A family affair

Two specialized clinics take on familial heart diseases
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 in 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.

Staff Directory and Services
To view our specialists and services, visit 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.

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
Children are not small adults, but they can develop diseases more commonly seen in adults. They can also inherit genes or be raised with lifestyles that dispose them to developing illnesses in adulthood.

When it comes to treating these young patients, we at Cleveland Clinic Children’s have an advantage: Being integrated with the adult-care specialists at Cleveland Clinic is one of our greatest strengths.

Every day, our pediatricians and pediatric specialists work side by side with some of the finest adult-care physicians and surgeons in the world. This collegial relationship allows them to learn from the adult experience and adapt their lessons to their young patients. The close relationship also provides access to human and technological resources that are invaluable for providing complex care.

When you read about our heart transplant program (p. 4) or our adoption of robotic surgery in children (p. 6), it will be clear how we have benefited from the adult experience. The issue’s opening and closing articles also make clear how support from adult-care specialists helps our specialists provide exceptional care for children with familial hyperlipidemia, inherited arrhythmias or liver disease (pp. 2 and 12).

Being part of Cleveland Clinic also reinforces the value of a multidisciplinary group practice. Our Cleft Lip and Palate Clinic (p. 8) is a shining example of a multidisciplinary clinic that provides truly comprehensive care.

Finally, being a hospital within a hospital means we can provide care for life. Our patients retain the same medical record when they graduate from pediatric to adult providers. And in many specialties — you will read about urology here (p. 10) — we ease the transition through special programs.

At Cleveland Clinic Children’s, our efforts to deliver the best possible patient care are paying off: This year, U.S. News & World Report named us a national leader in 10 of 10 specialties. But this should be no surprise, since we are part of Cleveland Clinic, one of the top 4 hospitals in the country.

Respectfully,

Giovanni Piedimonte, MD
Physician-in-Chief, Cleveland Clinic Children’s | Chairman, Pediatric Institute
President, Cleveland Clinic Children’s Hospital for Rehabilitation
piedimg@ccf.org
A Family Affair

Specialized clinics offer hope for children and families with inherited lipidemias or arrhythmias.

Familial Hyperlipidemia Clinic

For individuals who inherit a defective gene that codes for the LDL receptor, or a mutation of apolipoprotein E or B, no amount of dietary change and exercise will lower cholesterol enough to protect against a cardiovascular event.

For children with these genetic abnormalities, Cleveland Clinic’s Familial Hyperlipidemia Clinic pools the expertise of a pediatric endocrinologist, an adult-care cardiologist and other clinicians to offer care that encompasses the entire family.

“We understand hyperlipidemia in children and how risk increases as the child grows,” says pediatric endocrinologist Douglas Rogers, MD, who directs the clinic with cardiologist Michael Rocco, MD. “When dietary and other lifestyle changes are insufficient to lower risk, we are comfortable using medications normally prescribed for adults.”

He adds that the clinic distinguishes itself by its ability to also treat the child’s parents. “In our experience, few parents of children with hypercholesterolemia know their own cholesterol levels,” he says. “In most cases, a parent has dyslipidemia too.”

Cleveland Clinic offers two multidisciplinary clinics for children and adults with genetic forms of hyperlipidemia and arrhythmia that require special diagnostic and management expertise. Family-centered care in these clinics is provided by pediatric and adult-care subspecialists with support from geneticists and the formidable resources of Cleveland Clinic.
Assessing pediatric risk

Any child age 2 or older is at risk if he or she has a family history of dyslipidemia or premature heart attack (before age 55 in males and before 65 in females), a parent with LDL-C levels greater than 240 mg/dL, or a medical condition such as diabetes, hypertension, lupus, chronic liver or kidney disease, chronic treatment with glucocorticoids or sirolimus, or history of organ transplantation.

Children ages 2 through 8 should undergo a lipid screening if they have two or more risk factors.

Pediatricians are advised to obtain fasting lipid levels, or nonfasting cholesterol and HDL-C levels, in all children between ages 9 and 11, before the onset of puberty. Any child with an LDL-C greater than 130 mg/dL, a total-C minus HDL-C over 160 mg/dL or a fasting triglyceride level over 400 mg/dL should be referred.

Treatment: A mix of lifestyle change and early drug therapy

Hyperlipidemia is treated first with diet modification. Families are instructed to avoid saturated fats and include stanols or sterols in the diet. These products compete with cholesterol for absorption in the gut.

Statins may be prescribed to children over age 10. “If the child has no other cardiovascular risk factors, we will start statin therapy when the LDL-C level reaches 190 mg/dL,” explains Dr. Rogers. “If the child has a family history of early heart disease or significant risk factors for early heart disease, then we recommend treatment at 160 mg/dL. The presence of diabetes or lupus requires treatment at 130 mg/dL.”

In very rare cases of extremely high LDL-C, plasmapheresis may be advised.

High triglyceride levels can be treated with additional exercise, elimination of sugar, and limitation of fats and oils. If levels remain high (> 400 mg/dL), omega-3 supplements and fenofibrate therapy may be started. Patients with high triglyceride levels or mixed hyperlipidemia may be screened for a condition such as metabolic syndrome, type 2 diabetes or polycystic ovary syndrome.

Dr. Rogers and his colleagues also see patients with mixed hyperlipidemia. “Because this is a lifestyle issue, our dietitian teaches them how to choose appropriate foods, and we help them figure out how to balance calorie intake against activity levels,” he says.

Inherited Arrhythmia Clinic

The Inherited Arrhythmia Clinic is a multidisciplinary effort aimed at managing electrical abnormalities associated with sudden cardiac death. The clinic brings together pediatric and adult electrophysiologists with geneticists to provide comprehensive, family-centered care to patients with inherited arrhythmia disorders.

A common cause of sudden death in the young

“These disorders are not very common, but they can be life-threatening,” says pediatric electrophysiologist Peter Aziz, MD, referring to long QT syndrome, Brugada syndrome and catecholaminergic polymorphic ventricular tachycardia (CPVT).

Inherited arrhythmias are a common cause of sudden death in young athletes and are believed to account for up to 15 percent of sudden infant death syndrome cases. The clinic’s goal is to identify at-risk children and institute preventive measures to avoid tragedies like these.

All in the family

A history of sudden death in a family member should prompt referral to an arrhythmia specialist, as should exertional syncope or a personal history suggestive of arrhythmia. The entire family — child, siblings and parents — will be screened and offered treatment, as appropriate.

A genetic counselor participates in diagnostic testing. “If a parent has an abnormality, there is often a 50 percent chance each child will have it,” Dr. Aziz explains. “This highlights the importance of a family-centered approach.”

Treatment depends on the arrhythmia subtype and may include medication (e.g., a beta-blocker), trigger avoidance or an implantable cardioverter-defibrillator.

Because long QT syndrome and CPVT are catecholamine-dependent, sports participation may need to be restricted, though there are no hard-and-fast rules. “Some children who are adherent to treatment and have appropriate safety mechanisms in place can play sports safely,” says Dr. Aziz.

To refer a patient to the Inherited Arrhythmia Clinic, please call 216.444.4735.

To refer a patient to the Familial Hyperlipidemia Clinic, please call 216.444.9353.
In Pediatric Heart Transplantation, Resourcefulness Is the Rule

When young hearts start to fail, optimal management involves forestalling transplant when possible — increasingly with LVADs — and being ready to transplant when needed.

Cardiomyopathy is an insidious disease causing vague, intermittent symptoms and a gradual decline in energy. By the time the child sees a doctor, the heart is often barely able to pump, and immediate medical attention is imperative.

**The case of Logan Martin**

Logan Martin's story is typical. A robust, soccer-playing teenager from Dover, Ohio, Logan developed intermittent abdominal pain in 2013. When it failed to resolve after several months, his mother took him to the doctor. Abdominal tests were negative, but a chest X-ray revealed fluid in the pleural spaces and an enlarged heart. When an ECG and echocardiogram confirmed heart failure, Logan was immediately transferred to Cleveland Clinic Children’s.

“Logan didn’t realize for a long time that something was wrong, because his energy level declined very slowly,” says Robert Stewart, MD, Surgical Director of Congenital Heart Surgery at Cleveland Clinic Children’s. “Suddenly, he deteriorated very quickly.”

**Job No. 1: Medical tune-up**

“When kids are transferred to our hospital, our first job is to stabilize them,” says Gerard Boyle, MD, Medical Director of Pediatric Heart Failure and Transplant Services. If they have difficulty breathing on their own, a cardiac anesthesiologist is called to insert a breathing tube. CPR is performed if the heart stops or slows dramatically. As a safety precaution, Dr. Stewart and his team stand by to support the patient with extracorporeal membrane oxygenation (ECMO) if it is necessary.

After intubation, patients generally require a couple of days to stabilize. When all goes well, a gradual transition to oral medication is accomplished. “This is often not the case, and we have to list the patient for transplant right away,” says Dr. Boyle.

**Making the most of medical management**

Logan was diagnosed with dilated cardiomyopathy with left-ventricular noncompaction. He was treated with oxygen, a diuretic and IV milrinone.

When patients are referred early, medical therapy may prevent deterioration and transplantation. “Heart transplantation is not a cure,” says Dr. Boyle. “It carries risks of its own. We help patients keep their own hearts as long as possible before subjecting them to the potential complications of the transplant procedure and the antirejection medications.”

For patients like Logan, meticulous medical management helps promote survival until a donor heart can be found.

**Emergency preparedness is key**

Logan was hospitalized for about 36 hours when he exhibited signs of stroke. The stroke team took immediate action. A CT revealed a clot in Logan’s left middle cerebral artery. He was taken to the neurointerventional suite, where the clot was extracted with a specialized catheter equipped with pincers.

“Thanks to these resources,” says Dr. Boyle, “we were able to identify and extract the clot within an hour of Logan’s first symptoms. Within three hours, he was back in his room and fully functional.”

**Using LVADs to bridge the gap**

Despite maximum medical therapy, Logan’s heart failure worsened. At this point, his cardiologists believed he might benefit from a left ventricular assist device (LVAD).
Three LVADs are available for pediatric patients. All require careful management of anticoagulation.

Logan was given a third-generation HeartWare® VAD. He began to gain lean body mass almost immediately and was able to begin physical therapy. As a result, he was in good condition to tolerate the transplant when a donor heart arrived six weeks later.

The measure of transplantation: Experience and outcomes

Logan was transplanted in April 2014 and has fared well since, recovering quickly and graduating from high school on time despite having missed seven months of classes.

His was one of five pediatric heart transplants performed at Cleveland Clinic Children’s in the first seven months of 2014, bringing the total to 145 since Cleveland Clinic’s pediatric heart transplant program began in 1985.

But the true measure of a heart transplant program is not how many patients are transplanted but how well they do before and after surgery. In this arena, Cleveland Clinic Children’s patient and graft survival rates are routinely at or above national averages and severity-adjusted expected levels. Moreover, its pediatric cardiologists have successfully bridged four young children to transplant using the Berlin Heart Excor® LVAD without a single pump-related major complication.

A lifelong relationship

Dr. Boyle will continue to monitor Logan’s progress for life, as he does for most of his patients. Nearly 75 pediatric heart transplant recipients are still being followed by Cleveland Clinic Children’s cardiologists.

Exceptions are those who develop conditions that require the expertise of adult-care cardiologists, such as becoming pregnant while taking antirejection medications. Because patients typically develop a tight bond with their pediatric cardiologist, a transition specialist helps them develop confidence in their new care team.

Meanwhile, Drs. Boyle and Stewart meet regularly with colleagues from Ohio’s other two pediatric heart transplant programs and discuss every patient they wait-list or transplant. “The more we share, the more we learn from our collective experience,” says Dr. Stewart.

Logan is of nearly 75 pediatric heart transplant recipients still being followed by Cleveland Clinic Children’s cardiologists.
Ready for the Robots

Advanced instrumentation and visualization bring exquisite precision to selected procedures in small bodies.

Above: Dr. Seifarth performing a robotic Nissen fundoplication.
Although robotic assistance enables certain open surgeries to be performed with both minimal invasiveness and high precision, only a small number of children’s hospitals use robots for selected general pediatric surgery procedures. Cleveland Clinic Children’s is one of them.

“Robotic surgery offers a solution to current challenges of minimally invasive surgery in children, particularly for delicate procedures requiring surgical dexterity within a small workspace,” says pediatric general surgeon Federico Seifarth, MD.

Dr. Seifarth currently uses the robot in pediatric patients undergoing the following procedures:

- Nissen fundoplication
- Choledochal cyst excision
- Adrenalectomy
- Complex abdominal surgeries such as removal of abdominal masses
- Reconstructive surgeries such as repair of congenital diaphragmatic hernia

Beyond laparoscopy: Hands vs. chopsticks

The primary benefits of robot-assisted minimally invasive surgery are realized through the improved dexterity enabled by articulating instruments, better visualization and reduction of hand tremor.

Whereas Dr. Seifarth likens the use of laparoscopic instruments to “operating with chopsticks,” he says robotic instruments move like hands. This flexibility enables him to reach behind a structure such as the esophagus — rather than moving it aside — and ensures finer dissection and more precise placement of sutures.

“There’s no question that the robot enables higher-quality stitch placement and repair,” he says. “The operation is not subject to technical limitations.”

A high degree of magnification and a 3-D view on the monitor allow the surgeon to visualize the anatomy in sharp detail and with depth perception. “The robot improves surgical outcome by enhancing the surgeon’s skills with technology that allows better visualization and tremor suppression,” Dr. Seifarth explains.

Borrowing from the adult experience

Robots have been used in adult urology and gynecology since 2005 and are increasingly embraced by other specialties. At Cleveland Clinic, a large number of surgeons in multiple disciplines keep five robots and two training robots in daily use. Dr. Seifarth takes advantage of the abundance of expertise among his adult-care colleagues to hone his skills, resulting in an enviable level of experience.

“Through collaboration with the adult robotics team, we’ve identified selected indications where we can use the robot to perform operations we’d normally do laparoscopically or with traditional open surgery,” he says. “We can get the same or better quality of operation, but with less pain and without a big scar.”

Although scar size may seem trivial in the context of a serious medical condition, he says it looms large for many children and parents. “Why should any child carry a big scar for life if he or she doesn’t have to?”

Today’s applications — and tomorrow’s

One of the procedures most commonly performed with robotic assistance at Cleveland Clinic Children’s is Nissen fundoplication, for which the robot offers clear advantages over laparoscopic instrumentation, especially in complex cases such as reoperations.

Dr. Seifarth also finds the robot particularly valuable for choledochal cyst excision, an operation for which a minimally invasive approach is not always routine, due to the challenge of meticulous dissection in babies using laparoscopic instruments. “Any bile duct anomaly is very demanding to operate on in a minimally invasive way, but the dexterity of the robot offers a significant advantage,” he observes.

Since minimal invasiveness is a guiding principle across Cleveland Clinic Children’s surgical services, Dr. Seifarth plans to apply robotic surgery to a number of new uses, including splenectomy, bowel resection and reconstruction, and various gynecologic and oncologic procedures.

“Robotic technology has evolved greatly in the past decade,” he notes. “Recent efforts succeeded in developing smaller, more flexible and more affordable instruments to benefit a wide range of pediatric patients. Robotic surgery is ready to be applied in children, and I hope other pediatric specialists follow us to develop its full potential for the most delicate patients.”
Cleft Lip and Palate Clinic Takes a Whole-Child Treatment Approach

Cleveland Clinic Children’s provides comprehensive, sophisticated care for youngsters with all types of cleft lip and palate abnormalities. Its multidisciplinary Cleft Lip and Palate Clinic brings together a team of experts to address diverse needs associated with these deformities while minimizing stress on patients and their families.

“Children with cleft lip and palate may require multiple operations by their teenage years,” says pediatric otolaryngologist Brandon Hopkins, MD, one of several at Cleveland Clinic Children’s with fellowship training in cleft and craniofacial care. “We keep the number of operations as low as possible by coordinating tests and procedures.

“Our overall goal is to deliver complete care from birth, enabling the child to graduate into life without a noticeable cleft or nasal deformity.”

Enduring care from a wide-ranging team

A simple cleft lip may be repaired in a single operation performed by a cleft surgeon. More complex deformities, often including a cleft palate, require care from a team of specialists throughout childhood. Cleveland Clinic Children’s is structured to provide all services required by patients with any level of deformity. The Cleft Lip and Palate Clinic team includes:

• Cleft surgeons (plastic surgeons and pediatric otolaryngologists) to ensure the child’s cosmetic appearance and functionality by repairing the cleft lip, performing palate repair, reconstructing ear deformities, correcting velopharyngeal insufficiency, addressing nasal deformities and performing orthognathic surgery. The pediatric otolaryngologist also may insert and replace ear tubes to minimize hearing loss, address nasal breathing issues and sleep apnea, and manage voice and swallowing concerns.
• Orthodontists to evaluate for braces, timing of alveolar bone grafting and orthognathic surgery
• A general pediatrician, who helps oversee the patient’s overall health during cleft therapy
• A speech pathologist to assist with feeding concerns, promote normal speech and help determine the procedures necessary to produce a normal voice
• An audiologist to conduct hearing tests and optimize hearing with hearing aids
• A geneticist to check for potential underlying causes of the cleft and provide comfort and counseling to the family
• Psychologists and social workers to address the often complex social situations and psychological stresses families face

Families meet with all specialists and receive a recommended treatment plan in a single morning.

Sophisticated repair techniques

When performing cleft lip repair, Dr. Hopkins re-establishes continuity between the mucosa, muscle and skin of the lip and then recreates the floor of the nose.

A primary tip rhinoplasty may be done at the same time as cleft lip repair to improve cosmetic appearance and function of the deformed nasal cartilages.

Preoperative and postoperative photos of two infants with cleft lip and palate who underwent repair surgeries at Cleveland Clinic Children’s. The top patient (left complete cleft) was photographed at 2 weeks of age and then at eight months after surgery. The bottom patient (left incomplete cleft) was photographed at 3 weeks of age and then at four months after repair.
The primary goal of cleft palate repair is to reconstruct an intact palate to allow for normal speech and swallowing development while ensuring harmonious facial growth and minimizing the incidence of oronasal fistulae. This is done by closing the cleft palate with oral and nasal mucosal flaps while reorienting the muscles of the soft palate.

In patients with cleft palate, hearing loss is often addressed with ear tubes. Multiple tubes may be needed over the first several years of life.

Dentition is managed as the patient grows. Interventions may include palatal expanders, braces and alveolar bone grafting using bone harvested from the hip to close the defect in the upper dental arch. Patients may also need orthognathic surgery to correct malocclusion inherent in their deformity or related to a previous surgery. The jaw may be lengthened to provide more room for the tongue.

All surgeries and procedures, including hearing testing, are carefully coordinated and performed under one administration of anesthesia whenever possible.

**Outcomes to stand by**

Although consensus is lacking on which palate repair technique yields optimal speech results with the lowest likelihood of oronasal fistulae, a review of all 64 patients who underwent cleft palate repair by the Cleft Lip and Palate Clinic team between September 2010 and December 2013 revealed no fistulae.

“These results are an important indicator that the techniques we use are time-tested and sound,” says Dr. Hopkins. “We do our best to help patients look forward to a normal appearance and a normal life.”

To refer a patient for cleft lip or palate repair, please call 216.444.6905.

### Adoption Program Promotes Successful Transitions

Cleft lip and palate is one of the most common medical conditions among children adopted from abroad. The Adoption Program at Cleveland Clinic Children’s offers comprehensive care for these children and others adopted from within the U.S. and abroad. The program offers a wide range of specialized services designed to address parents’ concerns and the unique issues that adopted children face.

“In international adoptions, transitioning a child from orphanage or foster care requires added sensitivity, insight and preparation,” says Elaine Schulte, MD, MPH, Medical Director of the Adoption Program. “The overwhelming majority of these children make a successful transition when parents are well-prepared.”

Adoptive parents complete an online pre-adoption evaluation (eclevelandclinic.org/adoption) to understand the child’s health status and help establish realistic developmental and behavioral expectations. “We believe a pre-adoption consultation is the best way to prepare parents for the unique challenges and joys of adoption,” notes Dr. Schulte.

A postadoption evaluation includes a physical examination, developmental assessment, immunizations and diagnostic tests. Dr. Schulte provides ongoing primary care for many children adopted through the program. Referrals to subspecialists such as pediatric cardiologists, pediatric endocrinologists and pediatric infectious disease physicians are readily available as well.

To contact Cleveland Clinic Children’s Adoption Program, please call 216.445.3033 or 800.223.2273, ext. 53033.
For Adolescents with Congenital Genitourinary Defects, Transitional Urology Balances Complex Needs

The genitourinary tract is the anatomical area most often affected by birth defects. Affected children can have problems such as abnormal size, shape or location of their penis or urethra, or lack of proper function in these areas. They may be missing reproductive organs or have duplicates of an organ.

Diagnoses that fit this category include myelomeningocele (spina bifida), exstrophy, hypospadias, disorders of sexual differentiation (intersex) and posterior urethral valves, among others.

Many of these children historically have been treated by pediatric specialists, including pediatric urologists, who tend to focus on kidney function and urinary control. Yet as advances enable more of these patients to reach adulthood, many need care that addresses issues such as sexuality, genital appearance/function and fertility.

Transitional urology helps bridge the gap

Cleveland Clinic Children’s transitional urology program is designed to help young adults with these problems make the move to adult-focused care and balance multiple complex — and sometimes competing — urological and personal needs.

“Few pediatric urologists specialize in the difficulties these patients have in caring for themselves independently and leading healthy adult lives,” says urologist Hadley Wood, MD, who created the transitional urology program at Cleveland Clinic.

She explains that care can be further complicated by other problems these patients may have, such as limited mobility, mental deficits, nutritional challenges, sleep apnea, epilepsy, restrictive airway disease, hypertension, chronic kidney insufficiency, dysphagia, gastroesophageal reflux disease and musculoskeletal issues.

“They also may struggle with personal hygiene and have an increased risk of being overweight,” she says. “Many have seen multiple providers over the years, so they may have fear and trust issues too.”

Because patients may be highly dependent on others for their daily functioning, input from their parents or personal caregivers is crucial.

Timing the transition

Several tools have been developed to evaluate readiness for transition for pediatric patients in general. They assess factors such as whether patients schedule their own appointments and can name all their medications, including dose and frequency.

In urology, additional factors may be involved. A 15-year-old female with a urinary diversion who is sexually active and considering pregnancy may be ready for transition given the “adult” nature of her urological issues. In contrast, a 24-year-old cognitively disabled patient who has around-the-clock assistance from his parents may not need to transition until later.

Initial visit and beyond

At a patient’s initial visit to the transitional urology program, the team takes a detailed history, with special attention to kidney function, urinary and bowel control, and sexual health. Age-related cancer screenings and any needed imaging or lab studies are also conducted.

“We seek to understand the patient’s goals, resource constraints, social challenges, and any new or worsening complaints,” Dr. Wood says. “Then we map out a plan of the best options to address them.”

Developing a care plan can require extended appointments, as patients must be educated about realistic expectations and other providers need to be consulted. Cleveland Clinic’s Center for Genitourinary Reconstruction offers advanced surgical treatment options when appropriate.

To refer a patient to the transitional urology program, call 216.444.2146.

Sampling of Conditions Treated by Transitional Urologists

- Urinary incontinence
- Problems catheterizing (e.g., stomal stenosis, urethral strictures)
- Curvature of the penis with erections
- Abnormalities of appearance of the penis
- Problems in patients born with abnormal vaginal development
- Renal insufficiency from kidney scarring
- Kidney stones
- Increased bladder cancer risk
- Infertility (male and female)
- Herniae from prior surgeries
- Chronic constipation from neurogenic bowel
Obtaining a diagnosis of dyslexia can be difficult. The challenge stems in part from differing terminologies used to describe the condition by professionals in differing fields. What's more, dyslexia was not specifically listed in the Diagnostic and Statistical Manual of Mental Disorders until that volume's latest edition (DSM-5) was issued in 2013. Even after a diagnosis is made, methods to address these shortfalls may continue to be elusive.

“Dyslexia is considered a medical diagnosis, but it’s uncommon for physicians to be trained in the psychological testing required to make the diagnosis,” says Katherine Lamparyk, PsyD, a psychologist in Cleveland Clinic Children’s Center for Pediatric Behavioral Health.

“While testing offered by the school system is often the same that would be done by a psychologist, the child with dyslexia may not receive a diagnosis any more specific than ‘specific learning disability,’” explains Dr. Lamparyk. “This leaves the family confused about what the test results mean — and what interventions and other recommendations will be effective.”

**Straight talk for confused families**

At Cleveland Clinic Children’s Learning Evaluation and Consultation Clinic, the specific diagnosis of dyslexia is not shied away from. The clinic, located at Cleveland Clinic Children’s Hospital for Rehabilitation, is designed to provide families with the help they need to obtain a diagnosis and, more important, start the child on a path to overcoming learning difficulties.

The clinic offers a comprehensive but targeted evaluation using tests that measure intellectual ability, including verbal and nonverbal reasoning, as well as various academic skills. Evaluators pay particular attention to:

- The discrepancy between phonological processing skills and other oral language skills
- How reading fluency and reading comprehension skills compare with oral fluency and comprehension

If recent testing has been completed through the child’s school system, it can be reviewed in place of repeating similar tests.

Each family is provided a specific diagnosis and tailored treatment recommendations, which are discussed in depth. “This enables the family to better advocate for their child, seek appropriate resources and develop a specific action plan,” says Dr. Lamparyk.

To refer a patient for dyslexia evaluation at the Learning Evaluation and Consultation Clinic, please call 216.445.7574.

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The clinic offers a comprehensive but targeted evaluation using tests that measure intellectual ability, including verbal and nonverbal reasoning, as well as various academic skills.
Silence Can Be Sinister in Pediatric Liver Disease

Early recognition and intervention are key to averting serious complications.

Pediatric liver diseases typically produce no symptoms in their early stages, making timely diagnosis a challenge.

“These diseases can be silent for years before causing serious complications,” says pediatric hepatologist Naim Alkhouri, MD, who directs Cleveland Clinic Children’s Metabolic Liver Disease Clinic.

The specialized clinic offers a comprehensive approach to help expedite recognition and management of these silent but sinister conditions, be they acquired disorders — including nonalcoholic fatty liver disease (NAFLD) and hepatitis B and C — or genetic diseases, such as Wilson disease, alpha-1 antitrypsin deficiency or hemochromatosis.

When to be suspicious

Suspicion should be based on the presence of obesity or associated comorbidities, such as insulin resistance, type 2 diabetes, polycystic ovary syndrome or a family history of liver disease.

Additionally, elevated ALT and AST, hepatomegaly, splenomegaly, jaundice or failure to thrive should prompt referral to a specialized program like the Metabolic Liver Disease Clinic for a thorough examination and complete biochemical profile.

Confirmation of the diagnosis may require liver enzyme testing, liver ultrasound or biopsy.

Evaluation and treatment: What families can expect

Families typically spend less than two hours in the initial evaluation. Follow-up visits are scheduled every month or two during the first year, then as needed.

At every visit, the patient sees a pediatric hepatologist and registered dietitian. An appointment may be made for the child to also see an exercise physiologist or pediatric psychologist. Whenever possible, the visits are accomplished on the same day.

When an associated medical condition is present, the child may be referred to pediatric endocrinology, nephrology, cardiology or sleep medicine — or even for liver transplant evaluation.

Treatment of the liver disease may involve medications, lifestyle changes or both.

“Our dietitian plays a key role, because NAFLD is the result of obesity,” says Dr. Alkhouri. “Other liver diseases can cause malnourishment or vitamin deficiency.” The dietitian also helps families plan healthy meals and snacks.

“By intervening early, we can often reverse the course and help the patient avoid consequences — which, in the case of NAFLD, may include liver transplantation,” Dr. Alkhouri adds.

Making diagnosis more child-friendly

The concentration of pediatric liver disease patients in a single multidisciplinary program has enabled the team to investigate ways to make the diagnostic process more child-friendly.

Recent research has focused on finding potential biomarkers for NAFLD and its severe form, nonalcoholic steatohepatitis. “Identifying a biomarker that successfully predicts the degree of liver damage will help us avoid the need for biopsy,” says Dr. Alkhouri.

The team is also looking at markers of liver disease in the breath, with the hope that changes in volatile organic compounds as measured by mass spectrometry may replace the need for blood work and liver biopsy.

To refer a patient to the Metabolic Liver Disease Clinic, please call 216.445.7126.
Cleveland Clinic Children’s welcomes the following new pediatric subspecialists:

**CARDIOLOGY**
- Rukmini Komarlu, MD
  - **SPECIALTY INTERESTS:** General cardiology, cardiac MRI, noninvasive imaging including transesophageal and fetal echocardiography
  - **LOCATION:** Main campus
  - **P:** 216.444.0450
  - **E:** komarlr@ccf.org

- Patcharapong Suntharos, MD
  - **SPECIALTY INTERESTS:** General cardiology
  - **LOCATION:** Main campus
  - **P:** 216.445.5015
  - **E:** sunthap@ccf.org

**CRITICAL CARE MEDICINE**
- Chidiebere Ezetendu, MD
  - **SPECIALTY INTERESTS:** Critical care medicine
  - **LOCATION:** Main campus
  - **P:** 216.444.3303
  - **E:** ezetenc@ccf.org

**HOSPITAL MEDICINE**
- Arnaldo Zayas-Santiago, MD
  - **SPECIALTY INTERESTS:** Newborn medicine, acute respiratory disorders, infectious diseases
  - **LOCATIONS:** Main campus, Fairview Hospital
  - **P:** 216.444.4998
  - **E:** zayasam@ccf.org

**NEONATOLOGY**
- Sreenivas Karnati, MD
  - **SPECIALTY INTERESTS:** Bronchopulmonary dysplasia prevention, necrotizing enterocolitis, growth and development of high-risk neonates
  - **LOCATIONS:** Main campus, Hillcrest Hospital
  - **P:** 216.444.2568
  - **E:** karnats@ccf.org

- Subhash Putheraya, MD
  - **SPECIALTY INTERESTS:** Neonatal-perinatal medicine
  - **LOCATION:** Main campus
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**NEUROLOGY**
- Mohammed Aldosari, MD
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Save the Date: June 11-13, 2015

**2nd Annual Perspectives in Pediatrics**

*Global Center for Health Innovation, Cleveland Convention Center, Cleveland, Ohio*

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*By Toby Cosgrove, MD*

**CEO and President of Cleveland Clinic**

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Your Guide to Cleveland Clinic Children's Outpatient Subspecialty Care in the Community

| Outpatient Subspecialties | Main Campus | Children's Hospital for Rehab | Euclid Hospital | Fairview Hospital | Hillcrest Hospital | Medina Hospital | Avon Family Health Center | Beachwood Family Health Center | Chagrin Falls Family Health Center | Gates Mills Family Health Center | Independence Family Health Center | Mentor Pub Building | Mentor Family Health Center | Strongsville Family Health Center | Twinsburg Family Health Center | Westlake Medical Campus | Willoughby Hills Family Health Center |
|---------------------------|-------------|-------------------------------|----------------|------------------|-------------------|-----------------|--------------------------|-----------------------------------|-----------------------------------|-----------------------------------|-------------------------------|-----------------------------|--------------------------------|--------------------------------|-------------------|--------------------------------|
| Allergy and Immunology    |              |                               |                |                  |                   |                 |                          |                                    |                                   |                                   |                               |                            |                                |                                |                   |                                |
| Cardiology                |              |                               |                |                  |                   |                 |                          |                                    |                                   |                                   |                               |                            |                                |                                |                   |                                |
| Dermatology               |              |                               |                |                  |                   |                 |                          |                                    |                                   |                                   |                               |                            |                                |                                |                   |                                |
| Developmental Pediatrics/PM&R |            |                               |                |                  |                   |                 |                          |                                    |                                   |                                   |                               |                            |                                |                                |                   |                                |
| Endocrinology             |              |                               |                |                  |                   |                 |                          |                                    |                                   |                                   |                               |                            |                                |                                |                   |                                |
| Epilepsy                  |              |                               |                |                  |                   |                 |                          |                                    |                                   |                                   |                               |                            |                                |                                |                   |                                |
| Gastroenterology          |              |                               |                |                  |                   |                 |                          |                                    |                                   |                                   |                               |                            |                                |                                |                   |                                |
| Nephrology                |              |                               |                |                  |                   |                 |                          |                                    |                                   |                                   |                               |                            |                                |                                |                   |                                |
| Neurology                 |              |                               |                |                  |                   |                 |                          |                                    |                                   |                                   |                               |                            |                                |                                |                   |                                |
| Orthopaedic Surgery       |              |                               |                |                  |                   |                 |                          |                                    |                                   |                                   |                               |                            |                                |                                |                   |                                |
| Otolaryngology            |              |                               |                |                  |                   |                 |                          |                                    |                                   |                                   |                               |                            |                                |                                |                   |                                |
| Psychiatry/Psychology      |              |                               |                |                  |                   |                 |                          |                                    |                                   |                                   |                               |                            |                                |                                |                   |                                |
| Pulmonary Medicine        |              |                               |                |                  |                   |                 |                          |                                    |                                   |                                   |                               |                            |                                |                                |                   |                                |
| Rheumatology              |              |                               |                |                  |                   |                 |                          |                                    |                                   |                                   |                               |                            |                                |                                |                   |                                |
| Sleep Medicine            |              |                               |                |                  |                   |                 |                          |                                    |                                   |                                   |                               |                            |                                |                                |                   |                                |
| Sports Health             |              |                               |                |                  |                   |                 |                          |                                    |                                   |                                   |                               |                            |                                |                                |                   |                                |
| Urology                   |              |                               |                |                  |                   |                 |                          |                                    |                                   |                                   |                               |                            |                                |                                |                   |                                |

▲ Cardiology also at Ashtabula County Medical Center, Lake West Medical Building, Parma Medical Arts Center, Pomphere Hospital, Warren Medical Office
▲ Developmental Pediatrics/PM&R also at Firelands Regional Medical Center
▲ Sleep Medicine also at Sleep Center at Fairhill
▲ Sports Health also at Lutheran Hospital, Brunswick Family Health Center, Mentor Rehabilitation and Sports Therapy, Middleburg Heights Orthopaedics, Wooster Family Health Center