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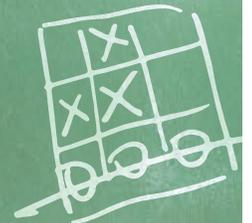
WITH

NEURODEVELOPMENTAL

CHALLENGES



Heart kids face hardships in school, but neurodevelopmental clinics and caregivers can help them get to the head of the class. By Stephanie Stephens



FOR LYDIA BUTLER, THE HEART Institute Neurodevelopmental and Education Clinic at Cincinnati Children's feels like a second home. "Going there just makes me happy," says the bubbly 11-year-old. "And I got to be in a video!"

Diagnosed with congenital heart disease when she was only five days old, at age 7 she appeared in the hospital's "Tell Me a Story" video to talk about being a "heart kid." Lydia was born with the

single-ventricle lesion called tricuspid atresia and needed an artificial tube inserted to allow blood to flow from her heart to her lungs and "pick up" oxygen.

"It was like 'replumbing,'" her mom, Lisa, says. The condition required three open-heart surgeries by the time Lydia was 4 years old. But the surgeries were only one small step in Lydia's heart journey. As Lydia began preschool, Lisa began to realize that her daughter may have cognitive problems.



Many CHD Patients Face Neurodevelopmental Problems

The most common birth defect in the United States, congenital heart disease or CHD, occurs in nearly 1 percent of — or about 40,000 — births per year. In addition, some CHDs bring risk factors for neurodevelopmental problems that include underlying syndromes or genetic and developmental disorders, according to a 2012 American Heart Association Scientific Statement (*see sidebar, “If Your Hospital Doesn’t Have Neurodevelopmental Services”*).

This means children with some forms of CHD may face developmental delays and challenges in school, and with living independently. According to the Cleveland Clinic’s Neurocardiac Clinic, approximately 30% to 50% of children who have undergone cardiopulmonary bypass for complex CHD will require remedial school services, and 15% will need full-time special education. However, with early screening for neurodevelopmental issues, children with CHD can thrive in school.

‘Variability In How Children Do’

In general, milder forms of CHD result in fewer issues (or no issues at all) compared to complex forms, according to Caitlin Rollins, M.D., Instructor of Neurology at Boston Children’s Hospital and co-author of a 2014 paper on the subject in the journal *Circulation*.

“There’s enormous variability in how children do because of so many different influences, and what’s true for one isn’t true for all,” says Dr. Rollins. “For example, some forms of heart disease can alter blood flow during the fetal period that affects in-utero brain development. Some children incur specific injuries that can have neurological consequences. I recommend parents be prepared to act

Family photo courtesy of the Butler family. Portrait courtesy of Caitlyn Rollins, M.D.



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—Caitlin Rollins, M.D.



preemptively and continue to think positively about a good outcome.”

Infants may show developmental delays such as low muscle tone, and then face challenges with feeding, language and social skills. Later, school attendance may unmask problems such as difficulty with calculation or concentration. In high school, as students balance multiple courses, they may have trouble with higher-level organizational issues.

Dr. Rollins adds that parents are often first to notice anything unusual, and that early identification is so important. A primary care doctor can refer a child to a developmental specialist — such as someone who works in early intervention services — or to a psychologist or other specialist if or when parents notice any concerns. “For certain forms of heart disease that carry higher risk, children should be evaluated even before concerns arise,” Dr. Rollins says.

For CHD children younger than



Caitlin Rollins, M.D.,
Department of
Neurology, Boston
Children’s Hospital



“When you bring [Cincinnati] Children’s Hospital into the mix, schools do seem to listen better,” says Lisa Butler, standing here with her daughter Lydia.



Lydia is doing well in school and is a competitive figure skater. Her T-shirt and boxing gloves were part of her costume for a skating championship competition, where she won first place. She performed to the popular *Fight Song*.

Who Is at Risk?

Children with milder forms of CHD, such as atrial septal defects, do not seem to have a higher incidence of developmental disabilities than their peers. Children who were on cardiopulmonary bypass during surgery or children who were born cyanotic (decreased blood oxygen) seem to be at the highest risk. Some types of CHD that increase the risk of neurodevelopmental issues include:

- Coarctation of the Aorta
 - Tetralogy of Fallot
 - Ventricular septal defect with comorbidities
 - Total anomalous pulmonary venous return
 - Single ventricle defects
 - Hypoplastic left heart syndrome
 - Hypoplastic right heart syndrome
 - Tricuspid atresia
 - Double outlet right ventricle
 - Double outlet left ventricle
 - Transposition of the great arteries
 - Truncus arteriosus
 - Interrupted aortic arch
- Children with syndromes associated with CHD
- Down syndrome
 - 22q11 deletion
 - Noonan syndrome
 - Williams syndrome

3 years, Dr. Rollins urges families to seek out free, federally mandated early intervention services that include periodic evaluations — “even if things appear to be going well.”

How Early Medical Issues Affect Learning

“We call ourselves ‘heart moms’ and we’re all a little ‘nuts,’” says Lisa Butler. “We handle ourselves differently than other moms do.”

Lisa recalls how she handled Lydia’s neurodevelopmental issues, beginning with kindergarten, where her daughter “lagged.” When Lisa blamed Lydia’s heart defect, school officials didn’t think the problems merited a special education curriculum. Then in first and second grade, when Lydia had trouble remembering things, teachers said she was “lazy.”

Her mom knew it was time to take action, and so she turned to the neurodevelopmental clinic, or NDEC, at

Cincinnati Children’s. Here, heart kids like Lydia go through a five-step process, starting with an initial screening, followed by a comprehensive evaluation and then a case conference. With detailed documentation and recommendations, an NDEC team member shares results with the child’s school, either in person or on the phone, to make sure the child has every opportunity to excel.

Long-term monitoring continues as the child grows and develops, with age-appropriate support, follow-up appointments every six to 12 months, reevaluation and assistance with recommended treatments.

The program sounded ideal for Lydia. Once at the clinic, Lydia saw a comprehensive interdisciplinary team of experts all at once without needing individual visits. Specialists followed a “whole child” approach with her treatment; Lydia had access to pediatric cardiologists, neurologists, nutritionists and occupational

Photo courtesy of the Butler family

therapists, as well as social workers, child life specialists, a school liaison and educational specialists.

“Lydia initially received a diagnosis of attention deficit hyperactivity disorder or ADHD — common among children with CHD — and was referred to occupational therapy to work on fine motor and functioning issues,” Lisa says. Lydia was also diagnosed with developmental coordination disorder.

A clinical special educator at the hospital who helped Lydia, Gretchen Carroll, M.A., works with schools to determine eligibility and implement necessary intervention services for children. These can involve speech therapy, occupational therapy, physical therapy and educational support under an Individualized Educational Program or IEP.

“We’re not just dealing with kids in a bubble, but trying to affect change for them in school,” Carroll says. “Many schools don’t know a child’s cardiac issues can impact school performance. We explain how early medical issues affect learning, attention, emotional anxiety, language, motor skills and more.”

The educator can help support a child’s case for a plan, and her suggestions also help school personnel better understand the child’s specific needs. Her own detailed outline differs from a school’s IEP, however.

“No outside agency can dictate to a school just because we think a child is qualified for an IEP,” Carroll says. “We want to be a partner, but schools go through their own eligibility process and sometimes this is a ‘dance.’”

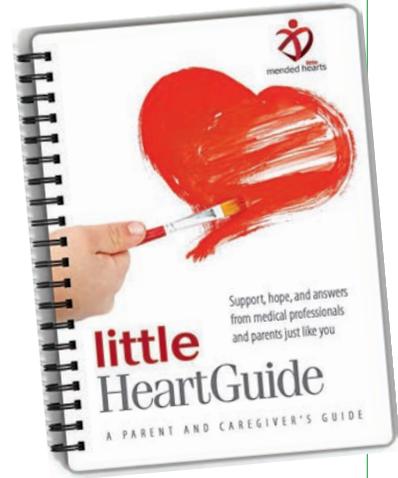
“We got our 504 plan and later, the IEP,” says Lisa. “When you bring Children’s Hospital into the mix, schools do seem to listen better.” The goal of any educational plan is to provide appropriate services while the student needs them

Need More Info?

The Mended *Little HeartGuide* includes a full chapter on neurodevelopmental issues in children with congenital heart defects. Written by Bradley Marino, M.D., MPP, MSCE, one of Lydia Butler’s physicians who is now at Northwestern Medicine, and edited by parents of heart kids, the chapter features recommendations such as when children with certain types of CHD should be screened for neurodevelopmental issues.

Download the digital Mended *Little HeartGuide* at www.mendedlittleheartguide.org.

A presentation by Dr. Marino called “Neurodevelopmental Issues and CHD,” is available at <http://bit.ly/28PknZz>.



— and eventually to get to the point where he or she no longer requires them.

Extra Help Is Here

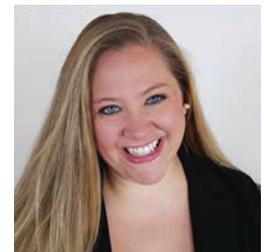
As a school intervention specialist at Children’s Hospital of Wisconsin’s Herma Heart

Center, Kyle Herma sees heart kids with neurodevelopmental needs. And yes, those surnames are the same.

When Kyle’s sister was born with hypoplastic left heart syndrome, the cardiology department was later named in her family’s honor to recognize their extensive contributions to eradicating heart disease. As a former classroom teacher, Kyle was hired to head the pilot neurodevelopmental program that began in February 2015.



Heart patient Lydia Butler talked about her story for a Cincinnati Children’s Hospital video series called “Tell Me a Story.”



As a school intervention specialist at the Children’s Hospital of Wisconsin, Kyle Herma meets with and counsels school staff.

If Your Hospital Doesn't Have Neurodevelopmental Services

If your child has surgery at a major heart center, ask the health care team for advice and suggestions about local connections that may be available closer to your home.

- Contact programs that offer neonatal intensive care follow-ups, since they may offer similar services. A good start is the Early Childhood Technical Assistance Center. Find them at <http://ectacenter.org/contact/ptccoord.asp>.
- Bring the 2012 American Heart Association Guideline to your pediatrician or to your child's school to address any concerns. You can find this at <http://circ.ahajournals.org/content/126/9/1143.full>.
- Talk to your child's pediatrician or primary care doctor.



Gretchen Carroll, M.A., clinical special educator for the neurodevelopmental clinic at Cincinnati Children's Hospital, helps school officials determine when a child with a congenital heart defect may need special intervention services.

She presented a poster — a “mini” scientific paper — at the International Society for Heart Lung Transplantation Scientific Sessions and Pediatric Academic Society's annual meeting, both in late April. A full manuscript is in the works on the complete pilot study.

In the paper, Kyle's team noted that children with complex health needs are at greater risk of poor student

engagement, disruptive behavior, low academic achievement and exposure to bullying. They also cited the rarity of structured programs for school re-entry and intervention.

At Children's Hospital of Wisconsin, patients receive individualized

assessments and tailored interventions to be shared with their schools, Kyle says. Kyle meets with and counsels school staff on best practices to foster children's progress, coaching teachers on appropriate modifications and accommodations and helping parents understand their rights and responsibilities when partnering with schools.

This means determining the problem first, then putting supports in place to address it, she says. These might include creating a personal and individualized checklist or schedule so the child can cross off tasks accomplished in anticipation of what's coming next. Maybe a child could benefit from a peer note-taker, sitting closer to the blackboard or teacher, or just carrying a water bottle throughout the day.

Kyle's previous teaching job at a high-risk school taught her about sending kids “off into the real world,” she says. “They may not know how to interact with society in a meaningful, productive way. Keeping them in a protective little bubble doesn't help, so I want parents and teachers to encourage safe risk-taking.”

Bright Future for Lydia

Lisa Butler does just that for Lydia, who has more big plans thanks to the neurodevelopmental support she received and continues to benefit from in Cincinnati. Lydia is always eager to go ice skating and play volleyball with her friends, while working on getting good grades at school.

“I want to do more fun things,” Lydia says. For those who love her and have followed her progress, there's no doubt she'll do much more.

“Having a heart kid is never easy,” says Lisa. “But having a team behind you that you know genuinely cares about your child — that is a priceless experience.”

Photo courtesy of Gretchen Carroll



CHOLESTEROL COUNTS: YEAR IN REVIEW

Cholesterol Counts rallied Americans to take an active role in understanding there is more to be done to control high LDL, or “bad” cholesterol, and reinvigorated the conversation on cholesterol management between patients and healthcare providers.



OUR GOAL

Educate Americans about the risks associated with high LDL cholesterol, encourage them to learn more about their individual cholesterol numbers, and empower individuals to talk to their healthcare providers about how they can lower their numbers.

REVEALING LDL CHOLESTEROL LEVELS ACROSS AMERICA

TOGETHER, SANOFI US, REGENERON, THE FOUNDATION OF THE NATIONAL LIPID ASSOCIATION, MENED HEARTS AND PREVENTIVE CARDIOVASCULAR NURSES ASSOCIATION (PCNA), DEVELOPED THIS PROGRAM TO HELP EDUCATE AMERICANS ABOUT LDL CHOLESTEROL.



The cornerstone of the program was the *Cholesterol Counts* Poll, which gauged how much Americans know about cholesterol, their numbers and the risks associated with high LDL-C cholesterol.



The results of the Poll were visualized through interactive maps, which depicted the levels of LDL cholesterol awareness and knowledge across the country.



The Poll and interactive maps, along with additional resources on LDL cholesterol, were shared on CholesterolCounts.com.

WHAT WE LEARNED

We raised cholesterol awareness by encouraging dialogue around cholesterol, fostering a better understanding of cholesterol numbers, and increasing cholesterol knowledge by surveying more than 15,000 American adults and showcasing the results.

CHOLESTEROL COUNTS GAUGED HOW MUCH AMERICANS KNOW ABOUT LDL CHOLESTEROL AND VISUALLY REPRESENTED AMERICANS' KNOWLEDGE AND AWARENESS ABOUT LDL CHOLESTEROL.

74%



OF RESPONDENTS REPORT THEY ARE NOT SURE OF OR DO NOT RECALL **THEIR LDL-C** (BAD CHOLESTEROL)



OF RESPONDENTS REPORT THEY COULD BE **DOING MORE TO MANAGE THEIR HIGH LDL-C** (BAD CHOLESTEROL)

41%



OF RESPONDENTS REPORT THEY ARE NOT SURE IF LDL CHOLESTEROL IS REFERRED TO AS “BAD” CHOLESTEROL

POLL RESULTS SHOW THERE ARE **GAPS IN KNOWLEDGE** ON THE TOPIC OF LDL CHOLESTEROL AND **MORE NEEDS TO BE DONE** TO EDUCATE AMERICANS ABOUT **HIGH LDL CHOLESTEROL**.

PATIENTS SHOULD GO TO THEIR HEALTHCARE PROVIDER TO GET THEIR CHOLESTEROL CHECKED, LEARN THEIR NUMBERS, AND ENCOURAGE FRIENDS AND FAMILY TO DO THE SAME.