## **CLINICAL HIGHLIGHT:** Improving the Overall Experience for Patients With Skeletal Dysplasia

Over the next few weeks, we've invited U.S. News-eligible specialties to share updates on their physician-led initiatives as part of our preparation for the next U.S. News clinical rankings survey submission in Spring 2021.

The Skeletal Dysplasia Program at Nemours/Alfred I. duPont Hospital for Children includes a uniquely talented and highly experienced team of experts that provide comprehensive care designed to meet every need of the patient — improving the overall experience and establishing Nemours as the premier destination for skeletal dysplasia.



### Unique International Skeletal Dysplasia Patients



Specific actions the Department of Orthopedics took to drive improvements included:

- Implemented a multidisciplinary team approach
  - » weekly skeletal dysplasia rounds with five medical specialties
  - » monthly coordinated rounds
- Coordinated subspecialty care
  - » Dedicated nursing and social work to schedule patient families with all sub-specialty providers during their 1-2 day outpatient visit
- Created a specialized transitional care program for patients up to 35 years of age, with adult services provided onsite, including joint replacement and spinal decompression and fusion

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- Introduction of an onsite advanced delivery program that allows neonates with skeletal dysplasia to receive expert care during, and immediately after, birth in our NICU
- Access to the Ronald McDonald House of Delaware includes lodging and meals, allowing families to stay together and close to their hospitalized child
- Access to state-of-the-art clinical and basic science research including: drug trials, natural history registries, physiologic studies, gait analysis and clinical outcomes
  » 95 publications in last 5 years



"The research and clinical volume of our multidisciplinary team has provided data on the natural history of skeletal dysplasias resulting in improved, cost-effective care with reduced complications. Education of caregivers around the world will improve outcomes for this population." — William G. Mackenzie, MD, chair, Orthopedics

## Likely to Recommend (Jan 1, 2020 – Dec 8, 2020)



"We came from Louisiana to meet the skeletal dysplasia doctors and it was a wonderful experience. Both doctors and their staff were amazing!" – Patient family

"The skeletal dysplasia team (Dr. Bober and Dr. Mackenzie) are awesome. They provide excellent care, enough that we travel from hundreds of miles away to visit them every year." — Patient family

## **CLINICAL HIGHLIGHT:** Improving Quality of Life and Outcomes for Pediatric Cardiac Patients

Over the next few weeks, we've invited U.S. News-eligible specialties to share updates on their physician-led initiatives as part of our preparation for the next U.S. News clinical rankings survey submission in Spring 2021.

The Nemours Cardiac Team is committed to upholding rigorous standards of excellence, by consistently achieving outstanding congenital heart surgery outcomes and providing early, ongoing neurodevelopmental support to help patients reach their full potential.

Actions taken by the cardiac team to bolster improvement:

- Implementation of an Integrated Practice Model in which a multidisciplinary team is organized and functions as a single Integrated Practice Unit, focused exclusively on the care of patients with congenital and acquired heart disease.
- Introduction of the on-site Advanced Delivery Program eliminated delays in the initiation of life-saving interventions for high-risk infants
  - » Within the first year of operation of the Advanced Delivery Program, **17 Infants with fetal** diagnosis of heart disease have been safely delivered at Nemours. All are thriving.
- Establish Neurodevelopmental Program one of the first programs in the nation to provide complex cardiac patients with early and appropriate neurodevelopmental intervention, resulting in the best possible quality of life
- Participation in STS public reporting of outcomes provides transparency



"In addition to excellent surgical outcomes, we are focused on maximizing the developmental potential in this high-risk population. The LEAD program, directed by Erica Sood, PhD, performs longitudinal psychological testing and studies interventions designed to help patients with congenital or pediatric heart disease achieve their maximal potential." – Christian Pizarro. MD. director. Nemours Cardiac Center.

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## **Risk Adjusted Surgical Outcomes:** Observed vs. Expected Mortality



Source: Society of Thoracic Surgeons Congenital Heart Surgery Database. Surgical Risk STAT Category



### Neurodevelopmental Assessments by Age Range



## **CLINICAL HIGHLIGHT:** Cardio-Oncology Program at Nemours/Alfred I. duPont Hospital for Children

Over the next few weeks, we've invited U.S. News-eligible specialties to share updates on their physician-led initiatives as part of our preparation for the next U.S. News clinical rankings survey submission in Spring 2021.

During 2020, the Nemours Center for Cancer and Blood Disorders (NCCBD) at Nemours/Alfred I. duPont Hospital for Children has continued to advance its expectations regarding quality and care delivery.

One initiative specifically focused on screening those who are at risk of developing cardiovascular diseases during and/or after receiving cancer treatment in childhood, and implementing necessary medical treatment and health promotion education to prevent future cardiovascular morbidity and mortality in adulthood.

Bidirectional collaborative interactions between the cardiology and oncology divisions were encouraged in order to share critical medical information and clinical concerns to identify preclinical phases of cardiovascular abnormality and those who are at risk for cardiovascular diseases. Specific actions taken included:

- Outpatient Surveillance for Asymptomatic Pediatric Cancer Survivors (PCS) In collaboration with the Oncology Survivorship Program, all oncology patients were referred to an exercise laboratory to assess their exercise performance, and to introduce the concept of exercise as an important part of saving lives.
- Inpatient/Outpatient Monitoring of Cardiovascular Status Two ways to monitor cardiovascular status in PCS:
  - » Surveillance echocardiogram Those patients who are having routine echocardiograms are monitored by Cardio-Oncology Cardiology team (COC), and any concerning findings will be addressed to the referring oncologist and Cardio-Oncology Oncology team (COO).
  - » Cardiology Consultation Service Any clinical problems referred to the cardiovascular system are open to cardiology consultation. Specific cardiologists will be assigned if the patients require further follow up.
- Promotion of Clinical Research
- Monthly meetings are held to review current patient caseload within the Cardio-Oncology Program and discuss specific cases, as required.

## **Oncofertility Program**

NCCBD offers fertility preservation consultation and services in coordination with fertility experts, including urologic and gynecologic surgeons. Services include sperm cryopreservation, testicular tissue collection and cryopreservation, egg retrieval and cryopreservation and ovarian tissue harvesting and cryopreservation. All services are offered to girls and boys regardless of age and independent of ability to pay.

### **Clinical Research**

Multiple published studies report that children with cancer clearly have better outcomes when enrolled on clinical trials at centers experienced in clinical research. Robust clinical research programs provide care according to national standards, submit themselves to external review and audit, and provide access to investigational therapies not otherwise available outside of a clinical trial. NCCBD strives to enroll all eligible patients, regardless of race, ethnicity or primary language spoken. We report anonymous results to our communities and funding sources at least annually.

NCCBD was second in the nation in total enrollments on NCI-funded clinical research studies. Robust clinical research requires that all racial and ethnic minorities are represented in clinical trials. We have worked intentionally to identify and minimize all barriers to clinical trial participation.



## **CLINICAL HIGHLIGHT:** Reducing Unplanned Extubations in the NICU

Over the next few weeks, we've invited U.S. News-eligible specialties to share updates on their physician-led initiatives as part of our preparation for the next U.S. News clinical rankings survey submission in Spring 2021.

The Division of Neonatology at Nemours/Alfred I. duPont Hospital for Children in Wilmington, Del., has committed to continuous advancement of quality and care delivery.

One specific initiative focused on the reduction of unplanned extubations (UE) in the NICU to  $\leq 0.6/100$  ETT days. UE in neonates can cause significant harm including cardiovascular collapse, airway injury, and prolonged need for mechanical ventilation.

Actions taken by the Neonatology Team to drive improvements:

- hands-on training of all staff in two standard methods (Neofit and tape) of ETT securement
- instituted an airway safety checklist to be performed on AM and PM rounds
- developed safer practices to allow infants with ETTs to be held by their parents during "Kangaroo Care"
- created a standardized event review process to learn from each UE event

"This project highlights our commitment to improving patient outcomes through quality improvement and safety science. Our multidisciplinary care model allows for the seamless integration of these processes and drives the sustainability of this work. I am extremely proud of our quality improvement team for all they have accomplished to advance the exceptional care we provide to our patients, their families and our community," said Elizabeth O'Donnell, MD, division chief of Neonatology.

### NICU Rate of Unplanned Extubations 2018 to 2020



*Figure 1* shows the rate of unplanned extubations per month of the study period in the Nemours/Alfred I. duPont Hospital for Children Neonatal Intensive Care Unit. The goal rate is 0.6/100 ETT days which was met and surpassed within 2 months of guideline implementation.



# **CLINICAL HIGHLIGHT:** Using Outpatient Respiratory Equipment Checks and Assessments to Improve Resource Utilization in Neuromuscular Children

Over the next few weeks, we've invited U.S. News-eligible specialties to share updates on their physician-led initiatives as part of our preparation for the next U.S. News clinical rankings survey submission in Spring 2021.

The Division of Pediatric Pulmonology at Nemours Children's Hospital in Orlando, has continued to advance its expectations regarding quality and care delivery.

One initiative specifically focused on using outpatient respiratory equipment checks and assessments to improve resource utilization in neuromuscular children.

Actions the pulmonology division took to drive improvements included:

- conducting equipment checks that consisted of re-education, setting changes, supply management and technique adjustment
- including patients with neuromuscular diseases, cerebral palsy or other diseases leading to hypotonia in the equipment check process
- conducting a statistical analysis using SPSS (v25); univariate analyses included paired t-test (primary outcomes), chi-squared (categorical variables) and gamma tests (ordinal categorical variables) as appropriate
- reviewing medical records from January 1, 2017 through June 30, 2019

"Periodic evaluation of airway clearance equipment and re-education did not decrease the need for respiratory-related care for exacerbations in all patients, but did show benefit for trach- and ventilator-dependent patients." — Floyd Livingston, MD, division chief of Pediatric Pulmonology at Nemours Children's Hospital

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## Improvement in hospitalizations for ventilator-dependent and tracheostomy patients following any intervention.



## Improvement in hospitalizations for neuromuscular patients with tracheostomy.



## **CLINICAL HIGHLIGHT:**

## Identifying Common Pathways for the Management of Undescended Testis in Male Pediatric Patients

Over the next few weeks, we've invited U.S. News-eligible specialties to share updates on their physician-led initiatives as part of our preparation for the next U.S. News clinical rankings survey submission in Spring 2021.

The Division of Pediatric Urology at Nemours Children's Hospital in Orlando, has continued to advance its expectations regarding quality and care delivery.

One initiative specifically focused on undescended testis (UDT), which is the most common congenital genital problem in male infants. In 2019, the division collaborated with urology clinicians throughout Nemours Children's Health System in the Delaware Valley, Orlando, and Jacksonville, Fla., to develop a common pathway (see Figure 1) for the management of this condition and identify a solution.

Actions the Urology division took to drive improvements included:

- assessment of established practices for the management of patients with undescended testis
- development of a process to 1) improve the age at surgery by one year of age as recommended by the American Urological Association, and 2) reduce or eliminate the use of screening ultrasounds for UDT
- education of patients and their families utilizing age-appropriate materials from KidsHealth.com

"In 2014, the American Urological Association developed guidelines for the evaluation and management of undescended testes. The guidelines focused on timely referral to a specialist (if testis not descended at 6 months of age), surgical intervention within 12 months of referral (18 months of age), and noted that ultrasound studies prior to a referral to specialist were unnecessary," said Pamela Ellsworth, MD, division chief for Pediatric Urology at Nemours Children's Hospital. "The focus of this project is to align pediatric and urologic practices within the enterprise with these practice guidelines to optimize patient outcomes and patient experience."



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### **Clinical Pathway for the Management of UDT**



*Figure 1* The Pediatric Urology Division developed a clinical pathway to improve the management of UDT in male pediatric patients.

## CLINICAL OUTLOOK: Improving the Timeliness of Care for Treatment of Patients with UDT

Nemours. Children's Specialty Care



**Purpose:** The Division of Pediatric Urology at Nemours Children's Specialty Care, Jacksonville, and Wolfson Children's Hospital of Jacksonville sought to improve the timeliness of care for patients with undescended testicles (UDT). Partnered

with Divisions of Urology across the Nemours Children's Health System, this process improvement project looked at all aspects of the health care delivery process, from referral to surgery, with a focus to improve outcomes.

Methods: Specific actions taken by this clinical work include:

- **Modified Process:** Streamlined the process in compliance with the American Urological Association (AUA) guidelines.
- **Increased Referring Physician Education:** Provided additional education on the on AUA guidelines to prompt timely referrals.
- **Reduced Unnecessary Testing:** Decreased the number of pre-ordered ultrasound studies, which led to reduced costs associated with the evaluation of UDT.



- Adjusted Age Recommendations: Reduced the age of patients at time of surgery. Earlier surgical intervention has been demonstrated to lead to healthier testicles.
- **Consistent Patient Education:** Standardized patient education materials for families across the Nemours enterprise, including those having surgery at Wolfson Children's.

**Results:** At the 180-day mark, this clinical standard work was able to reduce the median age of patients undergoing surgery for UDT from a baseline of 46 months to 36 months. The number of ultrasounds ordered prior to clinic visit was also reduced from 14.1% to 11.3%, achieving the clinical standard works goal by the 180-day mark. 12-month data is pending as the process is ongoing.

**Significance:** Timeliness of care for patients with UDT, from referral to surgery, has been demonstrated to improve the value of treatment through improved quality and decreased costs. Earlier surgical intervention may lead to healthier testicles, lowering the risk of future issues such as infertility and facilitating easier testicular cancer screening.



"Undescended testicle management is a seemingly simple topic, but as a group, we attacked it with a broad approach to incorporate all aspects of process improvement, from referral from the primary care provider through the post-operative period following surgical correction. Our goals of standardizing education, facilitating timelier referrals, optimizing outcomes and minimizing unnecessary tests have already been realized 180 days into the project. It is exciting to be a part of streamlining and improving care for the individual, as well as care for the pediatric population."

Andrew A. Stec, MD Chief of Pediatric Urology, Wolfson Children's Hospital of Jacksonville Chief of Pediatric Urology, Nemours Children's Specialty Care, Jacksonville

To connect with Dr. Stec or any of his pediatric urology colleagues with Wolfson Children's Hospital of Jacksonville and Nemours Children's Specialty Care, Jacksonville, please email <u>Andrew.Stec@nemours.org</u> or call <u>904.697.3600</u>.



## CLINICAL OUTLOOK: Improving the Care of Patients with Diabetes in the Emergency Room



**Purpose:** The Northeast Florida Pediatric Diabetes Center at Wolfson Children's Hospital of Jacksonville and the Division of Pediatric Diabetes and Endocrinology at Nemours Children's Specialty Care, Jacksonville, have continued to advance their expectations regarding quality and care delivery. One initiative focused on streamlining the evaluation and management of children with diabetes in the emergency room at Wolfson Children's Hospital, along with other emergency departments (EDs) in the community.

Action: Using evidence-based guidelines, a multidisciplinary team developed streamlined clinical pathways for ED physicians for management of the following conditions:

- Diabetic ketoacidosis (DKA)
- New-onset type 1 or type 2 diabetes mellitus
- High blood sugars (hyperglycemia) in children known to have diabetes
- Low blood sugars (hypoglycemia) in children known to have diabetes

**Results:** These guidelines help expedite discharge from the ED or admission to the hospital, reducing the ED length of stay.

**Significance:** Reduced length of stay decreases overall medical costs and increases patient/family satisfaction.





"The guidelines not only reduce length of stay for patients and families in the ED, but also have facilitated communication between the ED physicians, nurses and other ED staff, and diabetes team members. Additionally, the guidelines provide consistency in the teaching of medical students, residents and fellows."

Larry A. Fox, MD

Medical Director, Northeast Florida Pediatric Diabetes Center at Wolfson Children's Hospital of Jacksonville Pediatric Endocrinologist, Nemours Children's Specialty Care, Jacksonville

To connect with Dr. Fox or any of his pediatric endocrinology colleagues with Wolfson Children's Hospital of Jacksonville and Nemours Children's Specialty Care, Jacksonville, or to receive a copy of the ED pathways described, please email Larry.Fox@nemours.org or call 904.697.3600.



## CLINICAL OUTLOOK: Improving Outcomes for GI Patients at High-Risk for CLABSIs



**Purpose:** The Pediatric Gastroenterology Unit at Wolfson Children's Hospital of Jacksonville sought to improve the outcomes for GI patients at high-risk for central-line associated bloodstream infections (CLABSIs) by quantifying the effectiveness of central-line bundles, which have demonstrated reduced risk of healthcare-acquired bloodstream infections. We enhanced our clinical practices and documented patient outcomes using bundle reliability audits.

Methods: The following interventions implemented on the unit include:

- **Modified Auditing Tools:** Quality leaders evaluated and revised the audit tool to align with Solutions for Patient Safety (SPS) bundle elements. All bundle elements for patients needed to be met in order to receive a positive score. Any missing element resulted in a negative score.
- **Increased Frequency of Auditing:** Assistant nurse managers performed real-time bundle audits and were able to provide just-in-time education to staff, as well as to patients and families.
- **CHG Treatment:** Leaders amended hospital policy and EHR documentation to change the terminology of daily CHG "bathing" to "treatment." Patients and families were less apt to refuse a prescribed treatment.

100%

• Nurse and Caregiver Education: Increased education and signage for high-risk factors of line contamination promoted a cleaner environment.

**Results:** General care units at Wolfson Children's have demonstrated increased compliance with all of the bundle elements in 2019, with a hospital centerline (87.23%), and consistently scored just above the SPS centerline (86.20%) for reliability to use of the bloodstream infections maintenance bundle.

**Significance:** Our GI patient population is particularly vulnerable to CLABSIs as many are dependent on parenteral (IV) nutrition to meet their caloric needs. The above clinical practice enhancements demonstrated reduced risk of nosocomial infections.







"Central venous catheters (CVCs) are an integral part of care and treatment for our GI patients, but put them at higher risk of bloodstream infections. By enhancing our clinical practices and increasing the frequency of surveillance, we've demonstrated a reduced risk of nosocomial infections and improved patient outcomes. We hope to continue improving our bundle reliability to more than 90% in the future."

Uwe Blecker, MD Chief of Gastroenterology, Wolfson Children's Hospital of Jacksonville Division Chief of Gastroenterology, Nemours Children's Specialty Care, Jacksonville

To connect with Dr. Blecker or any of his pediatric GI colleagues with Wolfson Children's Hospital of Jacksonville and Nemours Children's Specialty Care, Jacksonville, please email <u>uwe.blecker@nemours.org</u> or call <u>904.697.3600</u>.

