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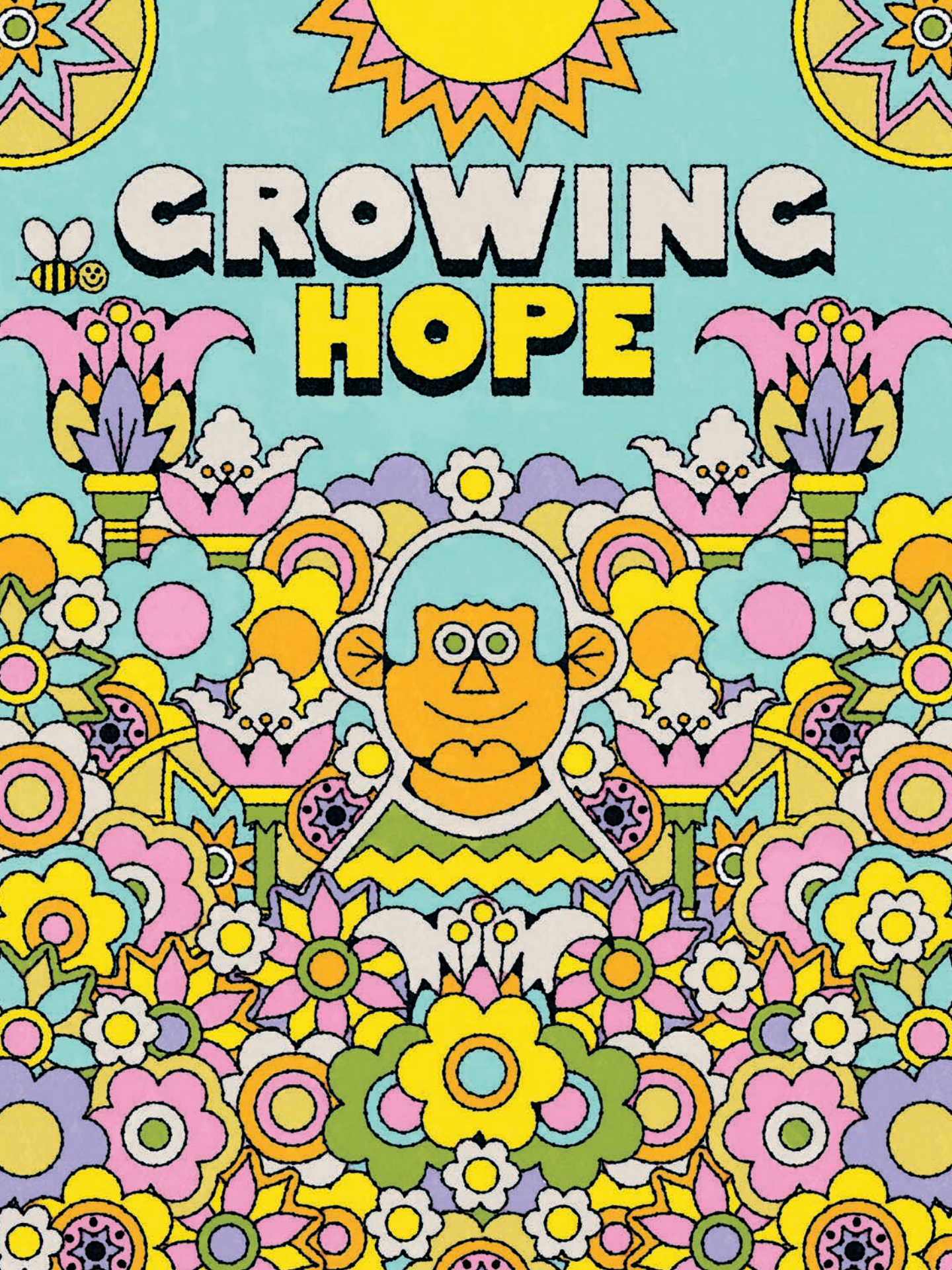


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DEVELOPING TRENDS IN THE USE OF CANNABIS IN PEDIATRIC CARE

STORY

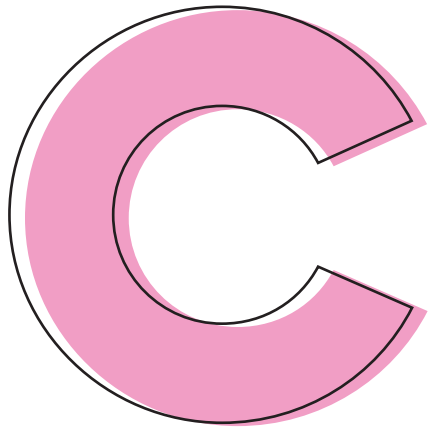
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ILLUSTRATIONS

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IN LATE 2013, Allison Ray Benavides came across a newspaper article that piqued her interest. It was about a man named Jason David who turned to medical cannabis to successfully ease the symptoms of his young son's rare seizure disorder. She thought it was "fascinating" made a mental note, and moved on — but not without thinking "I feel like this story is going to affect my life somehow" she says in a recent phone interview.



ALL IT MOTHER S INTUITION.

About two weeks later, Benavides says, the unthinkable happened: Her son, Robby, then about a year old, had a seizure. Then he had another one. Eventually, Robby was suffering up to 10 grand mal seizures a day.

Two months later, she and Robby's father realized he wasn't responding well to his prescribed medication, Depakote, a popular treatment for epilepsy disorders. She remembered reading about David and his son, Jayden, discovered the Facebook community he had founded documenting their medical ordeal (now 24,000 followers strong), and emailed him. They began corresponding, and Benavides realized that using a cannabidiol (CBD)-rich cannabis oil, as David and Jayden had, was pretty much our only option, she says. David connected Benavides with the person making Jayden's cannabis oil, which she bought but never used, admitting she was nervous and afraid. It got moldy while sitting on the countertop; Robby's dire condition continued unabated.



FIND OUT MORE
Jason David and Jayden
thejaydensjuice.com

Realm of Caring
realmofcaring.org.

Benavides, who was then living in California, continued her research and soon connected with Realm of Caring, a Colorado-based medical cannabis advocacy organization that also conducts rigorous studies on medical cannabis use. The

organization was compiling a list of initial patient recipients for the first batch of cannabis oil produced by the Stanley brothers, two growers who formulated a high-CBD cultivar called Charlotte's Web. It was named for Charlotte Figi, a young girl with Dravet syndrome, a rare epilepsy disorder causing symptoms not unlike Robby's, whose mother, Paige, helped found the organization. The oil made from this cultivar helped Charlotte, and, thanks to her mother, the Stanley brothers, and other parents and patient advocates, a movement was born. It was small and quiet at the time because administering cannabis to children, even nonintoxicating CBD, was then—and in many places still is—illegal.

Robby got on the list as one of the first 20 recipients of the first batch of cannabis oil and received his initial treatment in early 2014. This time, thanks in part to Realm of Caring's involvement, Benavides felt more comfortable administering it to him. Still technically an infant, Robby became an official medical cannabis patient, joining the ranks of an untold number of kids across the world who use cannabis for medical treatment.

Though he's far from alone, it's an admittedly exclusive club. Even today, most parents who turn to



medical cannabis as treatment for their children do so as a last resort, says Michelle Sexton, a Bastyr University-trained naturopathic doctor on staff at the Center for Integrative Medicine at the University of California San Diego: "The first cannabis clinic in a major medical institution," she writes on her LinkedIn profile.

"The families we've worked with tend to have kids with genetic abnormalities, and there isn't a cure for what they have," Sexton says. "There might not even be any good treatment. There may be some drugs to try to minimize symptoms, and that's about it, and some of those drugs given to the children are potentially harmful in

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some ways. It could just be heavy sedation, but [the drugs] could also be affecting their development.

Sexton first started working with cannabis, and with kids in tandem, in Washington State in 2010. "CBD had just burst onto the scene," she says, adding that she began treating two kids with

Dravet syndrome from different families who were not seeing success with mainstream medicines.

"There was nobody there," she says of the "dead" look in the kids' eyes. "They were just stoned out of their minds on these drugs," Sexton adds, using a term typically reserved for cannabis intoxication rather than traditional pharmaceutical treatments.

The CBD oil helped her new patients so much that Sexton gave a talk lauding the use of CBD-rich extracts for pediatric epilepsy treatments at the 2013 International Cannabinoid Research Society Symposium on the Cannabinoids. "It was a huge room," she recalls, adding that it was "filled with scientists studying the endocannabinoid system," many of whom were already open to medical cannabis use, though maybe not for children, especially as most of them were still studying it in nonhuman animals. She says that there was "hardly a dry eye in the house" after she told stories of kids riding bikes for the first time or "coming back to life" after using cannabis to treat epilepsy disorders.

After sensing the excitement in the medical community, Sexton and her care team worked with the two parents whose children she was treating (who were also nurses) to design a dosing paradigm to pass around the national network of families wondering

about using cannabis to treat their kids. Because not everyone lived in a weed-friendly state like Washington, Sexton says, they sometimes had to implement creative solutions to get cannabis and the proper dosing information to parents.

"I still have the original Excel file that we made up," she says. "We instructed people to put in the child's weight and the percent CBD of the extract, and it calculated how much oil to add and how much to dose, and that paradigm got passed across the United States really rapidly."

Beyond treating epilepsy disorders with CBD—which has been so successful that an FDA-approved drug, Epidiolex, with the popular cannabinoid as its active ingredient, now exists—there are other uses for medical cannabis for kids. Other conditions are well treated with THC-rich formulas, says Sexton, which is more controversial as THC is intoxicating and the part of the plant that's still federally illegal.

"There's a lot of hype about CBD, some of it deserved; but also, there's a lot of CBD that needs to get sold," she says about the glut of hemp-derived CBD that arrived on the market after the federal government legalized hemp cultivation and minor cannabinoid extract production in 2018. "But THC is really kind of the magic molecule. It's the one that's directly

acting on the endocannabinoid system. And it's so efficient and effective for spasticity. It can work in kids with cerebral palsy and neurodivergent conditions like autism and ADHD."

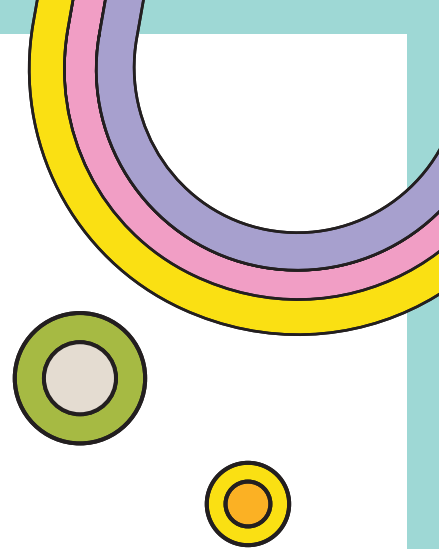
Sasha Kalcheff-Korn, executive director of Realm of Caring, agrees that THC is a more taboo but potentially life-changing molecule that needs to be an equal part of the kids' and cannabis conversation. She says it's becoming a more frontline solution for curious parents desperate for a remedy, especially those inclined toward more so-called "natural" solutions. "We've started to see, especially in the last couple years, this sort of shift," she says. "[These parents] don't want to go the pharmaceutical route because they have heard about the damaging side effects of a lot of these medications. So they're actually going to cannabinoid therapy as a first line, which is always cool to see. We're seeing that a lot more when it comes to autism spectrum disorders."

Sexton adds that parents can obviously be squeamish about using THC on their children, but she explains a risk-benefit ratio that reminds them that "normal" is already out the window considering the severity of the conditions that drive parents to seek this kind of treatment in the first place. "THC can actually make them more 'normal' instead of worse off, as is assumed," she says. She points out

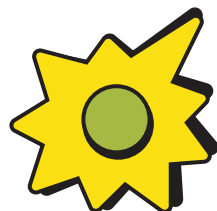
that none of her patients, or any patients that she knows of, have reported what she would consider to be "extreme negative" reactions to cannabis treatments. "Sedation is probably the most common side effect," says Sexton. "With high-CBD treatments, there is always the potential for a gastrointestinal stir disturbance, too." She also cautions would-be patients to watch out for drug interactions, as kids using this kind of treatment are often on many other medications.

Sexton doesn't see many children as part of her practice today, partially because she believes a lot of this information has been passed through social networks, which are tight-knit, independently active, and well versed in treatment protocols due to the extreme nature of severe pediatric illnesses and the stigma and legal risk surrounding so-called experimental treatments.

"My experience was that the parents trusted each other even more than they would trust me, even as a naturopathic doctor, to pass the knowledge on," she says. "Interestingly, I met an Israeli researcher in Australia a few years ago who described the exact same



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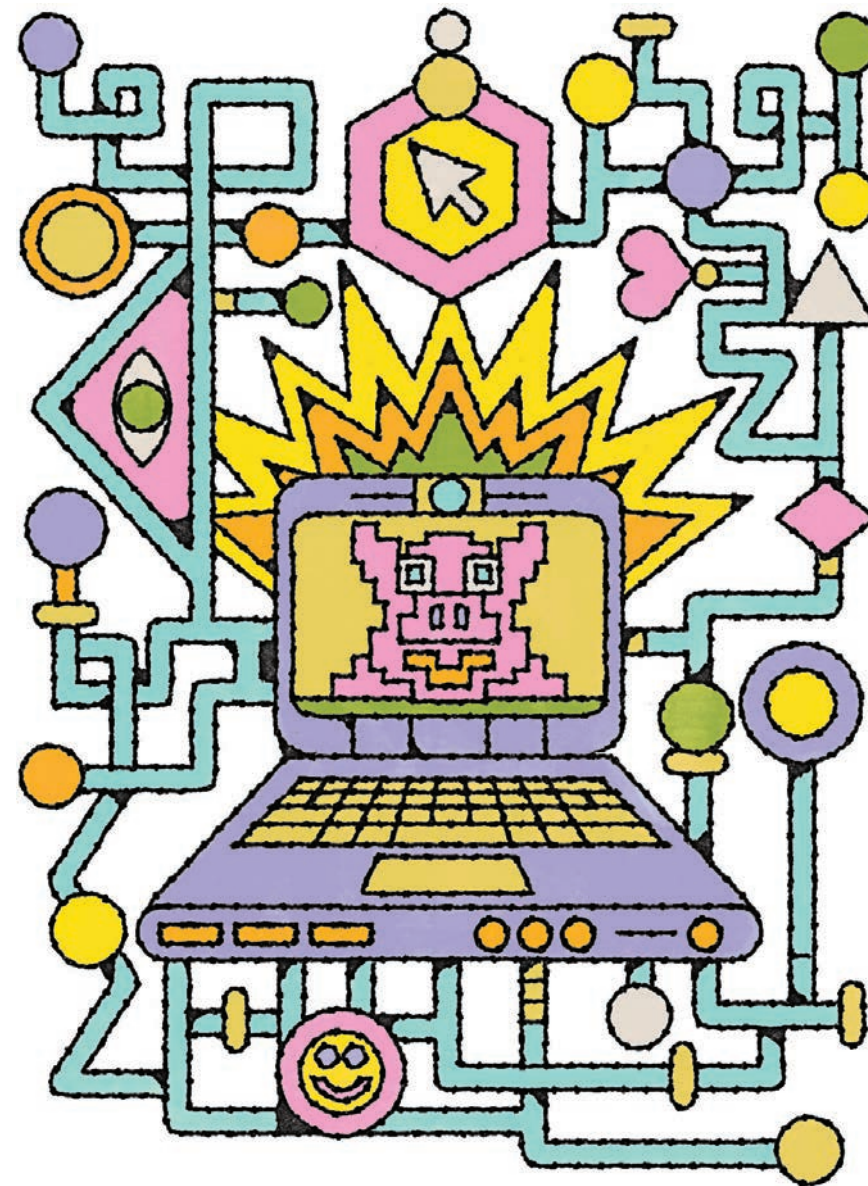
phenomenon, even though he was a medical professional open to cannabis and willing to help patients. They were not seeking him out; they were passing on knowledge from person to person through their social network. She suspects that is still the case today.

Another result of those strong social networks and the political advocacy that comes with them has been a lot of amended state-by-state regulation over the years, especially regarding cannabidiol access and compassionate use allowances for kids who lack other treatment options for conditions shown to be alleviated by cannabis. Though the work on Epidiolex had been underway before Realm of Caring and Charlotte Figi's story became national news, the drug's progression to FDA approval and

the lifting of illegality, especially in more conservative states (Rep. Matt Gaetz of Florida often credits Figi's experience with changing his mind about cannabis), happened on a similar timeline. It's hard to overstate the effect these kids had on the subsequent avalanche of loosening medical (and even adult-use) marijuana restrictions around the United States since they started making headlines in the early 2010s.

That said, significant speed bumps still exist for kids who use medical cannabis. Sadly, Charlotte Figi died in April 2020 after an unconfirmed but suspected bout of COVID-19 that sent her into cardiac arrest and brought back her seizures. Sexton and Benavides caution that while cannabis can be incredibly — and sometimes seemingly miraculously — effective at treating serious conditions for which nothing else seems to work, as with all medical treatments, results may vary depending on the patient and their individual circumstances. Cannabis use can be curative, but in many cases, it's palliative. Success can look different in each patient: Sometimes their condition may appear to be cured; other times their symptoms are lessened and they may be on fewer pharmaceutical drugs than if they weren't using cannabis.

There have also been legal setbacks. The increasingly polarized political tensions in the United States have not helped the movement, especially the growing national conversation questioning



the safety of high-THC treatments for adolescents, which Kalcheff Korn says always increases the potential stigma on kids who use medical cannabis.

In 2021, despite Colorado being one of the first and most open

states to cannabis use, Figi's home, and Realm of Caring's headquarters, Colorado's state legislature made it so caregivers for minors who are cannabis patients need to get doctor's notes twice a year, says Kalcheff Korn, which she adds

can be prohibitively expensive as the fee for one doctor's visit can be around \$200, especially as this type of visit isn't covered by insurance.

Setbacks are to be expected, particularly in the treatment of extremely sick children. Still, there are many bright spots worth celebrating. Robby Benavides, who now lives in Texas with his family, is 13 years old and thriving.

Robby went off Depakote for good at age nine after a few scary experiences of finding the right balance between that medication and the CBD oil. At first, Benavides didn't titrate the Depakote dose, and using it in conjunction with high-dose CBD caused him to have more seizures. It was Paige Figi who told her to wean off Depakote, which Robby's physician (to his credit, Benavides says) approved. It worked. They kept him on that balance for years, until he was two years seizure-free. They ultimately weaned him off the CBD oil, too, and today he remains seizure-free and treatment-free.

"I can't believe it's our story sometimes," says Benavides. "I could bawl my eyes out. He's just doing phenomenally." ☺

