

THE LATEST NEWS FOR PEDIATRICIANS FROM CLEVELAND CLINIC CHILDREN'S | WINTER 2017



## Neurodevelopmental Issues in Congenital Heart Disease: The Case for Multidisciplinary Care

By Neil R. Friedman, MBChB

Advances in the surgical treatment of congenital heart disease (CHD) over the past 40 years have been dramatic, to the point that there are now more adults surviving with CHD than there are children with the condition.

With improved survival, neurological injury has become the major extracardiac complication from cardiopulmonary bypass and CHD. Early morbidity includes stroke, seizures and epilepsy, but increasing attention is now being paid to the long-term neurodevelopmental disabilities.

#### Distinctive profiles

Although initially attributed to the effects of cardiopulmonary bypass surgery, the incidence of neurodevelopmental disability did not decrease despite efforts in the 1980s and 1990s to optimize bypass surgery variables. Today, it is well-appreciated that impaired fetal brain development and circulation, coexisting genetic syndromes, and pre- and postsurgical hemodynamic instability are equally important factors contributing to brain injury and neurodevelopmental outcome.

Distinctive neurodevelopmental profiles in children with CHD are now recognized, including:

- Learning disabilities
- Language delay
- Behavioral difficulties (attention deficit hyperactivity disorder [ADHD], executive dysfunction)
- Difficulties with communication (pragmatic language) or adaptive behaviors
- Visual-spatial dysfunction and coordination (fine motor, oromotor) difficulties

About 30 to 50 percent of children who have undergone cardiopulmonary bypass for complex CHD will require remedial school services, and 15 percent will need

full-time special education. Early identification of neurodevelopmental impairments offers the best opportunity for intervention and treatment to maximize the child's potential and minimize disabilities. The American Heart Association recommends periodic developmental surveillance, screening and evaluation of children with CHD.

#### An interdisciplinary approach

At Cleveland Clinic, the Neurocardiac Clinic is one of only a handful of U.S. clinics dedicated to the multidisciplinary management of the neurodevelopmental disabilities common in children with CHD — and one of fewer still housed within a neurology infrastructure. Specialists include pediatric neurologists, cardiologists, medical geneticists, neuropsychologists, behavioral health specialists, and speech, occupational and physical therapists.

More than 260 children have been evaluated in the clinic as of 2015, providing unique insights into the long-term disabilities these children face and the impact of these disabilities on their quality of life.

Our group also is involved in research in two important areas: migraines and ADHD medication concerns. Our work has highlighted the frequency and severity of migraines in this population — a condition that is underrecognized and undertreated and has a significant impact on children's quality of life. Other research involves assessing the safety and optimal monitoring of ADHD medications in this vulnerable population, given the frequency of ADHD and concerns regarding use of ADHD medication in children with CHD.

Dr. Friedman is Director of Pediatric Neurosciences at Cleveland Clinic and Head of the Pediatric Neurocardiology Program.

#### **NEW STAFF**

### We searched for the best of the best — and are proud to announce the arrival of the newest members of our team:

#### Raidour Ahmed, MD

**SPECIALTY:** Pediatric hospital medicine

**EDUCATION:** Medical degree, University of Aleppo; residency, Aleppo University Hospitals; pediatric residency, Cleveland Clinic Children's

**EXPERIENCE:** Main interests include newborn nursery management, quality improvement and patient safety.

#### Malek El Yaman, MD

**SPECIALTY:** Pediatric cardiology

**EDUCATION:** Medical degree, American University of Beirut; residency, Duke University Medical Center; pediatric cardiology fellowship, Mayo Graduate School of Medicine

**EXPERIENCE:** Main interests include pediatric cardiology, fetal echocardiography, transesophageal echocardiography and cardiovascular MRI.

#### Michael Fedak, MD

**SPECIALTY:** General pediatrics

**EDUCATION:** Medical degree, Saint Louis University School of Medicine; pediatric residency, Cardinal Glennon Children's Hospital

**EXPERIENCE:** Previously worked for Rainbow Ambulatory Practice at University Hospitals Rainbow Babies & Children's Hospital, followed by 26 years for Ohio Permanente Medical Group and HealthSpan. Interests include ADHD, dermatology and sports medicine.

#### Deborah Goldman, MD

**SPECIALTY:** Pediatric gastroenterology

**EDUCATION:** Medical degree, University of Pennsylvania School of Medicine; pediatric residency, Boston Children's Hospital; pediatric gastroenterology fellowship, Tufts-New England Medical Center

**EXPERIENCE:** Previously at the University of Minnesota. Interests include pancreatic disease, liver disease, motility disorders, growth and nutrition, and teaching fellows, residents and medical students.

#### Mohammed Hamzah, MD

**SPECIALTY:** Pediatric critical care medicine

**EDUCATION:** Medical degree, Sana'a University; pediatric residency, Columbia University Medical Center affiliation at Harlem Hospital; pediatric critical care medicine fellowship, University of Wisconsin-Madison; pediatric cardiac critical care medicine fellowship, Children's Hospital of Wisconsin

**EXPERIENCE:** Main interests include pediatric critical care; pediatric cardiac intensive care for infants, children and young adults with congenital and acquired heart disease; and improving early and late outcomes following congenital heart surgery

#### William Hanna, MD

SPECIALTY: Pediatric critical care medicine

**EDUCATION:** Medical degree, University of Kentucky College of Medicine; internal medicine/pediatrics residency, University of Massachusetts; critical care fellowship, Cincinnati Children's Hospital; pediatric cardiac critical care fellowship, The Hospital for Sick Children

**EXPERIENCE:** Main interests include cardiac intensive care, high-fidelity simulation and education.

#### Anika Kumar, MD

SPECIALTY: Pediatric hospital medicine

**EDUCATION:** Medical degree, Wayne State University School of Medicine; pediatric residency, University Hospitals Rainbow Babies & Children's Hospital

**EXPERIENCE:** Main interests include quality improvement, medical education, patient safety, and care paths research for quality improvement in medical operations.

#### Jeremy Lamkin, MD

SPECIALTY: Pediatric critical care medicine

**EDUCATION:** Medical degree, University of Cincinnati College of Medicine; pediatric residency, Harbor-UCLA Medical Center; pediatric

critical care fellowship, University of Michigan Medical School

**EXPERIENCE:** Specialty/research interests include early prediction of acute hemodynamic instability, decompensation using digital ECG waveform analysis and machine-learning techniques and extracorporeal support.

#### Samir Latifi, MD

SPECIALTY: Pediatric critical care medicine

**EDUCATION:** Medical degree, Guy's Hospital, University of London; residency, University Hospitals of Cleveland; critical care fellowship, University Hospitals of Cleveland

**EXPERIENCE:** Previously practiced in London at Royal Brompton Hospital PICU, and served as PICU Clinical Director at Addenbrooke's Hospital, Cambridge, England. He also was an attending in the PICU at MetroHealth Medical Center and Akron Children's Hospital, and serves as Associate Medical Director of Lifebanc. His clinical interests are pediatric cardiac intensive care, point-of-care ultrasound and sepsis; his research interest are sepsis and multi-organ dysfunction syndrome, and organ donation.

#### Jessica Madden, MD

**SPECIALTY:** Neonatology

**EDUCATION:** Medical degree, The Ohio State University College of Medicine; pediatric residency, University of Massachusetts Medical School; neonatal-perinatal medicine fellowship, University Hospitals Rainbow Babies & Children's Hospital

**EXPERIENCE:** Served as Director of the NICU Follow-Up Clinic at Aurora BayCare Medical Center, and most recently practiced as a neonatologist at Boston Children's Hospital.

#### Brittany Ponziani, MD

**SPECIALTY:** General pediatrics

**EDUCATION:** Medical degree, University of Toledo College of Medicine; pediatric residency, University Hospitals Rainbow Babies & Children's Hospital

**EXPERIENCE:** Special interests include newborn and adolescent care, and childhood obesity.

#### T. Shawn Sullivan, PhD

SPECIALTY: Pediatric behavioral health

**EDUCATION:** Doctoral degree, Boston College; clinical psychology residency, Bedford VA; clinical neuropsychology fellowships, University of Illinois College of Medicine and Cleveland Clinic.

**EXPERIENCE:** Working in clinical neuropsychology since 1996. Main focuses are learning disability and ADHD. Special interests include executive dysfunction and fostering success attributes in children with learning disability.

#### J. Michael Wertman, MD

SPECIALTY: General pediatrics

**EDUCATION:** Medical degree, West Virginia University; emergency medicine residency, Cincinnati General Hospital; pediatric residency, West Virginia University Hospitals

**EXPERIENCE:** Worked in small-practice settings and in a multispecialty group.

#### Stacey Zahler, DO

**SPECIALTY:** Pediatric hematology oncology; blood and marrow transplantation

**EDUCATION:** Medical degree, Philadelphia College of Osteopathic Medicine; residency, Maria Fareri Children's Hospital at Westchester Medical Center; pediatric hematology, oncology and stem cell transplant fellowship, Maria Fareri Children's Hospital at Westchester Medical Center

**EXPERIENCE:** Interest in pediatric solid tumors (sarcomas, neuroblastoma, retinoblastoma, pediatric brain tumors), tumor immunology and cellular and immunotherapy, tumor vaccines, pediatric cancer wellness and survivorship.



**ON THE COVER** Cleveland Clinic Children's Hospital for Rehabilitation is one of fewer than a dozen accredited, freestanding rehabilitation hospitals in the U.S. that serve pediatric patients exclusively. In 2015, it provided 85,663 outpatient therapy visits systemwide, 4,373 infant/toddler feeding program treatments, 1,573 day hospital rehab visits, 1,484 dialysis treatments and 197 acute rehab admissions.

**SIGN UP TODAY** Get our quarterly e-newsletter for pediatricians at clevelandclinic.org/eupdate.



#### **DEAR COLLEAGUES**



We are committed to the well-being of your pediatric patients through our multidisciplinary approach. Cleveland Clinic Children's is here to serve as a trusted collaborator in your patients' care. We are committed to the well-being of your pediatric patients through our multidisciplinary approach to the most serious diseases and conditions of childhood.

This issue of *Pediatric Update* provides several notable examples of this multidisciplinary approach. The demographic profile of congenital heart disease has changed drastically in recent years. Neurological injury has become a major extracardiac concern. Our Neurocardiac Center brings together a broad array of specialists in the heart, the brain and development to address these issues in the most comprehensive fashion.

Our Sickle Cell Disease Clinic is the meeting ground for an array of subspecialists who have the the skills and expertise to care for all aspects of this difficult condition. Liver transplantation is challenging, but it is with great pride that I note that our multidisciplinary pediatric liver transplant team has performed 110 transplants in its 31 years.

Our multidisciplinary approach is much in evidence at our new hub at Hillcrest Pediatrics in Mayfield Heights. Here we have two full floors of complete outpatient services, with the most advanced technology, patient amenities, and the ability to consult among specialties that only comes from convenient access to one another in leading-edge facilities.

I hope you find this issue of interest. We look forward to hearing from you with comments or questions on pediatric care at any of Cleveland Clinic Children's 40+ locations.

Sincerely,

#### Giovanni Piedimonte, MD

Physician-in-Chief, Cleveland Clinic Children's | Chairman, Pediatric Institute President, Cleveland Clinic Children's Hospital for Rehabilitation piedimg@ccf.org

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#### **TRANSPLANT**

#### LIVER TRANSPLANTATION

#### BY THE NUMBERS

#### **31** YEARS

Our pediatric liver transplantation team is one of the most experienced in the U.S., dating back to 1985.

#### **4** MEMBERS

A pediatric liver transplant medical director and a team of three additional pediatric hepatologists manage the program.

#### 110 TRANSPLANTS

Number of liver transplants performed in pediatric patients to date.

#### **O** DEATHS

Observed deaths in first month of liver transplant in patients July 1, 2012–Dec. 31, 2014, at Cleveland Clinic Children's (vs. 25 nationwide).

#### >50%

More than half of the transplants performed are split livers from deceased donors or partial livers (left lateral segments) from living donors.

#### 20-30%

Amount of adult liver given to a child in a living-donor transplant.

#### 1 YFAR

The length of time it takes for the adult liver to regenerate to 90 percent of its original size.



Wait time for a living donor vs. 86 days for a deceased-donor liver.



#### **GI/PSYCH**

#### **INTRODUCING:**

### Toileting Clinic for Kids and Parents

#### Group sessions address constipation and other barriers to toilet training

Toileting Clinic shared medical appointments are a joint initiative of Cleveland Clinic's pediatric behavioral health and pediatric gastroenterology. Since 2015, these group sessions have offered effective toilet training — and reassurance for families who thought their kids were the only ones struggling with constipation or leaky stool.

Each child is evaluated and treated by pediatric gastroenterologist Lisa Feinberg, MD, and child psychologist Katherine Lamparyk, PsyD. Children then meet weekly in a small group led by a child life specialist and psychology assistant while parents meet in a separate group with the psychologist.

Over four weeks, groups discuss the causes of functional constipation, the physiology of stooling and toilet training steps. Families then follow up as needed in the same group format until toilet training is complete.

"Not only is the Toileting Clinic improving access to care, but patients are having much greater success in the group setting," says Dr. Lamparyk, of Cleveland Clinic's Center for Pediatric Behavioral Health. "We follow these kids until they're 100 percent toilet trained."

Cleveland Clinic's Toileting Clinic is for children with functional constipation (with or without encopresis) that is not resolved with medication. Children are ages 3 to 8 and must be suitable for group appointments. (Those with significant developmental delays or behavioral issues should be seen individually.) New groups begin every 6 to 8 weeks.



Refer to the Toileting Clinic: 855.REFER.123.

#### **HEMATOLOGY/ONCOLOGY**

#### Service Spotlight: Sickle Cell Disease

THE TEAM: Along with a core team of two nurse practitioners, a social worker and a child psychologist, pediatric hematologist Grace Onimoe, MD, works with pediatricians and general practitioners to coordinate care and obtain subspecialty expertise from across Cleveland Clinic Children's when needed for the diverse complications of sickle cell disease.

THE PHILOSOPHY: We are well-equipped to handle the challenges our patients present — including clinical complications, frequently spotty treatment adherence and a need for intensive patient education.

Cleveland Clinic Children's Sickle Cell Program relies on a proactive, team-based strategy to ensure excellent care.

SERVICES OFFERED: A full complement of medications is considered for symptom management, along with iron overload therapy. The FDA-approved agent hydroxyurea is used to reduce the frequency of pain crises and increase the hemoglobin count.

Blood and marrow transplantation (BMT) may be considered for selected patients with frequent, severe complications and uncontrolled pain. Consultation with Cleveland Clinic Children's expert team of BMT specialists is readily available to the sickle cell population. Haploidentical transplantation may be considered on a research basis for patients who have no matched donors.



#### **REHABILITATION**

## Frequency-Specific Microcurrent Therapy

Our team at Cleveland Clinic Children's Hospital for Rehabilitation is excited about the potential that frequency-specific microcurrent (FSM) therapy holds for helping young patients. This new modality is quickly becoming the one most commonly used in our rehabilitation services.

"It is subsensory (painless) and noninvasive, and has lasting effects," explains Benjamin Katholi, MD, a pediatric physiatrist and Director of the Center for Pediatric Complementary Medicine. "Research suggests that delivering micro-amperage current while using specific frequencies to resonate with damaged tissues can reduce inflammation, improve ATP production and enhance healing.

"We've found FSM therapy highly effective for nerve and muscle pain, acute and chronic musculoskeletal injuries, and arthritis in children."



consultqd. clevel and clinic. org/FSM

#### **OUTPATIENT CARE**

## INTRODUCING: Hillcrest Hospital Pediatrics

Our newest location on the East Side offers comprehensive pediatric outpatient services, staffed by Cleveland Clinic Children's specialists, all under one roof.



6801 Mayfield Road, Mayfield Heights, OH 44124



hillcresthospital.org/specialtypeds

#### **ENDOCRINOLOGY**

## Do You Know When to Screen for Cardiovascular Risk Factors?

Given the increase in recent decades in the number of children who develop risk factors for atherosclerosis, including obesity, dyslipidemia and Type 2 diabetes, pediatricians are in an ideal position to watch for early warning signs and intervene to inhibit progression toward clinical disease.

It is important for PCPs to be aware of these issues, and to screen and counsel patients appropriately," says Cleveland Clinic pediatric endocrinologist Roy Kim, MD. "They need to make sure there are no complications and educate parents on the benefits of starting early with healthy eating and an active lifestyle."

#### Identification and management of risk factors

That's why Dr. Kim recommends the Expert Panel on Integrated Guidelines for Cardiovascular Health and Risk Reduction in Children and Adolescents, issued by the National Heart, Lung, and Blood Institute.

These comprehensive guidelines serve two purposes:

- > Risk factor prevention
- Prevention of cardiovascular disease by effective management of identified risk factors

Among its key recommendations:

- > Blood pressure checks begin at age 3 (page 27) and lipid screenings between ages 9 and 11 (page 42).
- Decause Type 2 diabetes is rare in early childhood, a fasting plasma glucose and hemoglobin A1c is recommended for children ages 10+ who are overweight and have additional risk factors based on race, ethnicity, family history of Type 2 diabetes, and darkening of neck skin — a sign of insulin resistance (page 67).
- Detailed testing recommendations for children with risk factors are condensed in a convenient table found on page 8.

Read more www.nhlbi.nih.gov/files/docs/peds\_guidelines\_sum.pdf



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