Cleveland Clinic Children's

Update

FOR AREA PEDIATRIC PROVIDERS | SPRING 2015

PAGE 4

Complementary care comes of age

New center enhances offerings in pediatric integrative medicine

Inside

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, at community hospitals and at family health centers. Cleveland Clinic Children's earned national rankings in 10 of 10 specialties in the 2014-15 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.

MANAGING EDITOR: Glenn R. Campbell
ART DIRECTOR: Chip Valleriano
PHOTOGRAPHY: Don Gerda, Russell Lee, Tom Merce

Dear Colleagues,

Many young patients with chronic conditions need more help than traditional interventions can offer. That's a big reason why about 12 percent of U.S. children use some form of complementary medicine, according to the NIH's National Center for Complementary and Integrative Health.

At Cleveland Clinic Children's, we recognize the growing interest in complementary therapies for children. And while we're encouraged by mounting evidence in support of many such therapies, we also recognize that these therapies must be offered judiciously and as a supplement to — not a replacement for — more evidence-based traditional treatments.

To promote the judicious use of complementary therapies, we recently launched a Center for Pediatric Integrative Medicine in a centralized, newly renovated space at Cleveland Clinic Children's Hospital for Rehabilitation.

Although we have been offering complementary and integrative therapies for years, this new formal center — one of the few of its kind in the nation — enables us to provide them in a more coordinated, collaborative and multidisciplinary fashion than before. It also will help us develop a robust research program to better define the utility of various integrative therapies for children. See the story on p. 4 for details.

As that article emphasizes, our integrative medicine specialists aim to enhance patients' existing medical care while working in tandem with the patients' traditional providers. That same commitment to working with our colleagues in the community underlies the other specialty services profiled in this issue, be they our therapy services (p. 6), autism management (p. 8), comprehensive transplant care (p. 10), vascular anomalies therapy (p. 12) or sickle cell management (p. 14).

Cleveland Clinic Children's caregivers value the privilege to partner with you when your pediatric patients need highly specialized diagnosis or treatment.

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

For HPV Vaccination, Gender May Matter in More Ways Than One

Much thought has been directed at explaining the stubbornly low rates of vaccination against the human papillomavirus (HPV) among U.S. children, but little attention has been paid to healthcare provider gender. Until now.

Cleveland Clinic Children's researchers, led by Ellen Rome, MD, MPH, Head of the Center for Adolescent Medicine, recently presented results of the first large-scale analysis of the effect of provider characteristics and practice location on HPV vaccination rates. The study's results included one provocative finding: "Male providers were less likely than female providers to initiate and complete the three-dose HPV vaccine series in their patients, especially when their patients were boys," says Dr. Rome.

The Study in Brief

The study was conducted among more than 5,000 patients ages 13 to 26 years presenting for well-care visits to 15 suburban family health centers and three urban care sites across the Cleveland Clinic health system in 2010. The objective was to analyze these patients' HPV vaccination rates according to practice location (urban vs. suburban) and patient and provider gender.

Among the study's key findings:

- Among girls, 62 percent received the first dose in the HPV vaccine series, and 47 percent completed the full three-dose series. These rates are higher than the 2012 national rates of 54 percent and 33 percent, respectively, as reported by the Centers for Disease Control and Prevention (CDC).
- Among boys, 19 percent received the first dose, and 8 percent completed the full series, rates comparable to the 2012 national rates of 21 and 7 percent, respectively, per the CDC.
- Male providers were less likely than female providers to administer the vaccine across the overall population due to a significantly lower likelihood of initiating the vaccine in their male patients (11 percent vs. 30 percent for female providers, $P = .002$).

Providers at suburban sites were less likely to vaccinate both boys and girls than providers at urban sites (18 vs. 41 percent for boys, $P = .005$; 58 vs. 81 percent for girls, $P = .003$).

Making Sense of the Findings

Dr. Rome notes that the higher vaccine uptake in urban practices was not unexpected, as it reflects findings from an earlier Cleveland Clinic Children's study (*J Pediatr Adolesc Gynecol.* 2011;24:66-70) on intention to vaccinate among mothers of children under age 10.

"In that study, urban parents were more likely to know someone infected with HPV or to recognize that their child might engage in sexual activity in high school, leading them to view vaccination more favorably," she explains. "Suburban parents were more likely to view adolescent sexual activity as 'something that happens to other people's children' and to view the HPV vaccine as 'too new.'"

She adds that this new study, which has been submitted for publication, indicates that "parental denial is not the only factor interfering with vaccination." She finds it particularly intriguing that the male providers' lower vaccination rates for boys did not carry over to girls. "These discrepancies by provider gender are worthy of further exploration in different and larger groups of providers," she says.

Why Vaccination Matters

Dr. Rome says the stakes are high, since HPV is the most common sexually transmitted infection in the U.S., with most new infections occurring in 15- to 24-year-olds. HPV accounts for 70 percent of cervical cancers; 90 percent of genital warts; and a majority of vulvar, vaginal, anal, penile and oropharyngeal cancers.

She recommends that children be vaccinated against HPV by age 11 or 12, before sexual activity starts. "Vaccines work best when given at a younger age, when immune responses are more robust," she says. "That said, older age or prior initiation of sexual activity are no excuses to forgo the vaccine. Providers must push for this protection."

Physicians can reach Dr. Rome at romee@ccf.org or 216.444.3566.

New Center for Pediatric Integrative Medicine Expands and Enhances Options for Hard-to-Manage Chronic Conditions

About 12% of U.S. children use some form of complementary medicine, according to the NIH's National Center for Complementary and Integrative Health. As the evidence in support of complementary and integrative medical techniques mounts, that percentage is likely to climb.

To meet this demand, Cleveland Clinic Children's has launched a Center for Pediatric Integrative Medicine to complement traditional medical care for patients with a range of difficult-to-manage chronic conditions.

Conceived as Complementary Care

"Going beyond a child's physical needs to address lifestyle and emotional needs can reduce the frequency of disease episodes, decrease stress related to chronic illness and improve quality of life," says Center Director Benjamin Katholi, MD, a pediatric physiatrist. He notes that integrative medicine techniques can reduce children's pain, improve sleep, lower blood pressure and improve bowel function.

Dr. Katholi emphasizes that the center's treatments are intended as a complement to — not a replacement for — traditional medical therapies. "Our aim is to enhance patients' existing medical care, to work in tandem with their traditional providers and to ensure patients are maintaining their relationships with those traditional providers."

A Multiplicity of Conditions Treated ...

The center — located at Cleveland Clinic Children's Hospital for Rehabilitation on Cleveland's east side, just 2.5 miles from Cleveland Clinic's main campus — treats a range of difficult-to-manage chronic conditions in children and adolescents, including:

- Anxiety and depression due to chronic illness
- Arthritis and musculoskeletal pain
- Asthma, allergies and other pulmonary problems
- Concussions and other brain injuries
- Chronic pain, including abdominal and myofascial pain
- Delayed wound healing
- Headache
- Impaired mobility
- Sports and traumatic injuries
- Vocal cord dysfunction

... By a Multiplicity of Specialists and Techniques

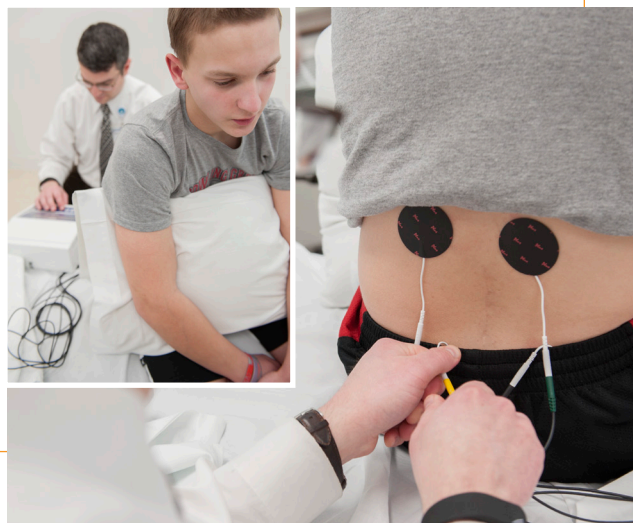
The center is staffed by a multidisciplinary team of dedicated pediatric specialists in behavioral medicine, physical medicine and rehabilitation, pain management, pulmonary medicine, general pediatrics and nutrition along with dedicated pediatric occupational and physical therapists.

Team members are certified in a host of therapeutic techniques, including:

- Acupuncture, acupressure and laser acupuncture
- Biofeedback
- Guided imagery and hypnosis
- Integrative dry needling
- Frequency-specific microcurrent therapy
- Craniosacral therapy
- Myofascial release and osteopathic manipulation
- Reiki and therapeutic touch (the latter for infants)
- Relaxation/breathing strategies and yoga

Dr. Katholi finds frequency-specific microcurrent (FSM) therapy particularly exciting. "It is subsensory (painless) and noninvasive, and has lasting effects," he says. "Research suggests that delivering micro-amperage current while using specific frequencies to resonate with damaged tissues can reduce inflammation, improve

"We are committed to providing evidence-based care at this center and helping to define the most effective complementary therapies for enhancing traditional care." — **BENJAMIN KATHOLI, MD**



Integrative medicine in action *Dr. Katholi uses frequency-specific microcurrent (FSM) therapy on Cole Sonner, a 14-year-old who contends with long-standing — and formerly debilitating — chronic pain related to a spine tumor during his infancy. Cole makes the 125-mile trek from Bowling Green, Ohio, to Cleveland every week for interventions at Cleveland Clinic Children's Center for Pediatric Integrative Medicine that include FSM therapy and acupuncture. "They've really helped him function much better," says his mother.*

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

One of Few Pediatric-Specific Integrative Medicine Centers

The new center is one of relatively few focused on using integrative medicine specifically in children, notes center team member David Burke, DO, a general pediatrician with long-standing interests in osteopathic manipulation and complementary medicine. "While Cleveland Clinic Children's has offered many integrative medicine services to children for years, this formal center has brought them all under one roof in a handsomely renovated space at the Children's Hospital for Rehabilitation, where many complex cases are managed," Dr. Burke says.

The center was the vision of Cleveland Clinic Children's Physician-in-Chief, Giovanni Piedimonte, MD, and was realized through efforts directed by Jennifer Manning-Detering, administrator of the Children's Hospital for Rehabilitation. "We concluded it was best to have a central location where we could all work together using a team approach to make visits convenient and efficient for patients, develop research protocols and monitor efficacy," Dr. Burke explains.

The payoffs include the ability for various pediatric subspecialists to see patients together. "Various staff from the center can be present to better serve patients," Dr. Burke says. "This allows us to learn from one another, streamline appointments for patients and complement each other's therapies."

A Research Mission Too

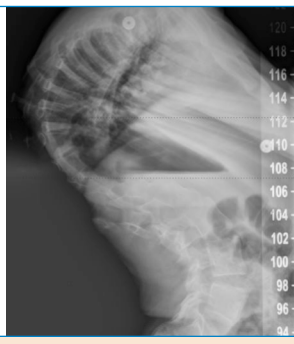
Another payoff is coordinated research efforts. Center staff are beginning research on several integrative treatments — including acupuncture, reiki and FSM therapy — to better define their potential benefits for children with various conditions.

"We are committed to providing evidence-based care at this center and helping to define the most effective complementary therapies for enhancing traditional care," says Dr. Katholi.

To refer a patient to the Center for Pediatric Integrative Medicine, call 216.448.6610. For more on the center, visit clevelandclinicchildrens.org/integrativemedicine.

For a case study

illustrating the value integrative medicine can bring to a medically complex case, visit **consultqd.org/pedsintegrative** on Cleveland Clinic's popular ConsultQD blog for healthcare professionals.



Therapy Services Expand Across Northeast Ohio

The offerings of Cleveland Clinic Children's Therapy Services are spreading across Northeast Ohio, closer to where your patients live. That's a help to busy families, especially those with children who need therapy one or more times a week.

At our six Therapy Services locations — now including Brunswick and Cuyahoga Falls — children from birth through age 21 receive specialized treatment from physical therapists, occupational therapists and speech/language pathologists for serious injuries, developmental delays, chronic/acute conditions that affect development, learning difficulties and challenges with ADLs.

A team of specialists evaluates each patient and custom-designs treatment to help increase the child's functional abilities and independence. The map below profiles a few of the distinctive therapies provided.

LYMPHEDEMA TREATMENT

Performed by occupational therapists

For children with primary or secondary lymphedema, treatment involves:

- Complete decongestive therapy, combining manual lymphatic drainage and compression therapy
- Age-appropriate home programs, including tailored exercises, a schedule for wearing compression garments and skin care advice
- Education for patients and caregivers

Care is delivered by a pediatric certified lymphedema therapist (CLT) who offers expertise in typical childhood development and how lymphedema can affect it. Therapy uses equipment sized for children and activities tailored to children's needs.

Available at:
Therapy Services Westlake
826 Westpoint Parkway, Suite 1200

INTERACTIVE METRONOME

Performed by occupational therapists

This computer-based program directs patients to perform repetitive hand and foot movements to a rhythmic beat. Audible tones signal how well each movement is in sync with the rhythm. The aim is to improve timing, attention and coordination in children with impaired:

- Cognitive abilities
- Speech and language
- Social-behavioral skills
- Motor skills
- Sensory processing and integration

Treatment typically requires 12 to 15 one-hour sessions over several weeks.

Available at:
Therapy Services Middleburg Heights
17800 Jefferson Park Road, Suite 101

THERAPEUTIC LISTENING

Performed by occupational therapists

This approach uses music and rhythmic sound patterns to stimulate brain regions used in listening and processing sensory information. These techniques are combined with movement and core-strengthening exercises to help patients improve:

- Focus and attention
- Motor skills
- Response to sounds/ verbal directions
- Eating and sleeping patterns
- Social skills/communication
- Mood and energy regulation
- Sensory defensive behaviors

Available at various locations, including:
Therapy Services Brunswick
3724 Center Road

CONCUSSION EVALUATION AND TREATMENT

Performed by speech/language pathologists

These evaluations are typically done three weeks after a concussion. Assessment and therapy address memory, attention, concentration and learning as well as potential deficits in executive function (e.g., planning, organizing, time management, task completion and inhibiting behavior). A treatment plan is developed and strategies and education are provided to target individual deficits.

Available at various locations, including:
Cleveland Clinic Children's Hospital for Rehabilitation
2801 Martin Luther King Jr. Drive

TORTICOLLIS THERAPY

Performed by physical therapists

Torticollis and plagiocephaly prevent a child from holding his or her head straight. If these conditions are present at birth, treatment mainly involves stretching the infant's neck muscles. Physical therapists conduct tailored positioning, rotating and reaching exercises and can train parents to do them at home with their child. Starting therapy within three months of birth improves chances of success.

Available at various locations, including:
Therapy Services Beachwood
3355 Richmond Road

UNIVERSAL EXERCISE UNIT

Performed by physical therapists

This system of pulleys and straps, also called the "Spider Cage," helps children improve strength, range of motion and flexibility. Children can exercise from a treatment bed or chair — or from a suspension system with a belt and elastic cords. Physical therapists use this unique system to isolate muscle groups, eliminate gravitational forces and more. It's helpful for treating conditions such as neurological disorders and developmental delays.

Available at various locations, including:
Therapy Services Cuyahoga Falls
63 Graham Road, Suite 2

Other Available Services

- Aquatic therapy
- Art and music therapy*
- Bibliotherapy (Reach Out and Read Program)*
- Constraint-induced movement therapy
- Horticulture therapy*
- Infant Feeding and Nutrition Clinic
- Pain Rehabilitation Program
- Recreational therapy*
- Respiratory therapy*
- Seating and Wheelchair Clinic
- Technology Resource Center (evaluation and treatment for children requiring adaptive/alternative communication)
- Upper Extremity Clinic

* *Offered only for inpatients at Children's Hospital for Rehabilitation*

216.636.KIDS (5437)

clevelandclinicchildrens.org/therapyservices

Center for Autism's Clinical Expertise Bears Rich Research Insights

New studies probe value of behavioral observation, symptoms in females and more

Behavioral observation is a key element in diagnosing young patients with autism spectrum disorder. But during a 10- or 20-minute medical visit, how much atypical behavior is enough to raise concern?

A new study in *Pediatrics* (2015;135[2]:e330-e338) evaluated the accuracy of identifying autism through brief observations. It's the first study to quantify high rates of typical behavior in young children with autism — behavior that can skew a clinician's decision whether to refer a child for further evaluation.

In the study, licensed pediatric psychologists with expertise in autism analyzed 10-minute videos of 42 children ages 15 to 33 months who were being evaluated for autism. For each child, experts recorded "atypical" or "typical" ratings for five behaviors (responding, initiating, vocalizing, play and response to name) and indicated which children should be further evaluated for autism. Their recommendations were then compared with formal screening and developmental testing results that had already identified the children as having autism, language delays or typical development.

Even in Autism, Typical Behavior Often Predominates

Not surprisingly, children in the autism group had higher rates of atypical behavior than did children in the language-delay and typical groups. However, typical behavior displayed by the children with autism still far exceeded their atypical behavior (89 vs. 11 percent, respectively).

In fact, experts misidentified nearly 40 percent of the study participants who had autism, not recommending them for further evaluation.

"Given these results, clinicians must be careful not to overemphasize brief clinical observations to the exclusion of other critical clinical information," says study co-author Leslie Speer, PhD, a pediatric psychologist with Cleveland Clinic Children's Center for Autism.

"There's often a belief that children with autism do not display typical behavior," notes Dr. Speer. "But they do. That's what makes evaluating these children difficult. This research and our clinical experiences suggest that behavioral observation should be used *in addition to* autism screening tools, parent observations, developmental testing and detailed history when making referral decisions."

Largest-Ever Studies of Autism in Females and Twins

The study from Dr. Speer and colleagues is just the latest in a string of notable research on autism characteristics coming out of the Center for Autism.

Center Director Thomas Frazier, PhD, published several important investigations last year, including:

- A study describing behavioral characteristics of autism spectrum disorder in the largest reported sample of female patients to date
- The largest reported study of clinically ascertained autism spectrum disorder in twins

The presence or absence of sex differences in the autism phenotype has been a long-standing knowledge gap, as the vast majority of subjects in autism studies have been male. Dr. Frazier's team addressed this gap with a study in the *Journal of the American Academy of Child and Adolescent Psychiatry* (2014;53[3]:329-340) supported by the Simons Foundation Autism Research Initiative.

After analyzing data from 304 females and 2,114 males with autism, the researchers found that females had:

- Lower levels of restricted interests but greater irritability and externalizing behavior
- Weaker social communication skills, lower overall cognitive ability and poorer daily living skills

"Our findings suggest that autism may be underidentified in females," notes Dr. Frazier, "and that missing these female cases may be due to a focus on male-centric representations of autism in diagnostic instruments or to genetic or developmental protective factors."

The twins study (*J Autism Dev Disord.* 2014;44[8]:2013-2025) compared concordance in 568 identical and fraternal twin pairs,

Double the research power
Twin pairs like these sisters were included in the Center for Autism's historically large recent study of twins with autism. These sisters, while not part of that study, are now being treated at the Center for Autism and benefiting from new insights from that study and another recent Cleveland Clinic Children's study on autism in females.

of whom 471 were affected with autism. It identified a strong genetic component to autism within this population, solidifying prior observations of strong genetic influences. Among the key findings:

- Shared environment was not supported as a causative factor, whereas genetic influences were strong.
- Social interaction and repetitive/flexible behaviors appear to be driven by highly overlapping genetic influences.

"This research supports the search for genetic influences on autism and suggests that environment may play only a minor role," Dr. Frazier says.

Leveraging Genetic Insights for Tailored Treatments

Dr. Frazier is helping lead that search for genetic influences, as recently reported in *Molecular Psychiatry* (2014 Oct 7 [Epub ahead of print]). He partnered with Charis Eng, MD, PhD, Chair of Cleveland Clinic's Genomic Medicine Institute, on a clinical study showing how a defect in the cancer-related gene *PTEN* can affect the brains of children with autism. They found that patients with autism who also had *PTEN* gene mutations had severe abnormalities in their brains' white matter, indicating problems with brain connectivity.

The study, which is detailed on Cleveland Clinic's ConsultQD blog for healthcare professionals (visit **consultqd.org/autismPTEN**), "opens the door to a more personalized approach to autism treatment," says Dr. Frazier, who is now conducting a longitudinal study of children with *PTEN*-associated autism. A medication trial based on the *PTEN* findings is also in the works.

Research Built on Clinical Expertise

This broad research portfolio is made possible by the Center for Autism's comprehensive clinical offerings, which center on multidisciplinary evaluation services for early autism detection as well as outpatient and school-based clinical services for children and young adults with autism spectrum disorder. The latter include the state-certified Lerner School for Autism and the innovative SPIES group training program to foster social thinking.

To refer a patient for evaluation or treatment at the Center for Autism, call 216.448.6440.

Want to learn the latest in autism?

Register for the autism track of the half-day symposium at the end of Cleveland Clinic Children's Pediatric Innovation Summit, Saturday, June 13, 1:30-5 p.m., at the Global Center for Health Innovation in downtown Cleveland. Designed for pediatricians who do not specialize in autism.

Visit **ccfcme.org/pediatrics** for program details and registration information.

Living-Donor Liver Transplantation Offers Families Swift Intervention and a Sense of Control

2015 marks the 30th anniversary of the first liver transplant performed in a child at Cleveland Clinic. Three decades and more than 100 pediatric liver transplants later, no development in liver transplantation at Cleveland Clinic Children's has been more significant than the advent of living-donor transplants.

When combined with split-liver transplants from deceased donors, transplants of partial liver grafts from living donors represent approximately half of all pediatric liver transplant cases at Cleveland Clinic Children's over the past 10 years. Together these options, which are offered aggressively at Cleveland Clinic Children's, are increasing transplant opportunities for pediatric patients with serious liver disease at a time of pressing organ shortages.

In addition to supplying smaller liver grafts well-matched to children's small bodies, living-donor liver transplantation can give young patients and their families the option of planning the timing of their transplant in advance. And it can slash wait times for ill infants and children in desperate need of a new liver, often with profound implications for their survival and development.

Angelo's Case

Little Angelo (pseudonym to protect his privacy) is a case in point. Born at Cleveland Clinic Children's in February 2014, Angelo's bilirubin levels escalated over his first few weeks of life. When his gallbladder could not be visualized on imaging, he was referred to Kadakkal Radhakrishnan, MD, of Cleveland Clinic Children's Department of Pediatric Gastroenterology, for a series of exams.

"Dr. Radhakrishnan suspected Angelo had biliary atresia, but its diagnosis is not straightforward," says Angelo's mother, Sara. "So he guided us through a stepwise process to confirm his suspicion or identify an alternate diagnosis."

That process included starting a medication to thin the child's bile and a special formula-based diet, but the success of these measures was short-lived. A rebound in bilirubin prompted an interventional cholangiogram by pediatric general surgeon David Magnuson, MD.

When the procedure revealed atretic biliary structures, biliary atresia was confirmed and Dr. Magnuson immediately performed a Kasai procedure to directly connect the porta hepatis to the small intestine to allow bile drainage. Angelo was just 6 weeks old at this point.

Modest reductions in his bilirubin followed, but three months later the levels began to rise again. By the time Angelo turned 6 months old, his condition had deteriorated significantly. "He was really sick, really weak," Sara says. And he had essentially stopped growing. "His height and weight stayed the same for three months," she adds.

'Time to Act Fast'

"That was the signal that a liver transplant was needed," says Dr. Radhakrishnan. "When these patients stop growing, it's time to act fast, before they deteriorate so much that the prospects of the surgery might be impaired as well."

So Angelo was listed for a liver transplant in early autumn. But because his pediatric end-stage liver disease (PELD) score was not dramatically elevated, it may have been months before he received a donor organ. "That would have been detrimental to his development and his overall health," Sara says.

So Angelo's parents each underwent evaluation to be a potential donor for their son under the counsel of Charles Miller, MD, Surgical Director of Cleveland Clinic's Liver Transplantation Program. "We felt a related living-donor transplant was the best solution," Sara says, "because it would let us plan the timing of Angelo's transplant and make it possible far sooner than his PELD score would have dictated."

Because Angelo was so small for his age as a result of his compromised health, his father's liver was deemed too large for him. His mother was determined to be an appropriate donor, and in mid-November 2014 Sara donated the lateral segment of her liver — about 20 percent of the organ's total size — to her son. The surgeries on both mother and child went smoothly, with Sara being discharged after one week and Angelo after two weeks.

Faring well four months postop *Angelo with his pediatric gastroenterologist, Kaddakal Radhakrishnan, MD (in purple), and team members at a checkup visit in March 2015.*

Resilience All Around

Both have recovered without problems, and Angelo has been free of rejection episodes. He was strong enough to successfully weather a bout of rotavirus in February, and his liver function values are optimal. And after the months of stagnant growth prior to the transplant, "he is growing impressively," Sara notes. "Angelo is his usual happy self again. It's like he's been reborn. Kids can be amazingly resilient."

Equally resilient is Sara's liver, which regenerated fully within five weeks of her operation. Her liver function values were back to normal by her second postoperative checkup, and she was back to work and her usual activities within six weeks of her surgery.

As Angelo's parents revel in the resumption of his growth, they credit his being back on track developmentally to having the option to offer him a living-donor transplant — a capability not all pediatric transplant centers offer. Sara adds that the fact his liver graft came from a related donor (indeed, one whose body was his home just a few months earlier) may allow Angelo to fare well with a relatively low-dose immunosuppressant regimen, although only time can confirm that.

Transplantation at Cleveland Clinic Children's: **Fast facts from 2014**

Cleveland Clinic Children's is one of the few centers in the world where a child can receive any type of transplant — all solid organ types, dual-organ, multivisceral, cellular or composite tissue — under one roof. That diversity of offerings was particularly evident in 2014:

Double Last year Cleveland Clinic Children's performed nearly twice as many pediatric solid-organ transplants as in 2013.

11 Number of pediatric heart transplants done in 2014 — the most in a single year at Cleveland Clinic. All patients were doing well as of early March 2015.

4 Number of ventricular-assist devices (VADs) placed in pediatric patients in 2014

3 Number of pediatric intestinal transplants performed in 2014 (including 1 multivisceral), one of the highest volumes in the nation

First Last year Cleveland Clinic Children's performed its first haploidentical hematopoietic cell transplant in a pediatric patient.

Infantile Hemangiomas: Successful Treatment Lies in Standardization

Our Vascular Anomalies Program uses the respected SCAMP paradigm to ensure consistently good outcomes

In the several years since French pediatricians serendipitously discovered that propranolol can produce dramatic improvements in infantile hemangiomas, this beta-blocker has gained increasing acceptance as a first-line therapy for the condition.

Since 2009, Cleveland Clinic Children's Vascular Anomalies Program (see sidebar, next page) has used propranolol to treat more than 150 children with infantile hemangiomas, with 100 percent success and no major side effects requiring therapy discontinuation.

It Takes a Team to Ensure Optimal Propranolol Use

"We believe treatment of infantile hemangiomas with propranolol is most safely and effectively accomplished by a multidisciplinary team," says pediatric dermatologist Joan Tamburro, DO. She notes that the team includes pediatric subspecialists in disciplines from dermatology to cardiology, plastic surgery, radiology, ophthalmology and otolaryngology. "Appropriate coordination of care among these subspecialties is indispensable for successful treatment."

"The diversity of presentation of infantile hemangiomas, the range of subspecialties involved and the challenge of assessing for cardiac risk were important considerations when we began to use propranolol as a treatment at Cleveland Clinic Children's," adds fellow Vascular Anomalies Program member Alex Golden, MD, a pediatric cardiologist. "Given the importance of systematizing the approach to allow an organized assessment of outcomes and any adverse events, we adopted the standardized clinical assessment and management plan (SCAMP) paradigm."

Standardizing the Team Approach with a SCAMP

SCAMPs have been used successfully in multiple medical specialties, including pediatric cardiology, to reduce variation in practice and resource utilization while optimizing patient care.

Central to the SCAMP approach is the ability to continuously revise the standardized treatment plan as new data emerge. This allows protocols to benefit from continuous improvement while preserving the ability to carefully measure and assess outcomes.

Drawing on the SCAMP methodology, Cleveland Clinic Children's Vascular Anomalies Committee developed a protocol for initiating treatment with propranolol in the outpatient setting. The protocol had three initial goals:

- Ensuring patient safety, with careful pretreatment cardiovascular evaluation and initiation of treatment under supervision of an experienced pediatric cardiologist
- Facilitating multidisciplinary involvement in patient care
- Carefully documenting methods and results to foster continuous quality improvement

"As our experience with propranolol for this indication increased," says Dr. Tamburro, "we improved dosing protocols, expanded and updated parent education materials, incorporated professional medical photography to monitor and document treatment response, and improved surveillance for comorbidities such as PHACES syndrome, among other updates."

Outcomes Speak for Themselves

The result of this application of the SCAMP methodology has been a track record of tremendous success across the more than 130 patients treated under the methodology to date:

- A full 100 percent of patients had arrest of hemangioma growth from the very first propranolol dose.
- In all cases significant shrinkage of the lesions was achieved (see sample case photos), usually in the first few weeks of therapy.

For the vast majority of patients, treatment is started in the outpatient setting, with monitoring of vital signs for two hours after the first dose. No patients have had side effects requiring therapy discontinuation. One patient with a severe retro-ocular infantile hemangioma causing compression of the optic nerve and vein had a prior history of reactive airway disease and developed chronic cough. Adjustment of his

Photos from representative cases of infantile hemangioma managed under the SCAMP paradigm for propranolol treatment in Cleveland Clinic Children's Vascular Anomalies Program. ***Top:*** *Forehead hemangioma with deep and superficial components at presentation at 6 months of age (note brow distortion) and after seven months of treatment.* ***Middle:*** *Facial lesion at presentation at 1 month of age and after 16 months of treatment.* ***Bottom:*** *Ulcerated hemangioma at presentation at 2 months of age (note distortion of the right cheek and jawline) and after 14 months of treatment.*

pulmonary medication regimen allowed successful continuation of propranolol therapy.

"To our knowledge, this is the first-ever application of the SCAMP paradigm in a pediatric dermatology setting," says Allison Vidimos, MD, Chair of the Department of Dermatology. "The SCAMP has helped our Vascular Anomalies Program bridge the central multidisciplinary aspects of effective care and communication that are essential for management of this distressing, but ultimately treatable, condition."

Vascular Anomalies Program: Hemangiomas and Beyond

Infantile hemangiomas are just one of many vascular anomalies diagnosed and managed by Cleveland Clinic Children's multidisciplinary Vascular Anomalies Program. The program, one of a limited number nationally, consists of pediatric and adult-care subspecialists in dermatology, radiology, cardiology, head and neck reconstructive surgery, hematology, pathology, ophthalmology, general surgery, orthopaedics and genetics, among other disciplines.

The program manages pediatric patients with a wide range of congenital anomalies of the blood vessels, including:

- Complex vascular malformations (Klippel-Trenaunay syndrome, Proteus syndrome, Maffucci syndrome, Parkes Weber syndrome and others)
- Fast-flow and slow-flow malformations
- Various hemangioma types, including infantile, intramuscular, noninvoluting congenital and rapidly involuting congenital
- Kaposiform hemangioendothelioma

In addition to medical treatments (like propranolol for infantile hemangioma), the program team employs therapies ranging from minimally invasive interventional procedures to extensive surgical repair, depending on the condition and its severity.

To refer a patient to the Vascular Anomalies Program (located on Cleveland Clinic's main campus), call 216.445.4726.

Meeting Sickle Cell's Challenges in Kind

Dedicated team takes a proactive approach to preventing complications

Sickle cell disease brings no shortage of management challenges, including a host of clinical complications, frequently spotty treatment adherence and a need for intensive patient education. In response, Cleveland Clinic Children's Sickle Cell Program relies on a proactive, team-based strategy to ensure excellent care despite such hurdles.

"We are well-equipped to handle the challenges our patients present," says Grace Onimoe, MD, a pediatric hematologist who specializes in sickle cell disease and leads the program.

Along with a core team of two nurse practitioners, a social worker and a child psychologist, Dr. Onimoe works with pediatricians and general practitioners to coordinate care and obtain subspecialty expertise from across Cleveland Clinic Children's when needed for the condition's diverse complications. They also work in collaboration with staff from the American Sickle Cell Anemia Association (ASCAA), which has an office on Cleveland Clinic's main campus. "Our team provides extensive education and works closely with families to overcome barriers to successful management," Dr. Onimoe says.

Approximately 1,000 infants with sickle cell disease are diagnosed in the U.S. each year through a screening blood test given at birth. In the most common form — sickle cell anemia — complications are common and can be severe. The disease's other forms tend to be milder, but complications and exacerbations can occur at any time. These include acute pain, anemia, infections, stroke, vision problems, kidney dysfunction, lung problems and heart dysfunction.

Proactivity Is Paramount

A proactive, patient-centered protocol helps prevent complications. The team provides ongoing care for a sizable population of patients, each of whom is seen for comprehensive assessments every two to three months, depending on genotype and frequency of complications.

"Our goal is to keep patients as healthy as possible," says Dr. Onimoe. Because complications are unpredictable, the team is always on standby Monday through Friday to provide rapid evaluation and triage of crises. Nights and weekends, a pediatric hematologist is on call.

Management Ranges from Meds to BMT

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

Blood and marrow transplantation (BMT) may be considered for selected patients with frequent, severe complications and uncontrolled pain. Consultation with Cleveland Clinic Children's expert team of BMT specialists is readily available to the sickle cell population.

Unfortunately, a lack of donors often prevents BMT from being used. "In northern Ohio, most sickle cell patients are African-American, and finding a bone marrow match in the African-American population is challenging," Dr. Onimoe notes. She adds, however, that haploidentical transplant — now being offered at Cleveland Clinic Children's — may be considered on a research basis for patients who have no matched donors.

Softening the Impact of Socioeconomic Issues

The Sickle Cell Program also has protocols designed to minimize the impact of the socioeconomic issues common to patients. Medication noncompliance is a common problem. When prescribing hydroxyurea, which must be taken daily, Dr. Onimoe gradually introduces the drug to families. Blood tests at each visit reveal whether the drug is being taken as prescribed. "We don't leave things to chance," she says.

Helping parents understand the importance of regular assessments can also be challenging, particularly when a parent is reluctant to take time off work for fear of losing a job. In cases like these, Dr. Onimoe calls on a counselor from the ASCAA for help in educating families and identifying resources to eliminate barriers to care.

Patients can be scheduled to see Dr. Onimoe, a social worker and a psychologist in a single one-hour visit by calling 216.444.5517.

CLEVELAND CLINIC CHILDREN'S

NEW STAFF

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

CARDIOLOGY

Adriana Prada-Ruiz, MD

LOCATIONS: Main campus, Strongsville Family Health and Surgery Center

P: 216.445.0376
E: pradaa@ccf.org

HEMATOLOGY, ONCOLOGY AND BMT

Grace Onimoe, MD

LOCATION: Main campus

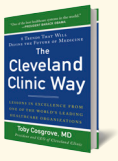
P: 216.445.9289
E: onimoeg@ccf.org

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

June 11-13, 2015
2nd Annual Pediatric Innovation Summit
Cleveland Convention Center, Cleveland, Ohio
See back cover of this issue for details.
Register today at ccfcme.org/pediatrics.

Aug. 31-Sept. 4, 2015
21st Annual Pediatric Board Review Symposium
Renaissance Cleveland Hotel, Cleveland, Ohio
Register today at ccfcme.org/GoPedReview.

Visit ccfcme.org for a complete listing of live and online pediatric CME offerings.



The Cleveland Clinic Way
By Toby Cosgrove, MD, CEO and President, Cleveland Clinic

Great things happen when a medical center puts patients first. Visit clevelandclinic.org/ClevelandClinicWay for details or to order a copy.

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 Dr**Connect** 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

Cleveland Clinic Children's

The Cleveland Clinic Foundation
Cleveland Clinic Children's Update
9500 Euclid Ave. / AC311
Cleveland, OH 44195

Don't Miss It! Pediatric Innovation Summit, June 11-13

Cleveland Clinic Children's Pediatric Innovation Summit

June 11-13, 2015

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

Join us for our second annual evidence-based review of pediatric care topics impacted by new data, screening tools or therapies. Sessions across the three-day CME-certified program focus on in-depth analysis of crucial data and their practice implications.

Faculty are drawn from Cleveland Clinic Children's expert staff and other leading institutions and societies.

PROGRAM HIGHLIGHTS

Two full-day symposium options on Thursday, June 11:

- 8th Annual Helen and Ronald Ross Symposium on pediatric congenital heart disease
- A nursing symposium exploring the latest advances in managing common pediatric conditions

Core summit program featuring:

- "The Future of Pediatric Healthcare," a panel discussion featuring nationally prominent guest faculty
- Keynote address by Benjamin Carson Sr., MD
- An update on immunization recommendations and controversies
- A spirited review of the year's top 10 pediatric papers
- Updates on topics from early and late puberty to enterovirus D68 and many more
- In-depth workshops on sports-related health, celiac disease, periodic fever syndromes and more

Half-day autism/ADHD symposium on Saturday, June 13:

- Reviews of latest screening and management options for autism
- Strategies for combining pharmacotherapy and behavioral therapy for optimal ADHD outcomes

Attendees may register for the whole three-day summit or just for the one or two days of greatest interest.

Visit **ccfcme.org/pediatrics** for full program and registration/accommodation info.

For registration questions, email **cmeregistration@ccf.org** or call **216.448.0777**.

This activity has been approved for *AMA PRA Category 1 Credit™*.