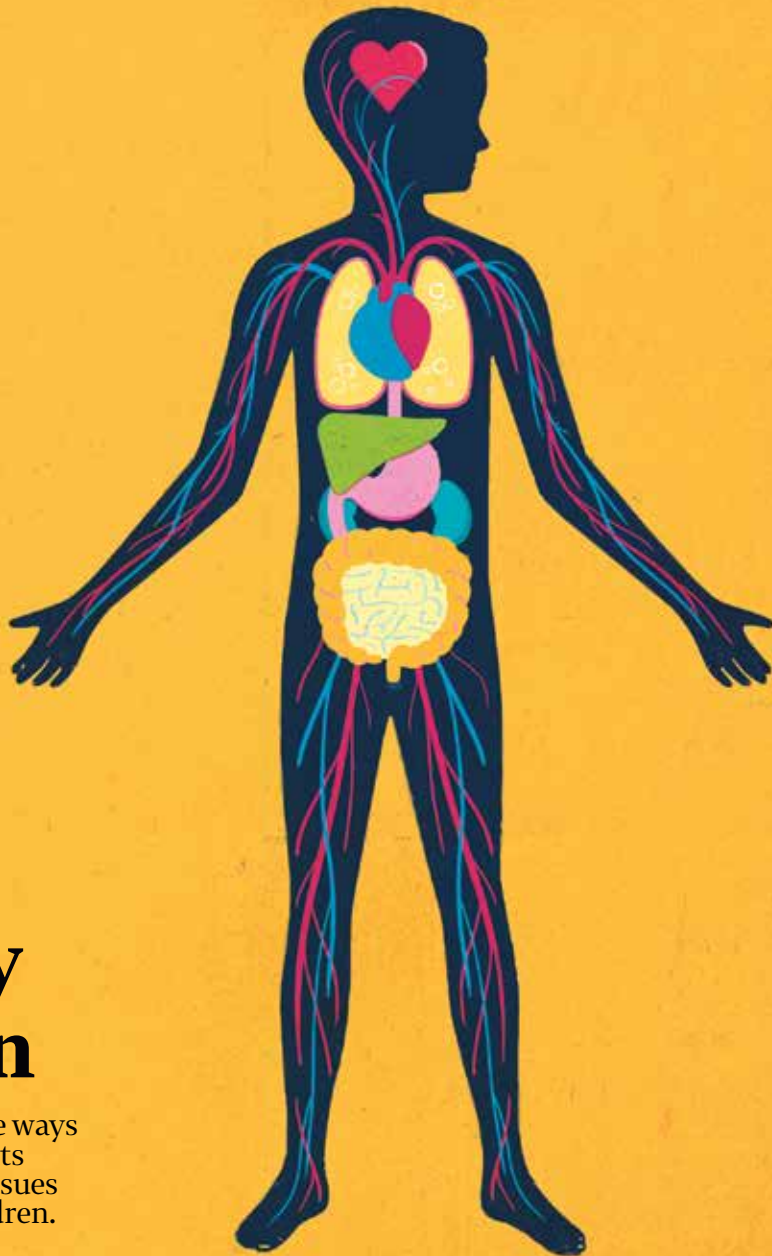


IN-DEPTH

CHILDREN'S
HEALTH



The Mind-Body Connection

Here are a few of the innovative ways hospitals, doctors and nonprofits are addressing the emotional issues surrounding the health of children.

ECHO MONTGOMERY GARRETT

On a recent Friday, Dr. James D. Fortenberry, the pediatrician in chief of Children's Healthcare of Atlanta, donned a cape before heading to work. He was one of thousands celebrating the third annual Cape Day by plastering photos of themselves in capes on social media as a message to young patients that their heroic battles against illness are recognized.

"It's a chance for us to encourage our kids and teens to unleash their

inner superhero and to say, 'I am strong and I am able to fight this,'" Fortenberry explains. "Children and teens have special needs. It takes a dedicated team of people to understand that mind-body connection and make sure we are addressing their needs emotionally, mentally and spiritually."

Those caring for kids have been seeking new ways to promote healing, improve quality of life and provide equality of care. Children's hospitals and clinics are adding

everything from guided imagery to canine therapy to music studios.

"We are doing whatever we can to help them take control of their thoughts and help take them to their happy places," says Fortenberry. "We want to decrease that child's stress. When we decrease stress, the child's heart function improves and the cells are better able to fight off infection."

GRATITUDE AND HEALING

For Lisa Honig Buksbaum, a trio of

tragedies—including watching her then 10-year-old son remain bedridden for months with rheumatic fever—led her to create Soaringwords, a New York City nonprofit that uses simple art projects, positive affirmations, journaling and writing to boost the spirits of pediatric patients with serious or chronic illnesses.

The Soaringwords model has seven components: somatics (taking physical action and being emotionally engaged), outcomes (measured empirically), altruism (gaining a sense of control by choosing to do something for others), resilience (having the capability to flourish in the face of difficulties), imagery (tapping into inner knowledge to heal), narrative (healing through storytelling, writing and reading) and gratitude—SOARING.

“If you invite a child to pay it forward, you are giving that child the gift of creativity, a sense of control and of purpose, altruism and resiliency,” says Buksbaum.

Over the past 15 years, more than



Soaringwords uses creative strategies to help kids cope.

135,000 Soaringwords volunteers have served more than a quarter of a

million hospitalized children in 196 hospitals and 25 Ronald McDonald Houses in 30 states and 12 countries. Soaringwords is also the charity of choice for Zumba Fitness, and each week hundreds of Zumba instructors volunteer to lead classes for families and patients. The evidence-based program demonstrates that young patients who participate in the program have improved outcomes both mentally and physically. In January, Buksbaum is launching a new study

of 2,000 patients in 17 hospitals worldwide, exploring the impact of the expressive arts projects and dance classes.

Says Buksbaum, “Hospitalization is stressful and often painful. The whole family is in crisis. We give an opportunity for a child to have control and to focus on the positive and celebrate the good. We tap into the healing power of stories and art.” Working with internationally renowned psychologists such as Jane Dutton and Barbara Fredrickson, as well as pioneering psychologist Angela Duckworth, author of *Grit: The Power of Passion and Perseverance*, Soaringwords’ founder has created online videos to promote positive connections for kids, families and caregivers.

DETECTING CYSTIC FIBROSIS EARLIER

A cystic fibrosis diagnosis can be devastating—especially for the families of the approximately 750 children under the age of 2 who are diagnosed with the disease every year.

Cystic fibrosis causes mucus to build up in the lungs and other organs. Sufferers contract frequent lung infections, and over time the disease limits the ability to breathe—leading to early death (the median age of survival is 40). There is no cure for CF, and day-to-day life can be extremely difficult, physically and emotionally, for kids affected by it.

A new clinical genetic test can help families prepare for a possible diagnosis much earlier by determining if parents are carriers of the genetic disorder before they even have children.

CF is a recessive genetic disorder, which means an individual’s parents must both have pathogenic variants in their carrier gene in order to develop the disease. If only one of the parents is positive for the carrier gene, they have a 50 percent risk of passing on the recessive gene to their offspring. The child will not be positive for the disease but has a risk of passing the gene on to his/her child. However, if both parents are carriers, the risk of having a child with cystic fibrosis is 25 percent. If you have a family history of cystic fibrosis and are considering having children, your doctor can order this test.

“It’s highly accurate—twice the industry standard,” says Holly Carpenter, Ph.D., co-founder of Aeon Global Health, the Gainesville, Georgia-based company that developed the test.

MUSIC MATTERS

In the last two years of Ariana Miller’s life, there was one bright spot that the young teen—who suffered from congenital heart disease—looked forward to each week: a visit from her music therapist from Resounding Joy. The San Diego nonprofit runs a program called Healing Notes for young children in hospital settings. With her music therapist, Ariana, who had six open-heart surgeries at Rady Children’s Hospital, wrote and played music, sang and dreamed of appearing on *American Idol*.

Research shows that music can be magic when it comes to healing—soothing stress by decreasing heart and breathing rates and helping raise oxygen levels.



Healing Notes uses music to help kids at Rady Children's Hospital in San Diego.

“Ariana had days where she didn’t want to get out of bed, but if she knew she had a music therapy appointment, she’d get up,” her father, Dr. Jeffrey Miller, a radiologist, says of the sessions’ effect on Ariana. “It completely elevated her mood and she was able to forget about the disease for an hour. Songwriting helped her focus on the good.”

When Ariana passed away at age 13 while waiting for a heart transplant, her parents decided to create a concert to raise money so that all young cardiac patients could receive the gift of music. Since 2010, the Ariana Miller Music with Heart Program has provided free music therapy sessions to more than 1,000 children in Rady’s cardiac unit.

“There is something special about how music connects with children when they are in a difficult, stressful situation,” says Rachel Gant, a music therapist and the director of the Healing Notes program.

Five days a week, Gant meets with the child-life specialist early in the day to get a list of high-priority patients in order to design individualized music therapy according to their primary needs. “I may have a teen who has just gotten a cancer diagnosis and needs a positive distraction, or a baby may not be feeding and needs soothing,” she says.

She and the other therapists

record data regarding mood, pain levels and vital signs. She currently has a full load of cardiac patients from newborns to teens, but recently a small grant allowed the program to branch out to the hematology and oncology units. Families often request that the music therapist be present when a child is undergoing a painful procedure.

In the past year, the Healing Notes program expanded to a palliative in-home program for children and teens with life-limiting or life-threatening illnesses or injuries.

“Playing an instrument can help strengthen a weak side of the body or grip, singing can help improve vocalization, listening to music can help with relaxation or sleep,” explains Lindsay Zehren, the music therapist who piloted and runs the in-home program. She brings a guitar and ukulele along with shakers and other visual aids. “The kids light up when they see me coming, because I’m not poking or prodding them,” she says. “I bring instruments for all different hand sizes and strengths.”

She consults with the family and the care team to meet their objectives. Some with terminal illnesses have requested legacy projects where they write and record songs with their families. “Our sessions bring some normalcy,” says Zehren.

The inspiration for Resounding Joy’s founder and executive director, Barbara Reuer, Ph.D., was

seeing the positive effect music had on the homebound. Then Ariana Miller’s parents, whom Reuer knew from church, devoted themselves to helping her expand the Healing Notes program, primarily through a Heart of a Child Benefit Concert. Says Reuer, “I wanted to be able to reach more children and teens with the gift of music, and [the Millers]’ determination makes that possible.”

Music is a key component at Seacrest Studios, started by Atlanta native Ryan Seacrest in 2010 and now in 10 hospitals across the United States. The studios provide a musical escape for tween and teenage patients (as well as some adult patients). On a recent afternoon at Seacrest Studios at Children’s Healthcare of Atlanta at Egleston, several young patients lined up to have their photo taken with Lady Antebellum and get autographs, after the hit country trio gave a private performance for them.

Wendy Threatt, Seacrest Studios’ program coordinator, worked at Atlanta radio station Star 94 for almost 24 years. “I reach[ed] out to record reps and brought in artists to meet the kids,” she says. “Atlanta is such a hub for music, so we get a lot of celebrity visits, and local artists drop by.”

Threatt tailors the day’s programming—she has an approximately 11,000-song catalog—to requests from the kids in the bright, cheerful studio. “Some days I put them on the

air, which is broadcast on a channel in all the hospital rooms,” she says, noting she’s now hosted thousands of kids in the studio. “I may get a request for 20 Taylor Swift songs in a row. They may be feeling high



LEFT: Kevin Spacey and patient at Seacrest Studios. RIGHT: A service dog rides the CT scanner.

energy and want to play games. Seeing a teen be able to enjoy music and forget the nausea from chemo for a little while—those are the moments that leave you with a lump in your throat. Music is very therapeutic, and I’ve seen so many miracles in this place.”

FOUR-LEGGED HEALERS

Lisa Kinsel, who manages the volunteer services office on CHOA’s Scottish Rite campus, was in charge of coordinating the visits of service dogs-in-training from Canine Assistants, a nonprofit in Milton, Georgia. She noticed how the children, who got to interact with the dogs, perked up on the one day a week the canine trainees came to the hospital. “It was hard to tell a child that they wouldn’t see that dog again for another week,” she says.

After a volunteer suggested placing a dog full-time in the hospital, Kinsel wrote a proposal for Canines for Kids and submitted it to CHOA’s chief medical officer, who quickly gave her a yes and asked how fast she could implement her idea.

Canines for Kids began in 2009 with Kinsel as the handler of Casper, a service dog from Canine Assistants. It marked the first time Canine Assistants had placed a dog full-time in a medical facility.



Kinsel worked with an infection control team and devised a protocol to ensure patient safety. As the medical health providers saw the positive impact that Casper brought with him, CHOA added more dogs to the team. Now there are very few restrictions on where the 12 dogs on staff can be within the hospital.

“Casper will ride the CT scanner to show a child that it’s no big deal,” she explains. Notes are kept in patients’ charts to chronicle the dogs’ impact.

While attending a nursing research conference with Casper, Kinsel was delighted to learn that there are now roughly 26 other service dogs—typically golden retrievers, Labradors or Goldendoodles—on staff at other children’s hospitals across the country.

THE IMPORTANCE OF BEING UNDERSTOOD

In the course of his specialty of caring for adolescents, Dr. David J. Breland noticed especially high rates of anxiety, depression and suicide among transgender or gender-nonconforming youth.

“I was concerned that their medical, social and behavioral needs were

not being met,” says Breland, who is now at Seattle Children’s Hospital and the University of Washington. So he wrote a grant and submitted it to the Center for Diversity and Health Equity, which approved it.

In October, SCH opened a new gender clinic for children, adolescents and young adults up to 21 years of age. The multidisciplinary clinic, one of only five in the United States, offers services to youth whose gender does not match their sex at birth or who do not identify with traditional definitions of male or female. Those services include mental health support, referrals for readiness discussions, pubertal blockers and cross-sex hormones. Breland, the clinic’s medical director, says that within the first month, 50 families had called for appointments.

“A lot of these families have struggled tremendously because it’s not an easy path to navigate the health care system for these youth,” he says. “They often get misdiagnosed and are given misinformation. There’s a lack of knowledgeable providers and a lot of insurance exclusions that hamper care, as well as uncoordinated care.”

The clinic’s care navigator works with patients and helps them set up all of the appropriate appointments. The care navigator may work with the child’s school to provide education on issues such as making sure the child has access to a safe bathroom and is being recognized as the sex with which they identify.

“The response has been overwhelming,” says Breland. “We really listened to the community, and coordinated care is the way to go. We provide endocrinologists and mental health counselors. We do everything here except surgeries. We give them a road map, referrals and a supportive environment to make sure everything is on the right path. We are trying to eliminate all the barriers to health that we can foresee.” ▽