they wanted a tangible way to support him. Within months of Cameron’s passing, his family and friends formed the Cure4Cam Childhood Cancer Foundation to help give others a fighting chance.

Creative events such as the Chester County Turkey Trot at Thanksgiving; the Muddy Shoes Relay inspired by one of Cam’s website posts; the “I Swam for Cam” swim relay, and the Cam-a-thon dance marathon all benefit the foundation. In addition, teens in the Downingtown area have made dozens of blankets to donate to kids in the midst of their cancer battles.

Cure4Cam donated to Nemours not only because Cameron was treated at Alfred I. duPont Hospital for Children but because of its promising ongoing work in childhood cancer research. Andy Kolb, MD, director, Nemours Center for Cancer and Blood Disorders, said, “Cameron always said that he wanted to make a difference. His life and his battle with leukemia have been a real inspiration to thousands. Cure4Cam is translating that inspiration into support for critically needed research that will help others for many years to come.”