

Children's Hospital LOS ANGELES

imagine

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STANDING TALL

Noah moves forward after surviving not one but two rare diseases.

A GIFT FOR GABRIEL

On Christmas Eve, one little boy receives a heart.

AHEAD OF THE CURVE

The Children's Orthopaedic Center helps Juliette stay in the game.

THE DAWN OF AVERY

Awakened at last, a transgender teen steps out into the light.

WHAT'S DRIVING JOSIE HULL?

By force of will, the onetime conjoined twin races on.



sHeLf-ConfiDEnCe

By Jeff Weinstock

In CHLA's Literally Healing Program, books are a means of recreation and therapy, providing children with an understanding of their condition and the strength to help them through treatment.

"So my name is Clai-i-i-re," the slender woman with the regal accent says as she kneels to greet little Miley, lingering on the single syllable in that splendidly British way, as if it were topped off with a swirl.

She gasps, seeing what's in the girl's hands. "Dr. Seuss! Do you know this bench right here looks like 'Green Eggs and Ham'? Look at the color. It's exactly like the book you're reading!"

It would be fair to say that Claire Austin is rounding. Like any dutiful care provider, she is checking on the patients in her charge, who include those this morning—and every weekday morning—in the Reading Room on the sixth floor of the Marion and John E. Anderson Pavilion at Children's Hospital Los Angeles, the heart of the Literally Healing Program that Austin founded 15 years ago.

The program promotes reading for all the lasting benefits of early literacy, but also for the relief and diversion it brings to patients and their families. The gifting library, kept within the Reading Room, teems with Harry Potter, Amelia Bedelia and whatever else Austin's relationships within the business and education communities can procure. The books are given to patients for keeps at the rate of one a day—two if they read for 20 minutes that day.

All told, Austin says Literally Healing distributes more than 30,000 books a year, all of them donated and the majority hand-delivered by volunteers either in the library or the hospital lobby—or bedside. Two Bookmoobiles, with their cow-painted exteriors, are wheeled room to room, carrying books to children whose conditions require them to be isolated.

"We service every floor in the hospital, every bed, every critical care unit and 20 clinics," she says. Plus, she adds after taking in the room, "it's peaceful in here."

A reading remedy

Literally Healing's crown jewel, however, is its other half—the therapeutic library, whose collection tops 1,000 books, shelved in one room of office space, comprising what Austin believes may be the largest volume of its kind in the world. The books provide patients and families a level of solace and support that is apart from clinical therapies. They cover the spectrum of childhood disorders and confront the starkest subjects. Sample titles include "When Nothing Matters Anymore," "All About Scars" and "Tear Soup," a book about grieving.

Austin oversees, handpicks and has even contributed to the library's resources. She explains that the books put words to questions that children may harbor but can't form, drawing them out on their terms. "A child will relate to a children's book," she says. "That's their world. They're less likely to relate to a hospital leaflet."

Case in point is Gracin Kerry, a CHLA patient diagnosed with kidney cancer as a toddler. Like most small children, Gracin had to be anesthetized before undergoing an imaging scan to ensure she would stay still. So it was until she received a book from the therapeutic library called "Bowregarde's Hospital Handbook," which explains CT scans and X-rays and describes what an MRI sounds like.

"It was a book written for her and what she would be thinking," says Gracin's mother, Nikki, who says her daughter, now 11, shows no evidence of disease. "Through that book we got her to calm down. They said she was one of the youngest patients who could lie still for a CT scan without being put to sleep."

Nikki says reading with Gracin meant something else to her and her husband. "It was a chance to sit back and breathe. It brought a bit of normal into a really significant life situation."

Is it a science?

As large as the therapeutic library is, Austin is scrupulous about what she allows into it. She screens every submission, and dismisses most. "For every book that goes into this collection, I read many more that don't," she says. "If you're going to ask families to trust a new genre of resources, it has to be the best."

There's not quite a book for every ailment, or what does exist falls short of Austin's standards. "There is no really great book to help children who are frightened of shots," she offers as an example.

One aspiring author hoping to add to the library is CHLA pediatrician Tamiko Jordan, MD, who has written a book titled "The Nose on Rose."

"It's about children who have a part of their body they don't like," Jordan says. "But even though they're teased about it when they're little, it turns out to be their biggest advantage when they're older."

She got favorable feedback from Austin, who set her up with a contact in the children's book industry. "It would be amazing, right, if I published a book and then got proceeds back to her program?"



Literally Healing provides bedside readings to patients who are unable to leave their rooms.

Jordan is Austin's main ally in literacy promotion at CHLA, serving as the site medical director of Reach Out and Read, a national organization whose participating pediatricians give books to patients at checkup visits. She and Austin are looking to team up on a study of a book that Austin co-authored for children with spina bifida, "Right Under My Nose."

"Our issue is finding what question we are trying to answer," Jordan says. "Does it improve kids' understanding or acceptance of their disease? Does it help their self-esteem? Does it improve compliance with therapy? If we could prove that, we could publish the results, and other spina bifida centers may adopt it as a therapeutic intervention."

Plus, that would start Austin on her long-held wish to demonstrate scientifically what she can confirm anecdotally—that reading holds genuine, discernible benefits for ailing children. An empirical study "is long overdue," she says, though for now too big an undertaking to be doable. But she has given it thought. "I've brought it up with psychologists and mental health professionals, and we know where we would start and with what conditions."

She cites one patient with a facial deformity who would draw pictures of her family during her therapy sessions, always portraying herself with half a mouth. After the girl's initial corrective surgery, her psychologist gave her a book from the therapeutic library called "Living Well With My Serious Illness."

Not long after, Austin says her phone rang. It was the psychologist. "She was squealing with delight: 'Guess what happened! She just drew herself with a complete mouth!'"

It was forward-looking, the shape of optimism—the shape of healing.



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—Claire Austin