

# Update

FOR AREA PEDIATRIC PROVIDERS | FALL 2015

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## **Ready for anything**

A case study from the area's most comprehensive pediatric kidney transplant program

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Cleveland Clinic Children's Update offers news and information from Cleveland Clinic Children's for area pediatric providers.

Cleveland Clinic Children's is backed by the full resources of Cleveland Clinic and offers complete medical, surgical and rehabilitative care for infants, children and adolescents. More than 300 pediatricians and pediatric subspecialists accommodate 750,000+ patient visits annually at our main campus, at

Cleveland Clinic Children's Hospital for Rehabilitation, and at regional hospitals and family health centers. Cleveland Clinic Children's earned national rankings in 10 of 10 specialties in the 2015-16 edition of U.S. News & World Report's "Best Children's Hospitals" report.

Cleveland Clinic Children's Update is written for medical professionals and is for medical education purposes only. It should not replace the independent judgment of providers about the appropriateness or risks of a procedure or service for a given patient.

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PHOTOGRAPHY: Russell Lee, Tom Merce, Steve Travarca

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## Dear Colleagues,

Any great health system is more than the sum of its parts, but that's not saying those individual parts don't matter a lot.

At Cleveland Clinic Children's, we've been working to attract standout subspecialist experts from around the nation and the region to make the sum of our parts greater than ever and to enhance care options for local children with exceptional medical needs.



This issue of *Children's Update* is full of examples of how those efforts are paying off:

- › On page 3 we profile our new Chair of Pediatric Cardiology, Tess Vickers Saarel, MD, who brings nationally recognized expertise in pediatric electrophysiology along with a fresh vision for our flourishing cardiology program.
- › On page 11 we introduce a global authority in pediatric osteosarcoma, Peter Anderson, MD, PhD, who has also developed deep expertise in immune therapies and targeted therapy over tenures at MD Anderson Cancer Center and Mayo Clinic.
- › On page 5 we check in on the work of pediatric pulmonologist and cystic fibrosis expert Nathan Kraynack, MD, to broaden and integrate our cystic fibrosis care offerings since he joined Cleveland Clinic Children's two years ago.

It's the subspecialty expertise of individuals like these that makes possible collaborative efforts like the new Pediatric Complex Care Clinic featured on page 4 and our comprehensive pediatric kidney transplant offerings profiled on page 8.

I am grateful to all of my subspecialist colleagues for the fact that Cleveland Clinic Children's was one of only 21 facilities — and the only one in northern Ohio — recognized for top care in all 10 specialties ranked by *U.S. News & World Report* in its "Best Children's Hospitals" rankings for 2015-16.

And I am grateful to you for your continuing confidence and collaboration.

Respectfully,

**Giovanni Piedimonte, MD**

Physician-in-Chief, Cleveland Clinic Children's | Chairman, Pediatric Institute  
President, Cleveland Clinic Children's Hospital for Rehabilitation  
[piedimonte@ccf.org](mailto:piedimonte@ccf.org)

## Meet Elizabeth Vickers Saarel, MD, New Chair of Pediatric Cardiology

After a national search, Cleveland Clinic Children's recently welcomed a new chair of its Department of Pediatric Cardiology: Elizabeth (Tess) Vickers Saarel, MD. In addition to being a national authority in pediatric electrophysiology, she's no stranger to Northeast Ohio (or Cleveland Clinic), as detailed in her responses below.

### **Q: What are your specialty interests?**

Pediatric and congenital cardiology, heart rhythm disorders in children and adults with congenital heart disease, and prevention of sudden cardiac death in the young.

### **Q: Tell us about your training and career so far.**

I completed medical school at UCLA, did my residency at Rainbow Babies & Children's Hospital in Cleveland and did a pediatric cardiology and electrophysiology fellowship at the University of Michigan. I was an associate staff member at Cleveland Clinic in 2004-05 and then moved to Utah, where I became Director of Cardiac Electrophysiology at Primary Children's Medical Center and Professor of Pediatrics at the University of Utah.

### **Q: What drew you to pediatric heart disease — and to Cleveland Clinic Children's?**

Young patients with heart disease have significant risk for mortality and morbidity. I wanted to help improve the longevity and quality of life for children and young adults with heart problems.

A big part of the draw to Cleveland Clinic was the physician-led, collegial practice here. That, along with the quality of care provided for children overall and for patients of all ages with heart disease, is what brought me back to Cleveland Clinic.



### **Q: What are your priorities for the Department of Pediatric Cardiology?**

Providing the best possible care will always be top priority. I plan to support that priority by putting even more of a premium on timely and open communication with our patients and referring physicians in the region and beyond.

### **Q: Tell us a bit about your research.**

My research interests currently focus on preventing sudden cardiac death and diagnosing/treating arrhythmias in children and young adults with congenital heart disease. I am particularly interested in determining the safety of sports participation for young patients with arrhythmias and congenital heart disease. One highlight is an active grant from the NIH-sponsored Pediatric Heart Network for its Normal Electrocardiogram Project, for which I am the PI. This project is establishing a database of ECGs in children with normal echocardiograms in order to better define normal ECG findings among U.S. children of both sexes and of all ages, races and ethnicities.

### **Q: What's one trend in pediatric heart care you'd like pediatricians to be aware of?**

There's a trend in the treatment of congenital heart disease toward catheter-based interventions, including valve replacement. There's also a growing emphasis on reducing radiation exposure in young patients who require heart catheterization and heart rhythm treatment procedures. As these positive developments gain even more ground, we aim to bring their benefits to more and more young patients in Ohio and beyond.

*Physicians may contact Dr. Saarel at [saarele@ccf.org](mailto:saarele@ccf.org) or 216.636.5042.*



# New Pediatric Complex Care Clinic Helps Families Get Coordinated, Quality Care

Medical complexity in children is a challenge that's hard to overstate, both for the healthcare system and for individual families.

While medically complex children (see box) represent less than 1 percent of U.S. children, they account for up to 33 percent of U.S. pediatric healthcare spending. On the individual level, their families often struggle to find a medical home, navigate the healthcare system and coordinate the multiple subspecialty visits required.

## Launch of the Pediatric Complex Care Clinic

Cleveland Clinic Children's has responded to these challenges by introducing its Pediatric Complex Care Clinic, located on Cleveland Clinic's main campus.

"Our vision for the clinic is to provide a family-centered medical home for children with significant medical complexity," says general pediatrician Skyler Kalady, MD, who serves as the clinic's medical director. "We seek to provide high-quality care in a cost-effective manner to enhance family satisfaction. We offer access to the full spectrum of primary and subspecialty care in a coordinated fashion."

In addition to Dr. Kalady, the clinic's team includes a dedicated pediatric nurse practitioner, a dedicated nurse who serves as primary care coordinator, a pediatric dietitian and a social worker. Together, the team collaborates closely with caregivers at home and other clinicians involved in the child's care.

## A Medical Home for a Unique Population

Children with medical complexity are challenging for primary care practices because they have a variety of special needs, including:

- › Longer appointment times to adequately address concerns
- › Increased outpatient acute access for frequent exacerbations, multiple subspecialty visits and scheduling challenges
- › Care coordination to integrate services

By providing proactive and comprehensive routine care as well as early and prompt acute care, the clinic seeks to reduce ED utilization, hospitalizations, readmissions, length of stay and care fragmentation while optimizing the patient's experience.

## DEFINING TERMS

A seminal 2011 paper in *Pediatrics* defined children with medical complexity as having four key features:

- › Substantial family-identified service needs
- › Multiple chronic and severe conditions
- › Major functional limitations often requiring medical technology
- › High healthcare utilization

## How the Complex Care Clinic Works

Patients and parents have an initial two-hour comprehensive evaluation with the clinic's team, during which an individualized care plan is developed. The care coordinator subsequently helps the family navigate the healthcare system, assisting with scheduling of multiple subspecialty appointments and providing other support as needed. Patients continue to see subspecialists as indicated and return for follow-up visits at the Pediatric Complex Care Clinic every three to six months. The team is available for same-day acute visits on weekdays as new concerns arise.

Patients have access to a dedicated phone line and secure electronic messaging through Cleveland Clinic's MyChart online tool. The care coordinator provides monthly check-ins via phone or MyChart to review the care plan and address interim challenges. A dedicated billing representative is made available to all patients.

## Who's a Candidate?

The clinic accepts new patients from birth to age 16 who:

- › Have or will have long-term complex healthcare needs
- › Have major functional limits (often requiring medical equipment)
- › Require the expertise of three or more pediatric subspecialists
- › Desire a primary medical home at the main campus

*Providers can refer potential patients by calling 216.445.1995.*

*Once a patient is deemed eligible, the clinic team will contact the family to schedule the initial evaluation.*

# Combating Cystic Fibrosis on All Fronts

Success lies in an integrated team of pediatric subspecialists with close ties to adult-care colleagues.

Cleveland Clinic Children's now offers comprehensive services to patients with cystic fibrosis, employing an aggressive, multidisciplinary approach to treatment.

"Cystic fibrosis affects multiple body systems, but most critically the lungs, gastrointestinal tract and pancreatic functions," says Nathan Kraynack, MD, who directs cystic fibrosis care offerings in the Center for Pediatric Pulmonary Medicine. "One of the leading advantages of Cleveland Clinic Children's is that we have experts in every subspecialty needed to care for these complex patients."

## All About Integration

The multidisciplinary team includes pediatric subspecialists in pulmonology, endocrinology, gastroenterology, infectious diseases, adolescent medicine and rheumatology. Patients can also benefit from specialized pediatric supporting services including nutrition, respiratory therapy and physical therapy. Center for Pediatric Pulmonary Medicine staff help patients and families navigate the network of necessary providers, arranging same-day appointments with any required specialists.

"The integrated nature of Cleveland Clinic Children's sets us apart," Dr. Kraynack notes. "All our specialists can easily talk to each other by simply walking down the hall or using our integrated healthcare record, which does not exist in all healthcare organizations."

## Tapping Adult-Care Colleagues as a Resource

Patients also benefit from the Center for Pediatric Pulmonary Medicine's close ties with Cleveland Clinic's Respiratory Institute, which treats adult cystic fibrosis patients.

Elliot Dasenbrook, MD, was recently recruited from University Hospitals to direct the Respiratory Institute's adult cystic fibrosis program. Both he and Dr. Kraynack, who previously headed the Cystic Fibrosis Center at Akron Children's Hospital, are leaders in their field. They will work closely to foster collaboration between the pediatric and adult programs.

"We can reach out to the Respiratory Institute and take advantage of its resources and expertise if something seems atypical in our patients," Dr. Kraynack says. "The relationship also allows us to offer pediatric patients seamless transition to the adult cystic fibrosis program."

Other notable Cleveland Clinic offerings to pediatric cystic fibrosis patients include:

- › Standardized protocols for care delivery that have been proven to improve outcomes
- › Specialized services, including interventional bronchoscopy
- › An active, experienced pediatric and adult lung transplant program
- › A robust research program, including use of cystic fibrosis lung explants to conduct basic-science research on the condition

## Advice on Screening and Referral

All 50 states now offer newborn screening for cystic fibrosis, and about 75 percent of U.S. patients are diagnosed through newborn screening. "Newborns with an abnormal screen can be referred to Cleveland Clinic Children's," says Dr. Kraynack. "They can come on a same-day visit, get their diagnostic sweat test, see a cystic fibrosis clinician and meet with a geneticist for genetic counseling."

He cautions, however, that screening is not perfect. "Some newborns with cystic fibrosis can be missed," he says. "If you have a patient who seems to be struggling to gain weight, you need to consider cystic fibrosis as a possibility and refer them for assessment."

Referral is also in order when older children with cystic fibrosis are not responding to treatment. "If you are concerned that one of your patients isn't doing as well as expected or you want a second opinion, we can offer that," Dr. Kraynack notes. "Every one of our pediatric pulmonologists has expertise in cystic fibrosis."

*To refer a patient for cystic fibrosis evaluation or care, call 216.445.2200.*

## 4 Tips for Easing Autism Screening and Referral

No pediatrician wants to tell parents that their child should be evaluated for autism spectrum disorder (ASD). The conversation can cause anxiety for both parties, admits Leslie Speer, PhD, NCSP, of Cleveland Clinic Children's Center for Autism.

Pediatricians can alleviate stress by conducting an accurate initial screening (avoiding unnecessary referrals) and then reassuring parents if their child truly does need further evaluation. Dr. Speer offers the following recommendations.

### RED FLAGS FOR AUTISM

#### Delays in Typical Development

- › Little to no response to name when called
- › Lack of reciprocal smile
- › Limitation in shared enjoyment
- › Reduced use of gestures to communicate
- › Delayed imitation skills
- › Lack of pretend/symbolic play
- › Failure to point to request or show interest
- › Limitation in joint attention
- › Reduced eye contact

#### Atypical Behaviors

- › Unusual or intense interests
- › Insistence on nonfunctional routines
- › Repetitive motor mannerisms
- › Repetitive use of objects
- › Interest in parts of objects
- › Unusual sensory interests

**1) Listen to parents when assessing for red flags.** “It’s difficult to identify red flags during a brief office visit — particularly when young patients are not in their usual surroundings and perhaps not performing as normal,” says Dr. Speer.

Beyond watching for red flags (see sidebar) that may or may not arise during a 10- to 20-minute visit, ask parents about their child’s day-to-day behavior. Does he typically smile at others? Does she point? Does he respond to his name? Ask parents if their child has any behaviors that concern them.

**2) Choose a screening tool that works for your practice.** There are multiple options, but the Modified Checklist for Autism in Toddlers (M-CHAT) is most widely used, typically at 18- and 24-month checkups. Recommended by the American Academy of Pediatrics, M-CHAT is a 23-item yes/no questionnaire completed by parents.

However, no screening tool is perfect. False positives can occur. The Modified Checklist for Autism in Toddlers, Revised with Follow-up (M-CHAT-R/F), provides an extra layer of detection. In addition to a simplified 20-item yes/no questionnaire, M-CHAT-R/F incorporates a five- to 10-minute follow-up interview with parents of children who screen positive. This follow-up — even if done a day or two after the initial M-CHAT or conducted by another staff member — can screen out false positives and increase pediatricians’ confidence when recommending further evaluation.

**3) If you’re unsure, refer — and offer parents peace of mind.** “It’s OK to say, ‘I’m not sure, but I have concerns,’” says Dr. Speer. “There’s no harm in referring. Getting a clear diagnosis can offer peace of mind.”

While some neurologists and psychologists have autism expertise, Dr. Speer recommends referring patients to an autism center or multidisciplinary team, such as Cleveland Clinic Children’s Autism Spectrum Evaluation Team (see sidebar).

“Experts will check for speech/language delays and other conditions, not just autism,” she says. “Identifying the issue and learning what to do about it can be empowering for parents.”

“The sky’s the limit for many kids when the right teaching and support are in place as soon as possible.” — LESLIE SPEER, PhD, NCSP



**4) Reassure parents about early diagnosis.** Don't take a wait-and-see approach, advises Dr. Speer. Early diagnosis and appropriate intervention can bring better quality of life for the child and the family.

“It's important to communicate to parents that even if their child is diagnosed with autism, he or she will still grow and progress,” she says. “The sky’s the limit for many kids when the right teaching and support are in place as soon as possible.”

### The Autism Spectrum Evaluation Team: Streamlining Assessment

The Autism Spectrum Evaluation Team (ASET) at Cleveland Clinic Children's Center for Autism provides a multidisciplinary assessment of patients up to 18 years old. Any child can be referred to the ASET.

Over two weeks, patients meet four times with a range of providers, including:

- › Pediatrician, developmental pediatrician, pediatric neurologist or psychiatrist
- › Psychologist
- › Psychology assistant
- › Speech-language pathologist

“It can be difficult for physicians to know where to refer patients with possible autism spectrum disorder and difficult for families to bounce from one specialist to another,” says Leslie Speer, PhD, NCSP, who co-directs the ASET. “We brought all resources together to provide comprehensive evaluations, making a potentially stressful process as easy as possible.”

Every patient referred to the ASET follows the same care path, which Cleveland Clinic pediatric neurologist Sumit Parikh, MD, ASET co-founder and co-director, helped develop eight years ago.

“We ensure that comorbidities in children on the spectrum — such as sleep problems and gastrointestinal issues — don't get overlooked,” says Dr. Parikh. “We also make sure families get genetic testing when needed.”

Families receive a comprehensive report, including next steps and resources available at Cleveland Clinic or elsewhere in the community.

“The ASET diagnoses autism only about 60 percent of the time,” says Dr. Parikh. “Even when a patient doesn't have autism, we can direct families to the right resources.”

*For questions about autism evaluation, or to refer a patient to the ASET, call 216.448.6440.*

## Pediatric Kidney Transplantation: All-Around Readiness Required

A 12-year-old's case showcases the merits of a comprehensive transplant and dialysis program.

Kidney transplantation is considered the gold-standard treatment for renal failure in children for its ability to restore quality and length of life. Cleveland Clinic has been performing kidney transplants in pediatric patients since 1963.

Today, kidney transplantation anchors a comprehensive Cleveland Clinic Children's program for the care of acute and chronic kidney disease that is unsurpassed in breadth and depth. The multidisciplinary team includes:

- › Kidney transplant surgeons with expertise in pediatric transplantation
- › A pediatric kidney transplant medical director plus three other pediatric transplant nephrologists
- › Pediatric urologists
- › A pediatric nephrology nurse practitioner
- › Pediatric dialysis nurses
- › A dedicated renal dietitian
- › Pediatric recreation therapists
- › Pediatric social workers, child psychologists and schoolteachers

"We can provide anything a child with kidney issues needs in the form of diagnosis, management, dialysis and transplantation," says Charles Kwon, MD, Head of Cleveland Clinic Children's Center for Pediatric Nephrology.

### From Diagnosis to Dialysis with Davion

Many of the program's resources were brought to bear for Davion Johnson, who received a kidney transplant in March 2015 for end-stage renal disease. The boy had been healthy until age 12, when he began complaining of muscle cramps.

"Such cramps are common in this age group, but his seemed more severe and frequent than I would suspect from growing pains or physical activity," says Davion's longtime Cleveland Clinic general pediatrician, Kimberly Giuliano, MD.

So Dr. Giuliano ordered blood tests, which revealed significantly abnormal electrolyte and muscle enzyme levels. "Davion's renal function was the worst I have ever seen in an outpatient," she says. "It was hard to believe he was still urinating."

She immediately called Dr. Kwon, who contacted Davion's mother. Only a couple of hours after Davion had seen Dr. Giuliano, he was admitted to the PICU for hemodialysis. "Metabolic and electrolyte issues are most effectively corrected urgently with hemodialysis," says Dr. Kwon.

As soon as the boy's condition was stabilized, he was transitioned to peritoneal dialysis. "The two dialysis methods have comparable outcomes for children," explains Dr. Kwon. "It's an issue of how much responsibility the family wants to assume."

### Centralized Resources and Expertise

Outpatient hemodialysis is provided — and peritoneal dialysis monitored — at the Judith M. Power Pediatric Dialysis Unit. Cleveland Clinic Children's has the only kidney transplant program in northern Ohio with a dedicated pediatric dialysis unit. For patient and family convenience, this child-friendly unit is located with all pediatric nephrology staff and services in a single location at Cleveland Clinic Children's Hospital for Rehabilitation.

"It's a huge advantage to have all services at one site, as it allows us to get to know our patients intimately," says Dr. Kwon.

The program's dedicated pediatric nephrology nurse practitioner serves as a sort of "hub" for patients and families, coordinating outpatient appointments and pre-/post-transplant care as well as facilitating communication with physicians.





**Above** Kidney transplant recipient Davion Johnson at his four-month follow-up appointment with a pediatric nephrology nurse practitioner.



**Below** Davion with his mom, several months post-transplant.

### Preparation for Transplant

Dialysis serves as a transition time to prepare the patient physically and emotionally for transplantation.

“Transplantation for kidney failure is never emergent,” explains Dr. Kwon. “We may delay the surgery until medical and psychosocial issues are optimized. This is especially important with teens, since the most common cause of kidney failure is treatment nonadherence. We never proceed until they are on board.”

In some cases when the child is known to the staff, preemptive transplantation may be offered before dialysis is needed.

In Davion’s case, the sudden diagnosis of end-stage renal disease rocked his life. “He didn’t see it coming,” says Dr. Kwon.

In short order, however, he took ownership of his disease and was approved for transplantation.

Cleveland Clinic Children’s offers living-donor and deceased-donor kidney transplants, as well as kidney-pancreas transplants. In March,

Davion received a deceased-donor organ, which began functioning immediately. He had an uneventful recovery and was discharged six days later. His appetite, energy and concentration quickly improved, as did his grades. He remains engaged and committed to his care.

“Davion is excited to be living life off dialysis,” says Dr. Giuliano, who continues to see him for routine care. “He’s all smiles.”

### Post-Transplant Care

Because kidneys typically last only 10 to 15 years, many young kidney recipients will require several kidney transplants over their lifetime. “Our goal is to keep every organ alive as long as possible,” says Halima Janjua, MD, Medical Director of Pediatric Kidney Transplantation.

Close monitoring is key. Patients continue to receive regular checkups until they are carefully transitioned to adult nephrology care around age 21.

*(Continued on next page.)*

Almost without exception, patients don't mind returning often to the Children's Hospital for Rehabilitation, where they are well known and warmly received. "It's a priority for kids and their families to feel comfortable," notes Dr. Kwon. "It makes for a positive experience."

### Takeaway Lessons from Davion's Case

Davion's dramatic kidney failure despite his mild symptoms was an unusual case, because his blood pressure was normal. High blood pressure is often the only sign of a congenital kidney malformation, the most common cause of renal failure in childhood. It's one reason the American College of Pediatricians advocates blood pressure screenings starting at age 3.

"Screening is quick and easy," says Dr. Janjua. "Without it, unless a malformation gets identified through prenatal ultrasound, the child may go on for years with low kidney function. At puberty, when the body is changing and undergoing stress, the kidneys may suddenly give out."

In the absence of high blood pressure, making the diagnosis requires more sleuthing. Dr. Giuliano advocates taking a thorough history, even for minor and typical problems. "Often something will emerge that indicates there may be a different or unusual process going on," she explains.

In Davion's case, it was an offhand comment by his father that led her to suspect the boy's leg cramps were more than growing pains. "He said his son was tough but that he'd occasionally limp and grimace," she says. "That level of severity told me we needed to look beyond the ordinary."

*To refer a patient for kidney transplant evaluation, call 855.REFER.123.*

## Another Service: Post-Transplant Rehab

Although it wasn't needed in Davion's case, post-transplant rehabilitation therapy is another tailored service among the comprehensive transplant-care offerings at Cleveland Clinic Children's Hospital for Rehabilitation.

About one-third of pediatric transplant patients at Cleveland Clinic Children's undergo rehab therapy at the Children's Hospital for Rehabilitation, says Michael McHugh, MD, who serves as the hospital's medical director.

"The main objectives of rehab therapy in pediatric transplant patients are building stamina and restoring muscle and joint function," Dr. McHugh notes. Therapy is most often needed in heart and liver transplant recipients, he adds. "Those patients can be highly debilitated by the time they get through their transplant, so they need a lot of functional recovery."

Patients can take advantage of the day hospital at the Children's Hospital for Rehabilitation, where they come two to five days a week for intensive physical and occupational therapy while being able to return home at night. "This way they can receive a significant amount of therapy while still getting integrated back into family life," says Dr. McHugh.

Most patients undergo two to three weeks of day hospital therapy, though some are treated longer. They follow this with a period of outpatient physical therapy as needed.

As one of only about a dozen freestanding children's rehab hospitals in the nation, the Children's Hospital for Rehabilitation is staffed exclusively by pediatric specialists. This offers several distinct advantages specifically for young transplant recipients:

- › **Deep familiarity with kids' developmental milestones.** "Our therapists have spent their whole professional lives working with children," says Dr. McHugh. "They know how and why to treat 8-year-olds, 14-year-olds and 18-year-olds differently from one another."
- › **Expertise in overcoming kids' refusal to participate.** Many children don't want to participate in therapy because it hurts or they're disillusioned and want to give up. "Our pediatric therapists know how to work kids through the crying and temper tantrums when adult-care therapists might not," says Dr. McHugh.
- › **Experience working with parents.** Providing efficacious yet empathic rehab therapy while keeping both the child and parents satisfied is a skill honed over time. "Adding a parent into the relationship may change the therapy approach," says Dr. McHugh. "You have to educate the whole family on the importance of movement and restoring strength."

# Introducing Clinician-Researcher

## Peter Anderson, MD, PhD

New staff pediatrician is nationally renowned for osteosarcoma expertise.

### AT A GLANCE

**Appointment:** Staff, Department of Pediatric Hematology, Oncology and Blood & Marrow Transplantation

**Specialty interests:** Pediatric osteosarcoma, solid tumors, cancer genetics and novel therapies, reducing toxicity of cancer treatment, outpatient therapy of cancer

**Background in brief:** Practiced at University of Texas MD Anderson Cancer Center, where he was section chief of non-neural solid tumors, and Mayo Clinic, where he launched the pediatric bone marrow transplant program. Medical degree from Mount Sinai School of Medicine. Residency in both internal medicine and pediatrics at Duke; fellowship in pediatric hematology-oncology at University of Minnesota.

**Research:** More than 120 peer-reviewed publications, most notably on immune therapies and bone-seeking radiopharmaceuticals as targeted agents for osteosarcoma. Principal investigator on numerous studies, including two very large (> 200 patients) osteosarcoma and Ewing sarcoma immunotherapy trials. Currently studying how to boost effectiveness of radiation treatment with new medications.

### IN HIS OWN WORDS

**Proudest discovery:** “In the 1990s, I became discouraged about a chemotherapy side effect, mouth sores. After studying how glutamine heals mucosal tissue, I discovered that putting glutamine in a sugar suspension could promote mucosal healing during chemotherapy. With help from several colleagues, my discovery was turned into a commercial enterprise, Healios Products, which now distributes the glutamine disaccharide powder to cancer patients — and it is free for children.”

**One of the key motivations behind his practice:** “I want to help families of children with cancer have more outpatient therapy — and thus be able to sleep in their own beds.”



**Collaborating with Taussig Cancer Institute:** “Only 5 percent of cancer cases are in children, so the best new childhood cancer treatments will develop from adult cancer treatments. It’s a major advantage to be in an organization like Cleveland Clinic that provides both pediatric and adult cancer care, and where physicians can collaborate to do cutting-edge research. In this way, children can also benefit from advances coming out of Cleveland Clinic’s Taussig Cancer Institute. My solid tumor group will work regularly with Taussig Cancer Institute colleagues.”

**Patient care:** “My focuses include improving communication with patients and families. We sometimes assume that families comprehend and remember most of what we tell them. To reinforce better understanding, I often provide a flash drive with files that include a one-page summary of the condition, key contact information, a personalized treatment calendar, images of the patient’s CT or PET scans (so they can visualize the tumor) and articles to help families become experts on the condition. These resources help educate and guide families.”

**Physicians can reach Dr. Anderson at [andersp@ccf.org](mailto:andersp@ccf.org) or 216.445.4044.**

# Adolescent Eating Disorders: Here's Help Keeping Up With an Evolving Field

Expanded diagnostic categories and family-centered therapy loom large among recent developments.

Among the latest revisions to the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* — as reflected in the DSM-5, released in 2013 — are expanded categories for feeding and eating disorders (see sidebar).

While earlier DSM versions included anorexia nervosa, bulimia nervosa and the catchall “eating disorder not otherwise specified” (ED-NOS), DSM-5 introduced two new categories — binge eating and avoidant/restrictive food intake disorder (ARFID) — to increase options for actionable diagnoses.

“Lumping together all those who did not have anorexia nervosa or bulimia into ED-NOS, or unspecified eating disorders, was not helpful for treatment centers trying to figure out what works best for distinct groups of patients,” explains Ellen Rome, MD, MPH, Head of the Center for Adolescent Medicine at Cleveland Clinic Children's.

“Some of the same treatments are useful, such as family-based refeeding for children and adolescents who restrict their intake, but we're still fine-tuning what works,” adds Dr. Rome, who was among the experts on a working group that proposed changes to the criteria for eating disorders in advance of DSM-5. “Having new categories for binge eating and ARFID allows us to look at outcomes for these patients and learn how to improve our quality of care.”

## Clinical Pearls from the Latest Literature

Since the release of DSM-5, Dr. Rome has co-authored several studies and other journal articles that point to the importance of the new categories and the impact on patients and providers. Here are a few examples and insights from each.

**1** In a retrospective case-control study of more than 700 8- to 18-year-olds (*J Adolesc Health*. 2014;55:49-52), Dr. Rome and peers at seven other hospitals confirmed that patients with ARFID are demographically and clinically distinct from those with anorexia nervosa and bulimia nervosa. Among the distinctions, they concluded that patients with ARFID are significantly underweight, have a longer duration of illness and are more likely to have comorbid medical or psychiatric symptoms.

**2** In a Society for Adolescent Health and Medicine position paper (*J Adolesc Health*. 2015;56:121-125), Dr. Rome and colleagues documented top-level evidence that most adolescent eating disorders can be managed on an outpatient basis and midlevel evidence that inpatient refeeding protocols for patients with anorexia nervosa can be more aggressive than previously recommended.

## Categories of Feeding and Eating Disorders in DSM-5

**Anorexia nervosa** — Characterized by an intense fear of gaining weight or becoming fat and a distorted body image that leads to extreme dieting.

**Binge eating disorder** — Characterized by recurring episodes of eating large amounts of food in a short time and a sense of lack of control over eating during the episodes.

**Bulimia nervosa** — Marked by frequent binge-eating episodes followed by inappropriate behaviors to avoid weight gain (e.g., self-induced vomiting; misuse of laxatives, diuretics and other medications; fasting; excessive exercise).

**Avoidant/restrictive food intake disorder (ARFID)** — Persistent failure to meet appropriate nutritional and/or energy needs associated with significant weight loss or failure to gain weight, substantial nutritional deficiency, dependence on enteral feeding and marked interference with psychosocial functioning.

**Feeding and eating disorders not otherwise specified** — Includes atypical anorexia nervosa (not yet underweight), purging disorder (no binges), subthreshold bulimia nervosa, subthreshold binge eating disorder and night eating syndrome.





## RED FLAGS FOR EATING DISORDERS

“If a family member, teacher, peer or pediatrician hears alarm bells about an eating disorder, pay attention,” advises Dr. Rome. “The adolescent may not have a disorder at that moment, but weekly or monthly follow-up may be needed to ensure they aren’t developing one.” She says warning signs include:

- › Skipping or avoiding meals
- › A change in eating habits, such as a switch to veganism or vegetarianism
- › Heart rate under 60
- › Repetitive dieting
- › Obsessive rituals around preparing and eating food
- › Repetitive body-checking behaviors, such as weighing oneself or waist-pinching
- › Fainting, dizziness or fatigue
- › Sensitivity to cold

**3** In a concurrent review article (*J Adolesc Health*. 2015;56:370-375), Dr. Rome and the rest of the position paper writing group from point 2 above emphasized that family-based therapy has strong support as first-line psychological treatment for adolescents with anorexia nervosa. They noted that it’s useful for other adolescent eating disorders too.

### Putting Family at the Fore

Dr. Rome says the centrality of family-based therapy, also known as the Maudsley method — where parents assume an important role in ensuring that their children achieve early and lasting weight restoration — is a relatively recent trend.

“It represents a change from the 1990s, when parents were cut out of the equation. We used to do ‘parentectomies,’” she quips. “But it turns out that kids get better faster if parents are part of the equation.”

One of the Maudsley method’s tenets is family-based refeeding, which can be supported by a pediatrician or dietitian versed in eating disorders. Family-based refeeding has three stages:

- 1) Parents are in charge of all meals.
- 2) Parents are in charge of all meals except one meal or snack.
- 3) Adolescents pick their food but ask parents if they are meeting all their nutritional needs. Parents help add to the plate if the teen underpicks portions or certain food groups.

“Patients in families that do the Maudsley method correctly — where the kid gains weight in the first month — are most likely to be recovered a year later,” says Dr. Rome.

“Our approach is to help empower parents to feed their kids appropriately and to free families from the eating disorder mindset,” she adds. “We try to help kids and their parents see the child/adolescent as separate from the eating disorder.”

*To refer a patient to the Center for Adolescent Medicine for specialized eating disorders care, call 216.444.4367.*

## Center for Adolescent Medicine Welcomes Its Newest Specialist



Cleveland Clinic Children’s is pleased to welcome adolescent medicine specialist **Veronica Issac, MD**, to its Center for Adolescent Medicine.

Dr. Issac comes to us from the University of Colorado, where she

did a fellowship in adolescent medicine after completing her pediatrics residency at the University of Pittsburgh. Her research interests center on reproductive health. Dr. Issac sees patients at Cleveland Clinic’s main campus.

## CLEVELAND CLINIC CHILDREN'S

## NEW STAFF

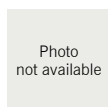
Cleveland Clinic Children's welcomes the following new pediatric subspecialists:

## ADOLESCENT MEDICINE



**Veronica Issac, MD**  
Main campus  
216.444.3566  
issacv@ccf.org

## ANESTHESIOLOGY



**Brett Elo, DO**  
Euclid and Fairview hospitals  
216.476.7052  
elob@ccf.org



**Katrina Morscher, MD**  
Fairview Hospital  
216.476.7052  
morschk@ccf.org

## CARDIOLOGY



**Elizabeth Vickers Saarel, MD**  
Main campus  
216.636.5042  
saarele@ccf.org

## CRITICAL CARE



**Orkun Baloglu, MD**  
Main campus  
216.518.3444  
baloglo@ccf.org

DEVELOPMENTAL &  
REHABILITATIVE PEDIATRICS

**Yana Shumyatcher, MD**  
Children's Hospital for  
Rehabilitation  
216.448.6254  
shumyay2@ccf.org

## GASTROENTEROLOGY



**Jacob Kurowski, MD**  
Main campus, Medina  
Medical Office Building  
216.445.9394  
kurowsj@ccf.org



**Sophia Patel, MD**  
Main campus, Avon  
(Richard E. Jacobs Health Center)  
216.444.9000  
patels5@ccf.org

## GENERAL SURGERY



**Richard Herman, MD**  
Main campus, Fairview and  
Hillcrest hospitals  
216.444.5522  
hermanr@ccf.org

HEMATOLOGY, ONCOLOGY AND BLOOD &  
MARROW TRANSPLANTATION

**Peter Anderson, MD**  
Main campus  
216.445.4044  
andersp@ccf.org



**Iliia Buhtoiarov, MD**  
Main campus  
216.444.3736  
buhtoi@ccf.org

## HOSPITAL MEDICINE



**Marisa Matthys, MD**  
Main campus  
216.952.1712  
matthym@ccf.org



**Heidi Szugye, DO**  
Hillcrest Hospital  
216.318.7353  
szugyeh@ccf.org

## PULMONARY MEDICINE



**Fariba Rezaee, MD**  
Main campus  
216.444.3916  
rezaeef@ccf.org

## Earn CME credit for pediatric courses from Cleveland Clinic's Center for Continuing Education

**Oct. 14, 2015, 6-9 p.m.**  
(dinner program)

### Important Cardiology Updates Impacting Women and Children

*Beachwood Family Health and Surgery Center, Beachwood, Ohio*

Join Cleveland Clinic's maternal-fetal medicine and pediatric cardiology specialists as they discuss important cardiology issues facing women and children. Dinner and moderated discussion for all attendees. Topics include:

- Pregnant mothers with congenital heart disease: cardiology, OB and primary care
- Genetic diseases of the heart: diagnosis and implications for sports participation
- Pediatric heart surgery from 1938 to 2015: an update

RSVP to Janet Zaibek at 216.448.6600 or [zaibekj@ccf.org](mailto:zaibekj@ccf.org).

**Oct. 20, 2015, 5:30-9 p.m.**  
(dinner program)

### A Comprehensive Review of Pediatric Hematology and Oncology


*Beachwood Family Health and Surgery Center, Beachwood, Ohio*

A comprehensive review of diseases, treatments and challenges in pediatric hematology and oncology, including sarcomas, leukemia, sickle cell disease and brain tumors. Dinner and moderated discussion for all attendees.

RSVP to Janet Zaibek at 216.448.6600 or [zaibekj@ccf.org](mailto:zaibekj@ccf.org).

Visit [ccfcme.org](http://ccfcme.org) for a complete listing of pediatric CME offerings, both live and online. Choose "Pediatrics" under "Browse by Specialty."

Your Guide to Cleveland Clinic Children’s **Care in the Community**

<div> Cleveland Clinic Children's</div>	Main campus	Children's Hospital for Rehabilitation	Euclid Hospital	Fairview Hospital	Hillcrest Hospital	Medina Hospital	Avon — Richard E. Jacobs Health Center	Avon Pointe Family Health Center	Beachwood Family Health Center	Brunswick Family Health Center	Chagrin Falls Family Health Center	Garfield Heights Sports Health Center	Independence Family Health Center	Mentor Polo Building	Solon Family Health Center	Strongsville Family Health Center	Twinsburg Family Health Center	Westlake Medical Campus	Willoughby Hills Family Health Center	Wooster Family Health Center
Allergy and Immunology 216.444.5437	•			•		•	•				•		•		•	•	•		•	
Behavioral Health 216.445.7574	•	•		•	•	•							•		•	•	•	•	•	
Cardiology & CT Surgery <sup>1</sup> 216.445.5015	•			•	•	•	•		•							•				•
Dermatology 216.444.5725	•						•						•							
Developmental & Rehabilitative Pediatrics <sup>2</sup> 216.448.6179		•		•		•	•							•		•	•			
Emergency Services				•	•															
Endocrinology 216.444.5437	•			•	•	•	•										•			
Gastroenterology 216.444.5437	•			•	•	•	•									•	•			
General Surgery 216.445.7878	•			•	•		•													
Genetics 216.636.1768	•																			
Gynecology <sup>3</sup> 216.444.6601	•					•				•			•							•
Hematology & Oncology 216.444.5517	•				•															
Inpatient Care/ Neonatology	•	•		•	•	•														
Integrative Medicine 216.448.6610		•																		
Nephrology 216.444.6123	•	•				•	•						•	•			•			
Neurology <sup>4</sup> 216.636.5860	•				•			•									•			
Neurosurgery 216.636.5860	•																			
Ophthalmology 216.444.2020	•																			
Orthopaedic Surgery 216.444.2606	•		•				•		•			•	•		•	•	•		•	
Otolaryngology 216.444.8500	•								•				•				•			
Plastic Surgery 216.444.6900	•						•													
Primary Care Pediatrics <sup>5</sup> 216.444.5437	•		•		•	•	•	•	•	•	•		•	•	•	•	•	•	•	•
Psychiatry 216.636.5860	•			•																
Pulmonary Medicine 216.444.5437	•			•	•	•	•										•			
Radiology 216.445.9597	•		•	•	•		•		•		•		•		•	•	•		•	
Rheumatology 216.444.5437	•						•										•			
Sports Health <sup>6</sup> 216.445.0096	•		•			•	•		•	•	•	•	•		•	•	•	•	•	•
Therapy Services <sup>7</sup> 216.636.5437		•																		
Urology 216.444.5600	•					•	•						•							

<sup>1</sup> Cardiology also at Ashtabula County Medical Center, Lorain Family Health Center and Pomerene Hospital  
<sup>2</sup> Developmental & Rehabilitative Pediatrics also at Firelands Regional Medical Center  
<sup>3</sup> Gynecology also at Marymount Hospital and at community locations in Brooklyn (Ridge Park) and Westlake (Columbia Road)  
<sup>4</sup> Sleep Medicine also at Sleep Center at Fairhill  
<sup>5</sup> Primary Care Pediatrics also at Elyria and Lorain family health centers, Stephanie Tubbs Jones Health Center, Westown Physicians Center, Mentor Medical Office Building and community locations in Broadview Heights, Chesterland, North Olmsted and Westlake (Gemini and Columbia Road)  
<sup>6</sup> Sports Health also at Lutheran Hospital, Mentor Rehabilitation and Sports Therapy and Middleburg Heights Orthopaedics  
<sup>7</sup> Therapy Services also at community locations in Beachwood, Brunswick, Cuyahoga Falls, Middleburg Heights and Westlake

#### CLEVELAND CLINIC CHILDREN'S

## Resources for Physicians

### 24/7 HOSPITAL TRANSFERS/ADMISSIONS

*Cleveland Clinic Children's, main campus*  
216.448.7000 or 866.547.1467

*Cleveland Clinic Children's Hospital for Rehabilitation*  
216.448.6400 or 800.635.2417

#### *Critical Care Transport*

To arrange a routine pediatric transfer via Cleveland Clinic Children's Critical Care Transport fleet, call 216.448.7000 or 866.547.1467. For our autolaunch protocol for neonatal and pediatric emergencies, call 877.379.CODE (2633).

### INFORMATIONAL RESOURCES

#### *Referring Physician Center and Hotline*

For 24/7 information on our pediatric specialists, call 855.REFER.123 (855.733.3712).

#### *Pediatric Physician Liaison*

For service-related issues or information about our pediatric specialists and services, contact Janet Zaibek, RN, [zaibekj@ccf.org](mailto:zaibekj@ccf.org).

#### *Staff Directory and Services*

To view our specialists and services, visit [clevelandclinicchildrens.org/staff](http://clevelandclinicchildrens.org/staff).

#### *Track Your Patients' Care Online*

Establish a secure online DrConnect account for real-time information about your patients' treatment at Cleveland Clinic. Visit [clevelandclinic.org/drconnect](http://clevelandclinic.org/drconnect).

### SINGLE CULTURE OF CARE, MULTIPLE ENTRY POINTS

Cleveland Clinic Children's offers comprehensive medical, surgical and rehabilitative care at more than 40 community locations throughout Northeast Ohio.

### OUTPATIENT CARE

*Diverse pediatric subspecialty outpatient services are available at:*

- Our main campus in Cleveland
- Fairview, Hillcrest and Medina hospitals
- Multiple family health centers across Northeast Ohio

### INPATIENT CARE HIGHLIGHTS

#### *Cleveland Clinic Children's, main campus*

- Inpatient unit with 24/7 pediatric hospitalist staffing and dedicated pediatric ancillary services (radiology, anesthesiology, general surgery, etc.)
- Special Delivery Unit and level IIIC NICU
- Child life services

#### *Cleveland Clinic Children's Hospital for Rehabilitation*

- Lerner School for Autism and Center for Autism
- Inpatient unit with 24/7 hospitalist coverage
- Day hospital
- Dedicated pediatric dialysis unit
- Outpatient care and therapy services (PT, OT, speech, aquatic)

#### *Fairview and Hillcrest hospitals*

- Inpatient unit with 24/7 pediatric hospitalist staffing and dedicated pediatric ancillary services (radiology, anesthesiology, general surgery, etc.)
- 24/7 pediatric emergency department
- Level III NICU
- Child life services

## Stay connected to Cleveland Clinic



Consult QD Blog for Clinicians  
[consultqd.clevelandclinic.org/pediatrics](http://consultqd.clevelandclinic.org/pediatrics)



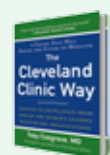
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### THE CLEVELAND CLINIC WAY

*By Toby Cosgrove, MD, CEO and President, Cleveland Clinic*

[clevelandclinic.org/ClevelandClinicWay](http://clevelandclinic.org/ClevelandClinicWay)