



Nemours Center for Cancer and Blood Disorders
2017 Report of Outcomes

Your child. Our promise.

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Nemours[®] Alfred I. duPont
Hospital for Children



Table of Contents

Letter From the Director	1
Introduction	2
Why Choose Us	3
Radiation Exposure Prevention	4
2017 Clinical Trial Accrual	4
Cancer Care Delivery Program	5
Cancer Conference Activity	7
Cancer Committee Members	8
Continuous Improvement Events	9
Program Milestones and Accomplishments	9



Letter From the Director

The Nemours Center for Cancer and Blood Disorders (NCCBD) now ranks among the top 10 percent of all pediatric cancer programs in the country. NCCBD, including all Nemours sites in the Delaware Valley, in Northern and Central Florida, is among the top enrolling sites in the country on National Cancer Institute–sponsored clinical cancer research studies for children. We are among the top three programs in enrollment on studies designed to reduce the side effects of cancer therapies. As a clinical and research program, NCCBD sets participation in national cancer clinical trials among our highest priorities. We recognize that our patients and families demand improved outcomes with fewer side effects from therapy. We are committed to working collaboratively with investigators around the world to develop, implement and complete the most innovative clinical research.

Anne Kazak, PhD, director of the Nemours Center for Healthcare Delivery Science, has continued her work to improve access to psychosocial care for children and families dealing with a cancer diagnosis, care and follow-up. In 2016, Dr. Kazak was co-editor of the Psychosocial Standards of Care, evidence-based supportive care for children with cancer. In 2017, Dr. Kazak and her team went to work describing our national capacity to implement the Psychosocial Standards of Care. The three resulting publications provide important benchmarking for the readiness of centers across the country to provide basic psychosocial care. They assessed current pediatric cancer psychosocial services available at 144 centers nationally. It is Dr. Kazak's vision that these landmark papers will help all pediatric cancer centers meet the basic needs of their patients and families navigating a cancer diagnosis.

The Nemours Center for Cancer and Blood Disorders is proud to serve our local, national and global communities. As our research program grows, so too does our ability to impact and improve the lives of children with cancer and blood disorders.

A handwritten signature in black ink, appearing to read 'E. Kolb', with a long horizontal flourish extending to the right.

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



Introduction

Finding out a child has cancer or a blood disorder can be overwhelming. Families need an experienced team that can deliver top-notch care and support them every step of the way. The Nemours Center for Cancer and Blood Disorders (NCCBD) offers family- and patient-centered pediatric oncology and hematology care. It includes expansive clinical and support services alongside internationally recognized research programs.

NCCBD isn't a single "place," but an established, multisite pediatric oncology and hematology program made up of four core locations. Each is a member of the Children's Oncology Group.

- **Nemours/Alfred I. duPont Hospital for Children; Wilmington, Del.**
- **Nemours Children's Specialty Care; Jacksonville, Fla.**
(in collaboration with Wolfson Children's Hospital)
- **Nemours Children's Specialty Care; Pensacola, Fla.**
- **Nemours Children's Hospital; Orlando, Fla.**

These core facilities, together with many satellite locations, pool resources and expertise to offer families care that crosses geographic lines — focusing on improving outcomes, reducing side effects, and providing state-of-the-art therapies.



Why Choose Us

NCORP

As a National Cancer Institute Community Oncology Research Program (NCORP) — and most particularly as one of only two pediatric NCORPs — we're a fully integrated pediatric cancer network with recognized excellence in clinical research, clinical care and quality improvement.

Cross-campus collaboration, deep expertise

When you come to NCCBD, it's like getting a second, third and fourth opinion based on our established care teams' collaborative insights and depth of experience.

Advanced research and care

We're as committed to researching new treatments and cures as we are to providing the very highest level of care to families. Everything we do at the bedside impacts our research — and everything we learn in the lab impacts our care.

Ongoing commitment to clinical trial participation

Our well-resourced, organization-wide efforts in clinical trials have led to national accolades and leadership. Each of our core locations is highly regarded for outstanding clinical trial participation, access and management.

Excellent outcomes

When compared with the three top-rated U.S. children's hospitals for pediatric oncology and hematology, we're on par with or exceed national benchmarks for infection prevention, five-year cancer survival rates, and bone marrow transplant survival rates.

High rankings

We're among the top 10 percent of children's oncology programs in the United States, as reported in *U.S. News and World Report*. The Leapfrog Group named two of our core locations a "Top Children's Hospital" (Nemours/Alfred I. duPont Hospital for Children for 2012, Nemours Children's Hospital for 2014). The duPont Hospital for Children is also ranked among the best for pediatric oncology by *U.S. News & World Report*.

Best Doctors in America®

Many of our physicians are selected as premier physicians in the country, year after year.

Center of excellence in sickle cell disease research

The National Institutes of Health designated our sickle cell research program a Center of Biomedical Research Excellence (COBRE).

Long-standing FACT designation

Our applicable programs are recognized by the Foundation for the Accreditation of Cellular Therapy (FACT) for meeting or exceeding the most rigorous standards in every aspect of blood and bone marrow transplant therapy.

Pioneer in family-centered care

For years, we've been at the forefront of "family-centered care," a philosophy that emphasizes collaboration with patients and their families.

Radiation Exposure Prevention

The cancer committee agreed in early 2017 that radiation exposure continues to be a major concern that affects our patient population and community. We chose to address this concern to reduce the incidence of radiation exposure going forward.

One hundred percent of patients with retinoblastoma germ line mutation diagnoses were educated on the risk of

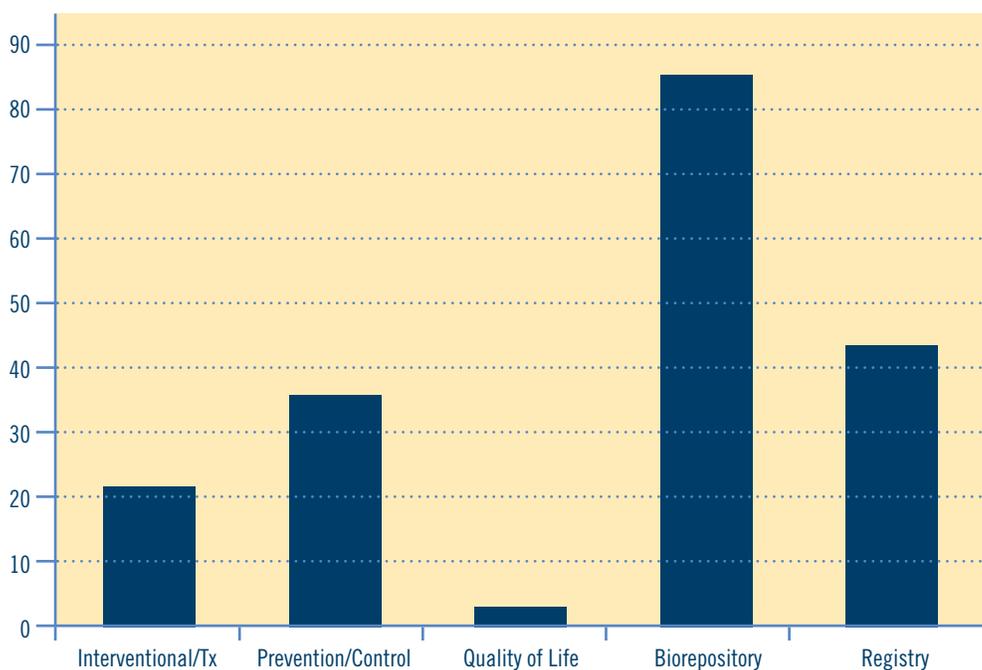
exposure and given guidelines for prevention. Physicians also discussed avoiding unnecessary exposure to excessive sunlight and diagnostic radiation.

For the radiation exposure prevention program, our protocol followed the evidence-based guidelines from the National Cancer Institute.

2017 Clinical Trial Accrual

There were 188 total enrollments to clinical trials at Nemours/Alfred I duPont Hospital for Children.

Total Enrollees



- Interventional studies involve giving and assessing treatment for a disease, or for a side effect of disease therapy.
- Prevention and control studies assess how to prevent or minimize side effects of treatment from occurring.
- Quality of life studies assess how disease and treatment affect the lives of patients and families, usually through questionnaires and noninvasive testing.
- Biorepository studies involve the collection of specimens for research testing.
- Registry studies involve the collection of data only.

Cancer Care Delivery Program

Cancer Care Delivery Research (CCDR) at Nemours

CCDR is a multidisciplinary field of scientific inquiry that examines how social factors, financing systems, organizational structures and processes, health technologies, and health care provider and individual behaviors affect cancer outcomes, access to and quality of care, cancer care costs, and the health and well-being of cancer patients and survivors.

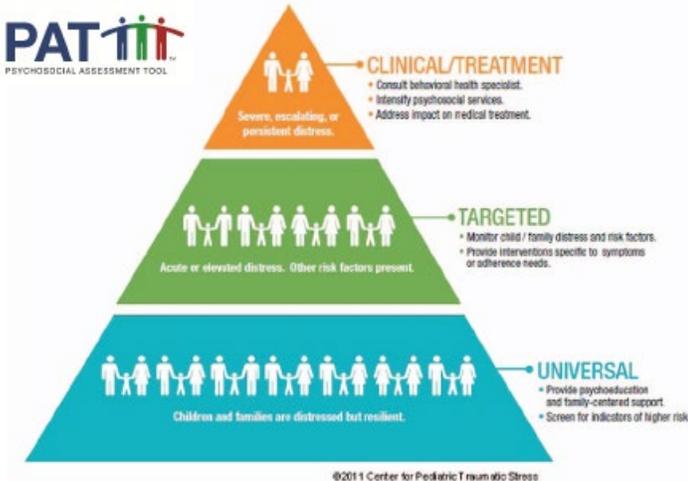
2017 Highlights

Ongoing research with the Psychosocial Assessment Tool (PAT)

psychosocialassessmenttool.org

Pediatric Psychosocial Preventive Health Model

ADDRESSING TRAUMATIC STRESS IN THE PEDIATRIC HEALTHCARE SETTING



PAT is a brief parent report screener of psychosocial risk in pediatric health. PAT identifies families' areas of risk and resilience across multiple domains (e.g., social support, acute stress, etc.). PAT is based on the Pediatric Psychosocial Preventive Health Model (PPPHM) (Kazak, 2006) providing a three-level determination of family risk (universal, targeted and clinical).

Provider perspectives on the implementation of psychosocial risk screening

funded by the American Cancer Society (RSG-13-015)

Aims

- To establish the validity of PAT (English and Spanish versions) as a screener of psychosocial risk with a tri-level classification (universal, targeted, clinical) in families of children with cancer
- To characterize patterns in psychosocial risk over time in English- and Spanish-speaking families of children with cancer, with special attention to how factors associated with health disparities change
- To identify potential barriers to clinical uptake of screening
- To identify ways in which identified risk can be systematically linked to resources and intervention

Kazak AE, Hwang WT, Chen FF, et al. Screening for family psychosocial risk in pediatric cancer: Validation of the Psychosocial Assessment Tool (PAT) Version 3, *Journal of Pediatric Psychology*. 2018;43(7). <https://doi.org/10.1093/jpepsy/jsy012>

2017 Highlights (continued)

Screen to intervene: A family-centered approach to identifying and communicating family psychosocial risk and developing evidence-based clinical pathways in Hematopoietic Stem Cell Transplant (HSCT) (PAT BMT)

funded by Alex's Lemonade Stand Foundation

Aims

- To validate a screener of psychosocial risk with multiple domains of risk, resulting in a tri-level classification in families of children prior to HSCT
- To evaluate the feasibility and acceptability of providing feedback to families regarding their risks as reported on the PAT
- To create psychosocial intervention pathways, in collaboration with families and consistent with the PPPHM

Implementing family psychosocial risk screening in English and Spanish

funded by CureSearch Community Impact Award

Aims

- To hold one-day workshop to support implementation of the Psychosocial Assessment Tool (PAT) in Florida
- To train multidisciplinary psychosocial professionals in the use of the PAT and deliver monthly follow-up consultations

Preparing to Implement Pediatric Psychosocial Standards: Current Staffing and Services (PIPS-CSS)

supported by the Center for Cancer and Blood Disorders and the Center for Healthcare Delivery Science

Aims

- To describe and evaluate the readiness of pediatric oncology treatment programs to implement psychosocial care consistent with the standards
- To document the number and type of psychosocial staff and services provided
- To obtain information regarding perceived barriers to implementation

Scialla MA, Canter KS, Chen FF, et al. Implementing the psychosocial standards in pediatric cancer: Current staffing and services available. *Pediatr Blood Cancer*. 2017;64:e26634. <https://doi.org/10.1002/pbc.26634>

Scialla MA, Canter KS, Chen FF, et al. Delivery of care consistent with the Psychosocial Standards in Pediatric Cancer: Current practices in the United States. *Pediatr Blood Cancer*. 2018;65:e26869. <https://doi.org/10.1002/pbc.26869>

Cancer Conference Activity

Ninety-three patients were discussed at the multidisciplinary cancer conference in 2017

The NCCBD cancer program is accredited by the American College of Surgeons Commission on Cancer — and has been since 2015.

One requirement for this accreditation is holding a cancer conference, also known as a tumor board. These conferences help to improve the monitoring of patient care by providing opportunities for multidisciplinary treatment planning and collaboration among physicians and allied medical staff.

Caring for patients with cancer requires a multidisciplinary approach involving numerous physicians and other professionals.

This meeting is attended by oncology, hematology, pathology, radiation oncology, radiology and surgery professionals and many others.

The conference was held nearly weekly in 2017, taking place **43 times**, with **93 patients** presented.

Accreditation is contingent upon establishment of the a Cancer Committee, as “the cancer committee is responsible for goal setting, planning, initiating, implementing, evaluating, and improving all cancer-related activities in the program.” The membership of the cancer committee is multidisciplinary, representing physicians from diagnostic and treatment specialties and other professionals from administrative and supportive services.



2017 Cancer Committee Members

Allison Aguado, MD
Interventional Radiology

Laura Baker, MGC, LCGC
Genetics

Debbie Bertz, CTR
Oncology Research

Heather Brady
Quality Coordinator

Dyane Bunnell, RN, CNS
Hematology/Oncology

Beth Carlough, CCLS
Child Life

Emi Caywood, MD
Blood and Bone Marrow Transplantation

Diana Corao, MD
Pathology

Brian Duffy, MD
General Surgery

Michell Fullmer, RD
Nutrition

Rochelle Glidden, PsyD
Psychology

Gregory Griffin, MD
Hematology/Oncology

Maureen Karmondy
Community Outreach

E. Anders Kolb, MD
Blood and Bone Marrow Transplantation

Dale Lowe, RN, MHA
Cancer Center Operations

Peter March, MSN, RN
Nursing Administration

Adrienne Miller, PharmD
Clinical Pharmacy

Elissa Miller, MD
Palliative Care

Robin Miller, MD
Hematology/Oncology

Danielle Morley
Cancer Care Coordinator/
Fertility Preservation

Mary E. Newman, RN
Nurse Manager

Danielle Perry, MPH, CHES
Blood and Bone Marrow Transplantation

Joseph Piatt, MD
Neurosurgery

Jonathan Powell, MD
Hematology/Oncology

Joanne Quillen, MSN, PNP-BC
Hematology/Oncology

Pam Cawood Rizzo, CCRP
Oncology Research

Brook Rowe
Leukemia Lymphoma Society

Jon Strasser, MD
Radiation Oncology

Mihir Thacker, MD
Orthopedic Surgery

Christine Tyrrell, RN
Quality and Regulatory Management

Andrew Walter, MD
Hematology/Oncology

Elizabeth Wood, LCSW
Social Services

Lisa Wray, MD
Hematology/Oncology

Andrea Wrightson, RN
Oncology Research

Christine Zwick, DPT
Rehab/Physical Therapy

Continuous Improvement Events

Fertility Preservation Program

In 2017, we began providing formal fertility preservation consults to patients likely to undergo treatment that could affect their fertility. During consultation, the physician discusses the risk of infertility associated with the planned treatment, as well as potential preservation options and future monitoring.

Through contracts with a local reproductive endocrinology and infertility specialist, we are able to offer sperm banking and egg harvesting to our pubertal patients.

Pathway to Home

A series of steps were designed to better prepare complex patients and families for discharge and follow-up.

The pathway identifies clinical, nutritional, educational, caregiver, activity and medication goals for discharge.

Families and patients are given a visual tool to help them understand the pathway.

Discharge kits include insulated bags and ice packs for medications, a thermometer, a pill splitter, a water bottle and a notepad.

Multidisciplinary Support for the Clinic for Special Children (Lancaster, Pa.) and KinderClinic (Dover, Del.)

Plain Consortium Clinics provide comprehensive local medical care, integrating basic science research and clinical medicine to improve the diagnosis and management of chronic diseases in the Plain Communities.

Nemours BBMT, immunology and diagnostic referral service work together to support these patients during the transplant process. Clinic for Special Children pediatricians, nurses and researchers also help with coordination of care.

The care plan encompasses home visits, telehealth visits, satellite clinics and tertiary care.

Program Milestones and Accomplishments

- Long-standing Foundation for the Accreditation of Cellular Therapy (FACT) accreditation
- National Marrow Donor Program (NMDP) Designated Transplant Center: 2010–present
- Center for International Blood and Bone Marrow Transplant Research (CIBMTR) Center in Good Standing: 2010–present
- Member of Pediatric Bone Marrow Transplant Consortium (PBMTC): 2012–present
- Member of Pediatric Immunodeficiency Treatment Consortium (PIDTC): 2013–present
- National Cancer Institute Community Oncology Research Program (NCORP): 2014–present
 - » One of only two designated pediatric NCORPs in the country; recognized by NCI as a fully integrated pediatric cancer network with excellence in research, clinical care and quality improvement.
- American College of Surgeons Commission on Cancer Accredited Facility: 2015–present
- Magnet designation in 2012; granted redesignation in 2017 by the American Nurses Credentialing Center (ANCC) Magnet Recognition Program
- Ranked by *U.S. News & World Report* as one of the best children's hospitals in the nation for cancer