



Advances and Answers in Pediatric Health



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It starts with a Q:

A letter from a fellow questioner at Children's Hospital Colorado

Dear colleagues,

Today, we are writing to you in our new capacities as vice chairs in the Department of Pediatrics, representing a dynamic fusion of clinical translational research and basic science research. Our journey to this point has been marked by a shared commitment to pediatric research, a passion for mentorship and a dedication to fostering collaboration across multiple disciplines.

As we step into these new roles, our collective vision is centered on promoting collaboration and cross-disciplinary research. We aim to bridge gaps between various sections within pediatrics and create opportunities for research across the lifespan, leveraging our unique campus environment.

Our goals include:

- The establishment of a pediatric research day
- Fostering a culture of recognition and support for individual researchers
- Ensuring smooth operation in multiple areas, including grant submissions and access to core facilities

A significant part of our mission involves mentoring young researchers and clinicians to foster a culture of learning and development. We've initiated a "Recent Recruits Group" to support faculty new to our department, and we are actively involved in shaping the direction of pediatric research through our roles in recruiting new faculty.

We believe that we can significantly contribute to the advancement of pediatric medicine through collaboration, mentorship and a steadfast commitment to research excellence.

Best regards,



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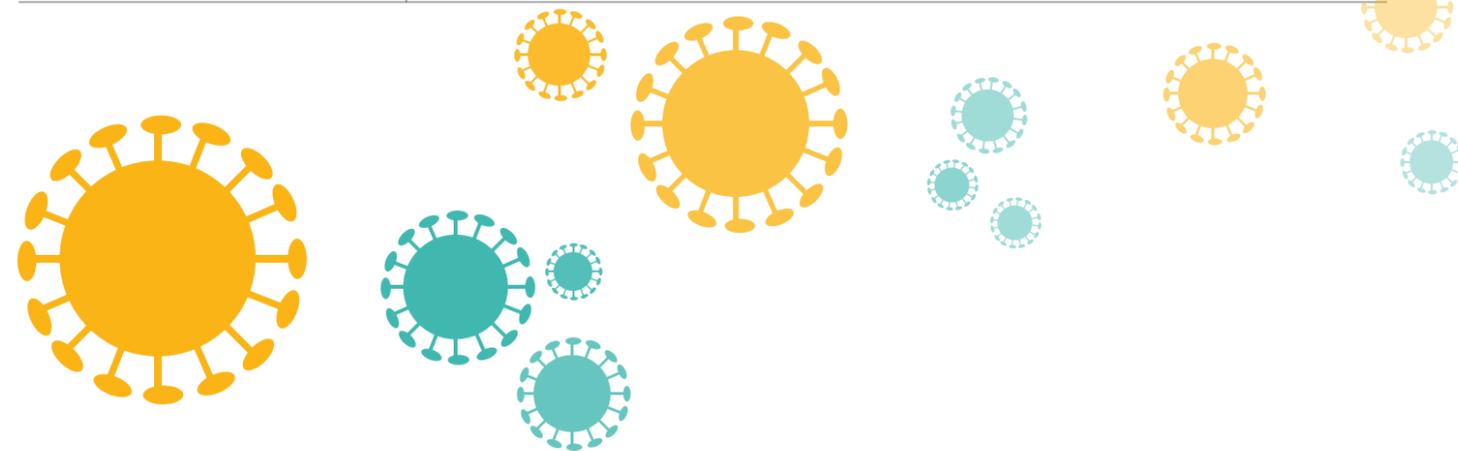
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A(:) List



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Living Proof

Q: When a dangerous disease resurges, how can new research overturn old ideas to keep patients safe in a changing world?

By the turn of the 20th century, 1 in every 7 people in the West had died from tuberculosis. The standard treatment involved clean air, sunlight and rest in a sanatorium. That changed in 1944 with the discovery of streptomycin, the first antibiotic for tuberculosis. Soon after, when sanatoriums shuttered in favor of antibiotics, streptomycin became a case study for how scientific research sometimes challenges common practice in pursuit of advancement. Today, Children's Hospital Colorado hepatologist Amy Feldman, MD, PhD, is tackling another long-held belief in medicine through research that transforms vaccine eligibility and boldly confronts the age of misinformation.

Live viral vaccinations help a person build immunity by exposing them to an attenuated, or weakened version, of the actual virus. Some of the most important immunizations for children are in this category, including the measles, mumps, rubella (MMR) vaccine and the varicella zoster virus (VZV), or chickenpox, vaccine. They have proven so effective that in 2000, the Centers for Disease Control and Prevention (CDC) declared measles eliminated in the United States.

Despite their success, live viral vaccinations historically haven't been given to liver and kidney transplant recipients, who are on lifelong immunosuppressive medications to prevent their bodies from rejecting the new organs. "People were concerned that live vaccines could cause a vaccine-strain viral infection in an immunocompromised patient," Dr. Feldman says.

ENTERING AN UNCERTAIN ERA

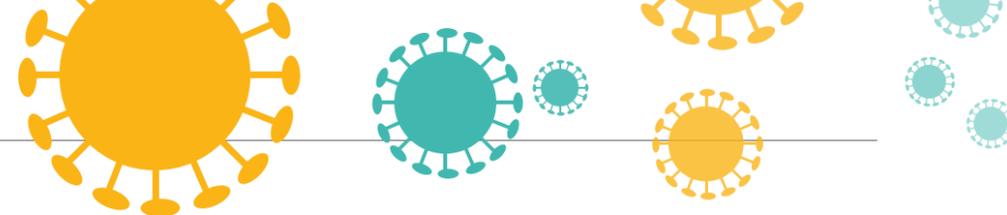
Not administering live vaccines to solid organ transplant recipients seemed sound 20 years ago, when measles outbreaks in the U.S. were nearly nonexistent. But that decision has new implications in a changing world.

Global vaccine hesitancy has spiked in recent years, a trend fueled by many complex factors including social inequity, COVID-19 and the spread of misinformation online. As a result, the World Health Organization reported that 4.7 million children missed their first measles vaccine in 2021, and an additional 14.7 million children missed their second dose. That leaves just 81% of children worldwide fully vaccinated against measles compared to the 89-94% needed for herd immunity, causing an alarming spike in this dangerous, highly communicable disease.

"Measles remains in the air for up to two hours after an infected person sneezes," Dr. Feldman says. "In immunocompromised patients, such as transplant recipients, measles can result in pneumonia, encephalitis and potentially death. Sadly, there are no treatments to offer to a child who acquires measles."

A string of outbreaks over the past decade demonstrates just how easily measles spreads in crowded places. In late 2014, an outbreak at Disneyland sickened 125 people, 50% of whom were not fully vaccinated (an additional 43% had unknown vaccination status). More recently, in 2023, an outbreak that began at an Ohio daycare led to 85 measles cases — all among unvaccinated children.

Continued on the following page



Living Proof continued

Air travel, too, poses a threat for the unvaccinated: If someone is exposed to the virus in an area with low immunization rates, they can bring the virus back home with them on the plane, potentially infecting people in their return destination as well as those they encountered along the way.

With measles cases rising, Dr. Feldman teamed up with University of Cincinnati colleague, Lara A. Danziger-Isakov, MD, to understand if it still made sense to leave organ transplant recipients unvaccinated. “We asked ourselves, ‘Is the historic recommendation still relevant? Is the risk-benefit ratio still the same?’”

To answer this question, Drs. Feldman and Danziger-Isakov created a consortium of 18 pediatric transplant centers that wanted to vaccinate eligible transplant recipients and collect data on vaccine safety, immunogenicity and clinical effectiveness.

GETTING A GREEN LIGHT

Between Jan. 1, 2002, and Feb. 28, 2023, 281 children received a full dose of the MMR and/or VZV vaccines as part of Dr. Feldman’s study (1). Of this group, 96% were liver transplant recipients, 3% were kidney recipients and 1% were liver and kidney recipients.

“We hypothesized that the vaccines would be both safe and immunogenic, and that’s exactly what we’ve found,” Dr. Feldman says. Data from participating centers showed that both vaccines resulted in immune protection in the majority of patients who’d received a transplant without making them sick. None of the children in the study developed measles, mumps or rubella, and five children developed a chickenpox rash that resolved within a week.

One year after vaccination, most of the children retained immune protection: 92% of children demonstrated protective antibodies against the measles virus, 94% showed protective immunity against rubella and 83% were protected against mumps. Additionally, 77% of children showed immunity from chickenpox.

The study design allowed each participating center to determine their own eligibility criteria for live vaccines, making the data more representative of the pediatric transplant population overall. “It created variability in the study so we could look at a cohort of patients with unique histories and different degrees of immunosuppression, and gain a bigger picture about more children,” Dr. Feldman says.

This research opens new doors for patients in need of a transplant, whose vaccination status typically prevents them from engaging in ordinary childhood activities that might expose them to illness, such as visiting a theme park or attending summer camp. A green light on vaccination means that these kids can finally be kids, the true impact of which is hard to measure.

“We hypothesized that the vaccines would be both safe and immunogenic, and that’s exactly what we’ve found.”

AMY FELDMAN, MD, PHD

“Now their parents have the opportunity to give them these vaccines, and they can develop protective antibodies,” Dr. Feldman says. “They can live out in the community without having to be scared that if they’re exposed to measles or chickenpox, their child is going to become infected.”

While the study is still ongoing, these initial results are already inspiring action. The 18 institutions involved are moving forward with giving vaccines to transplant patients, and more centers have joined the consortium since the paper was published. This will provide Dr. Feldman’s team with more long-term data about how long immune protection lasts, which will help them understand when and if certain children may need boosters.

PAVING THE ROAD TO TRUST

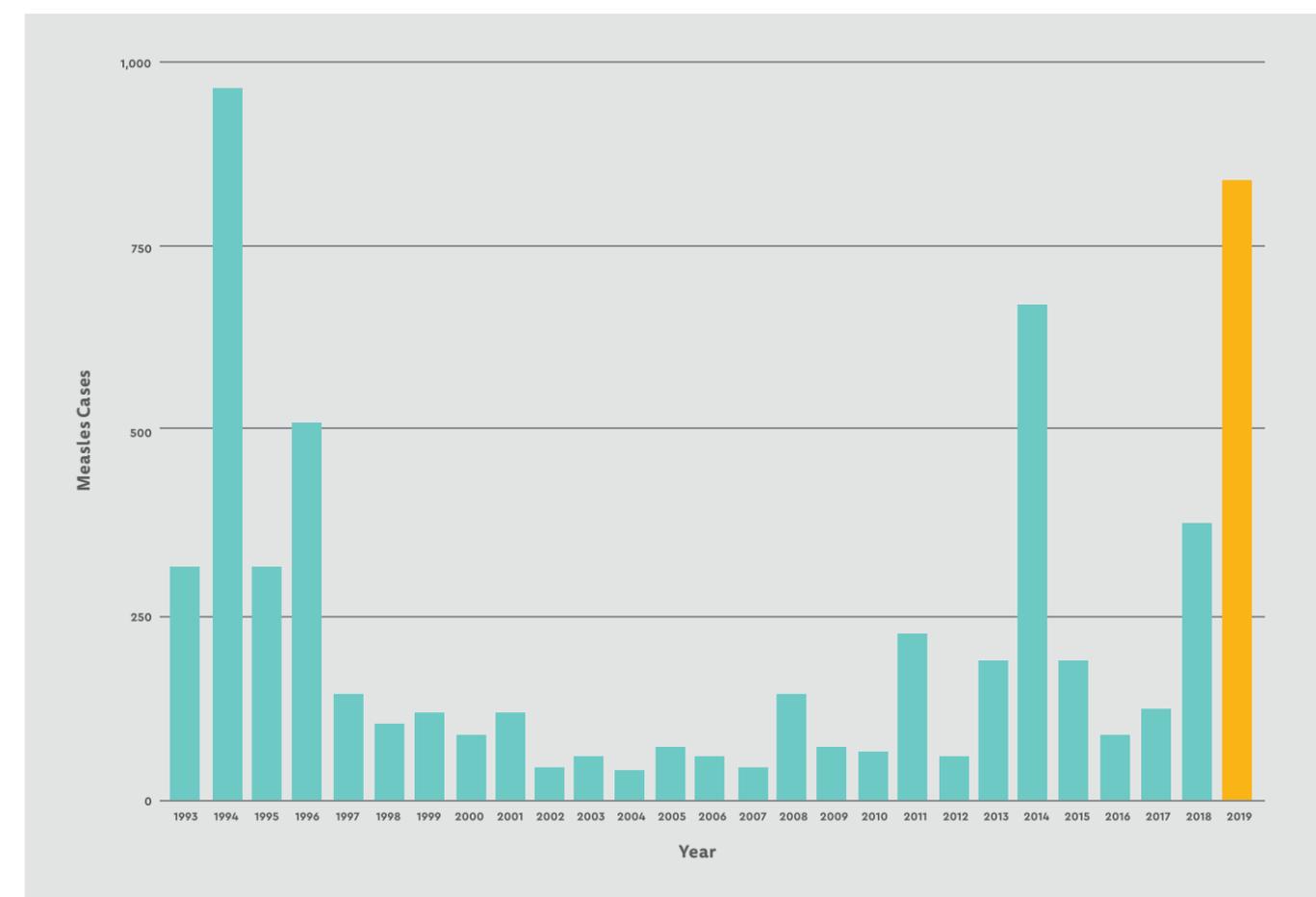
Despite these wins, Dr. Feldman’s findings alone are not enough. She knows that this discovery, not unlike the first antibiotic for tuberculosis, must garner trust from both parents and providers before it can have a positive impact. “We need to find a way to implement new practices and guidelines that we know are right,” she says, “but that are very different from what we used to say.”

Dr. Feldman and her team are currently writing a grant for a project that will tackle this challenge. “We need to understand the barriers to implementation of novel recommendations, then develop educational tools to address and overcome these barriers,” she says. Their main goal is to implement new, evidence-based vaccination guidelines that reach parents and providers across the country.

“Providers want to be innovative, but they’re scared that they could give measles to someone via the shot, even though that’s never happened in a transplant recipient,” Dr. Feldman explains. “That’s why we needed to do this study — to provide people with enough data to feel confident about making a practice change.”

Upending long-held convictions is neither easy nor comfortable, yet it’s intrinsic to human progress.

“We’re living in a different world than we were 10 or 20 years ago,” Dr. Feldman says, referring to the rise in vaccine hesitancy and global measles resurgence.



Consulting new research and communicating with other experts is important for helping providers identify when a previously ineligible transplant patient may become a good candidate. For example, different institutions have their own criteria for vaccine eligibility, such as how long a patient must wait after their body rejects a transplant. New research can help standardize these practices and determine if it might be safe for a child to get vaccinated sooner than previously believed.

“This is a great example of collaboration between primary care doctors who most frequently give vaccines, and their subspecialists and transplant teams,” Dr. Feldman says. “They can discuss together which patients might be appropriate, and we can start thinking about giving vaccines to more and more kids who weren’t previously eligible.”

Now that data proves the safety of live vaccines for most patients in need of a transplant, fear of change may be the greatest obstacle preventing them from a less quarantined life. Assuaging these

concerns by confronting misinformation is no doubt a gargantuan task, but for Dr. Feldman, it’s the very notion of freedom that propels her through such daunting work.

“Our goal for transplant recipients is that they live normal lives, and live viral vaccines help make that possible,” Dr. Feldman says. “We want them at college; we want them to be able to go to Disneyland; we want them out on an airplane traveling the world.” ●

1. Feldman, Amy G et al. “Safety and Immunogenicity of Live Viral Vaccines in a Multicenter Cohort of Pediatric Transplant Recipients.” *JAMA network open* vol. 6,10 e2337602. 2 Oct. 2023, doi:10.1001/jamanetworkopen.2023.37602.



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Reflections and Revelations on Access

Q: Are there disparities in care for patients with eosinophilic esophagitis?

Eosinophilic esophagitis (EoE), a chronic allergy-related condition of the esophagus, has been increasing in prevalence for the past three decades. During this time, doctors have been working to uncover more about this condition — learning who is most impacted, what causes and triggers the disease, and different avenues of care. Children’s Hospital Colorado has a significantly larger EoE patient population compared to other hospitals across the country, so pediatric gastroenterologist Pooja Mehta, MD, decided to analyze data from these children to discover trends in care.

For the past 10 years, Dr. Mehta and her team have studied the EoE patient population, which includes more than 2,000 kids at Children’s Colorado. Together, they analyzed demographic features and compared them to how patients’ conditions were managed to see whether race, ethnicity or broader social determinants of health had an impact on care. The team used a gauge called the Area Deprivation Index (ADI) to look granularly at each patient’s address to determine

their neighborhood’s level of advantage or disadvantage based on the surroundings. The ADI factors in income, education level, housing quality and employment.

“The importance of using the ADI is really trying to understand if there are barriers in diagnosing EoE,” Dr. Mehta says. “Are there structural factors that are playing a role in preventing children who might be from these marginalized communities from getting an

appropriate diagnosis or to getting equal care?”

The team’s findings tell a story, and there may in fact be differences in diagnosis and management of EoE that need to be explored further. The study found that Black children tended to be younger at diagnosis than white children, and while more research is needed, the group speculates that this is because only Black children with more severe disease features are being seen and treated. Dr. Mehta worries this could mean other more mild cases are slipping through the cracks and not receiving a proper diagnosis or treatment.

“Could it possibly be that kids who have more subtle symptoms are not getting appropriate care or are not getting evaluated?” Dr. Mehta asks.

The findings also showed that children living in rural areas were seen by feeding therapy specialists less often, and children from more disadvantaged neighborhoods had fewer instances of radiographic evaluation of their disease. Both of these findings indicate that future research should examine each patient’s ease of access to a pediatric specialist. “Because EoE requires seeing a pediatric gastroenterologist and having an endoscopy for diagnosis, if you don’t ever see a pediatric gastroenterologist, you’re never going to be diagnosed,” Dr. Mehta adds.

“The reason we’re finding these disparities is likely not genetics,” she says. “It is due to these kinds of structural factors, historical racism, and then poverty and inequity that play a big role in diagnosis and management. Institutions are really trying to take a deeper dive to ask, ‘Is there equal access? Do we have policies that promote equity, not equality?’”

Her plan is to share this data with colleagues widely to create an opportunity for a bigger conversation.

“I would want colleagues to take a deep dive into their data and use it as an opportunity for growth and learning,” Dr. Mehta says. “This research is really patient-centric. It’s making sure that we keep our patients in mind in everything that we do, and constantly reassess whether we are providing the best care.” •

1. Mehta, Pooja et al. “Examining Disparities in Pediatric Eosinophilic Esophagitis.” *The Journal of Allergy and Clinical Immunology. In practice* vol. 11,9 (2023): 2855-2859. doi:10.1016/j.jaip.2023.06.011.



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Breaking down the data

STUDY: EXAMINING DISPARITIES IN PEDIATRIC EOSINOPHILIC ESOPHAGITIS

STUDY POPULATION:

2,117 Children with EoE

FINDINGS:



Children with greater neighborhood disadvantage (higher ADI scores) had less radiographic evaluation.



Children from rural areas were less likely to be seen by feeding therapy specialists (**3.9%** compared to **9.9%**).



Black children were younger than white children at diagnosis (**8.3** years old vs. **10** years old).



Children from rural areas were younger at their first visit (**2.3** years compared to **4.3** years).

Measuring the Intangible

Q: Does a patient's grit have an impact on the postoperative experience after ACL reconstruction?

Whether they're stepping out under the Friday night lights — down by a landslide in the last quarter of the game — or approaching the microphone during the spelling bee's last round, all kids experience nerves and pressure during childhood. In the face of that resistance, there are two options: push forward with a focused mind or crack under the pressure. The resilience to persevere and achieve an end goal despite adversity is the intangible quality inside us that leads to success: grit. Children's Hospital Colorado sports medicine physician Aubrey Armento, MD, wondered how a patient's grit level might impact the postoperative experience after anterior cruciate ligament (ACL) surgery. She teamed up with Jay Albright, MD, Curtis Vandenberg, MD, and David Howell, PhD, to search for answers.

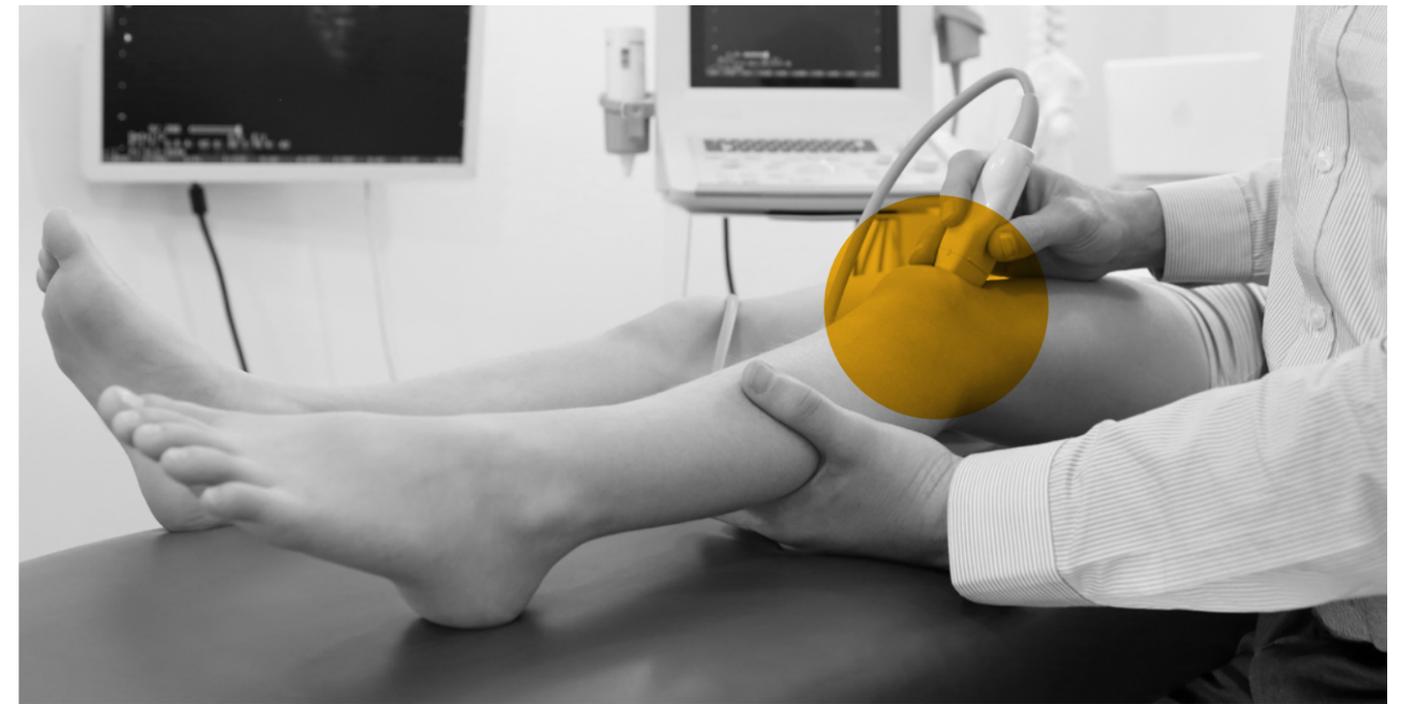
The first hurdle was to bottle up this difficult-to-measure quality and clearly define grit: What is it and how can you measure it in a patient? For this study, Dr. Armento and her team classified grit as the "passion and perseverance to pursue long-term goals despite challenges or setbacks," and they used a validated measure of grit called the short grit scale created by psychologist Angela Duckworth, PhD (1). This questionnaire asks patients to read a series of statements and rate how much each statement applies to them.

Measuring grit with the short grit scale

Patients are asked to identify how much they relate to the eight questions below on a five-point scale from "not like me at all" to "very much like me."

- 1 New ideas and projects sometimes distract me from previous ones.
- 2 Setbacks don't discourage me.
- 3 I have been obsessed with a certain idea or project for a short time but later lost interest.
- 4 I am a hard worker.
- 5 I often set a goal but later choose to pursue a different one.
- 6 I have difficulty maintaining my focus on projects that take more than a few months to complete.
- 7 I finish whatever I begin.
- 8 I am diligent.

1. Duckworth, A.L., & Quinn, P.D. (2009). Development and validation of the Short Grit Scale (GritS). *Journal of Personality Assessment*, 91, 166-174. <http://www.sas.upenn.edu/~duckwort/images/Duckworth%20and%20Quinn.pdf>.
2. Duckworth, A.L., Peterson, C., Matthews, M.D., & Kelly, D.R. (2007). Grit: Perseverance and passion for long-term goals. *Journal of Personality and Social Psychology*, 9, 1087-1101. <http://www.sas.upenn.edu/~duckwort/images/Grit%20JSP.pdf>.



Along with the short grit scale, Dr. Armento also evaluated patients in two other categories: knee symptomatology (such as pain, swelling and range of motion) and physical function and activity-level outcomes. The team gathered these responses prior to surgery, then three times after surgery at three, six and 12 months postoperatively. The participants included 137 patients whose average age was almost 16 years old.

The study found those with higher preoperative grit achieved greater physical function and activity levels over time than those with lower grit. "I think athletes who tend to have higher grit are more dedicated to the rehab and recovery process and continue to show up even when it's more challenging," Dr. Armento says.

The team did not find a connection between grit and knee symptomatology, which Dr. Armento says is because improvement of knee symptoms may not be perceived as a more tangible goal when compared to attainment of psychical function and activity levels.

"I think one of the takeaways from this is that assessment of grit, especially in that preoperative stage, may be a useful predictor of success in recovery over time," Dr. Armento says. "I think it's probably most applicable to physical therapists who are working week in, week out with these patients over a year's time and identification of those who may have lower grit. [Those patients] may need an alternative approach to keep [them] more engaged and dedicated to their physical therapy and their rehab process."

The team also found that grit levels typically remained consistent before and after surgery.

"It is proposed that grit can be grown over time," Dr. Armento explains. "We think it's a little bit more of an innate personality trait but can be influenced by environment."

She hopes to explore ways to increase grit in athletes along with studying how this might relate to an athlete's success in returning to their sport after surgery and physical therapy. ●

1. Armento, Aubrey et al. "Association of Grit With Postoperative Knee Outcomes and Physical Function After ACL Reconstruction in Adolescent Athletes." *The American journal of sports medicine* vol. 51,11 (2023): 2900-2907. doi:10.1177/03635465231187040.



AUBREY ARMENTO, MD

Primary care sports medicine physician, Medical Director, Runner's Clinic for Young Athletes, Children's Hospital Colorado

Assistant professor and associate program director, CU Sports Medicine Fellowship, Department of Pediatrics, University of Colorado School of Medicine

Translating Training to Change

Q: How do research fellowships play a role in creating more equitable care for patients and their families?

The Surgical/Subspecialist Clinical Outcomes Research (SCORE) fellowship by ACCORDS at the University of Colorado empowers outstanding junior and midcareer physician-researchers through training and funding that allows them to pursue projects they're passionate about. Now in its 10th year, the SCORE fellowship provides its fellows with a career development curriculum and support in writing research grants. Children's Hospital Colorado team members Shannon Acker, MD, and Jose Diaz-Miron, MD, who completed the research fellowship during their first years as pediatric surgery faculty, are using their clinical research skills to improve equity for patients and their families.

During their fellowship experience, Drs. Acker and Diaz-Miron noticed that language barriers posed a persistent challenge for their patients. In fact, the state's population of Hispanic and Latinx residents is expected to grow to 1 in 3 over the next two decades. Although a significant portion of the state population speaks Spanish as a primary language, there isn't a standardized approach to translating important health information to families in a surgery setting.

Drs. Acker and Diaz-Miron set out to address this gap to ensure that all patients are more informed before, during and after surgery. Using the tools they learned during their time as SCORE fellows, they're demonstrating what's possible when surgeons are given an opportunity to research their areas of interest and put those findings directly into action.

TUNING IN TO LITERACY

Dr. Acker, a pediatric surgeon, is using her fellowship training to pursue a health literacy initiative that addresses the inequities resulting from language barriers during surgical consultations.

Current practice for surgical consultation involves the surgeon or team member visiting a patient's hospital room, explaining key details in English with the help of an interpreter when needed and answering any questions. While educational materials are sometimes handed out, Dr. Acker says these are usually only available for common procedures, such as an appendectomy.

"This system is inefficient for clinicians, not ideal for families, and provides inequitable care for families with known health disparities, which often results in poor patient outcomes," Dr. Acker says. To improve this system, Dr. Acker and her team developed the One-4-ALL Initiative. This work is designed to improve processes and employ technology to increase patient throughput, reduce clinician burden and address health disparities.



The project aims to shift the current model of care into an interactive, online, self-service program that educates families using health literacy materials in their preferred language. "This educational model was designed to ensure all families, independent of their level of health literacy or ability to read and understand English or Spanish, would have access to the same information and be able to access it on their own time," Dr. Acker says.

Currently, she is leading a pilot study for families of patients who need a feeding gastrostomy tube, or G-tube, placement. The study involves providing families with access to an online portal where they can choose their preferred language and watch animated, medically accurate videos about why their child needs a G-tube and what to expect from the surgery. The team's goal is to grow its library of health literacy videos so they can be distributed to surgical teams across the country.

Such work wouldn't be possible without training from the SCORE fellowship, which helped Dr. Acker expand her experiences in clinical research. "My motivation to pursue a career in research was

to obtain a health services research skillset — an opportunity that was never part of my clinical training," she says.

BREAKING DOWN BARRIERS

Dr. Diaz-Miron, a pediatric surgeon, is also applying his SCORE fellowship education to further a more equitable environment for pediatric surgery patients. He started Clínica de Cirugía Pediátrica, the first Spanish-speaking pediatric surgery clinic in the state of Colorado and in the mountain region. As a native Spanish speaker, Dr. Diaz-Miron created the clinic at Children's Colorado to provide Spanish-speaking families with consultations regarding the medical conditions and surgeries their children may be facing.

These efforts serve a significant population. In 2020, Hispanic and Latinx patients accounted for 29% of total visits to the Department of Pediatric Surgery. Of those, 23% reported Spanish as their primary language, with 9% requiring interpreter services in Spanish.

In addition to helping these families feel more informed and confident regarding their care, the clinic also serves as a research tool to help Dr. Diaz-Miron better understand how interpretation services decrease health disparities. "We are looking at the effect of language-concordant care for our Hispanic population, trying to figure out how that affects the care that they receive and the access to information that they have," he says.

Similar to Dr. Acker, Dr. Diaz-Miron credits the SCORE fellowship with helping him shape his future in medicine. Dr. Diaz-Miron also recently obtained a career development award as a K12 CCTSI scholar, a grant that will further support his research.

Both Drs. Acker and Diaz-Miron have a wide range of surgical research interests, but they share a common thread across each of their projects. They agree that the SCORE fellowship helped them define and launch their careers, so now, they can work toward the shared goals of improving patient outcomes, uniting research with clinical care and making patient education more equitable for all surgery patients. ●



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SHANNON ACKER, MD

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Retracing Steps, Rewriting Stories

Q: Why do some children die within 30 days of a cancer diagnosis, and how can doctors help them live longer?

Technology has made an indelible mark on health research. By using new tools, scientists have sped up processes, found ways to comb through more data in minutes than might be humanly possible over a lifetime and employed artificial intelligence to make laser-accurate predictions about outcomes. But sometimes, there's just no substitution for the old-fashioned way. That's the approach Katie Lind, MD, a pediatric hematology/oncology fellow at Children's Hospital Colorado, used to uncover new truths about children who die within the first month of a cancer diagnosis. Dr. Lind meticulously combed through dozens of patient charts and records in a yearslong, Holmesian search for clues.

In the United States, 7.5% of childhood cancer deaths are considered early deaths (1), or deaths that occur within 30 days of diagnosis. Because these children rarely have the opportunity to enroll in clinical trials, researchers have very little data about them.

Dr. Lind's recent retrospective study zeroed in on this population (2), building on findings brought forth through earlier research conducted by Children's Colorado oncologist Adam Green, MD, who serves as her research mentor. In 2017, Dr. Green published a study that employed the National Cancer Institute's massive Surveillance, Epidemiology and End Results database to learn more about these patients (1). That work

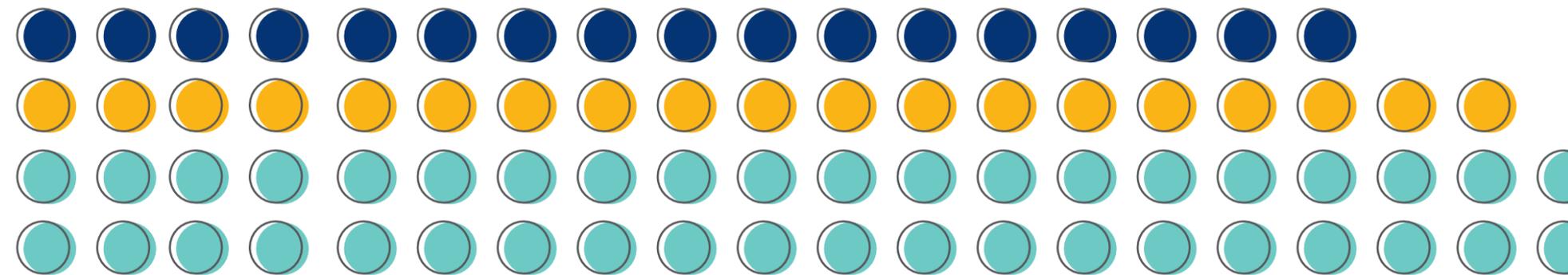
found associations between early death and race, ethnicity and socioeconomic status, but questions remained.

"Some of the questions that Adam was answering were: Who are these kids? Are we following them? Do we know what's going on with them? And what he found was that we actually don't have data on them," Dr. Lind says. "They're this separate group of patients who are not benefiting from all the advances that are otherwise helping kids survive cancer. There is a lot of information about these patients' stories that just isn't available in databases."

Drs. Lind and Green hoped that by filling in some of the blanks and analyzing detailed

information on each patient's journey from symptom onset through diagnosis, treatment and death, they might better understand these variables and find new opportunities for intervention. They identified 45 patients who sought care at Children's Colorado between 1995 and 2016 and who passed away within 30 days of diagnosis. Their records were compared to 44 children diagnosed with cancer who survived beyond the first month.

"I went through the charts of all of the kids, and we pulled out all of the notes from the medical team, their primary doctors, social workers and the intensive care unit," Dr. Lind explains. "And then we got death certificates as well,



trying to understand who these patients were, what they experienced and where there are opportunities for us to maybe identify them and help them to benefit from all these other advances. What can we do better in the future?"

THE FINDINGS

Though the study didn't uncover any significant revelations regarding social and economic factors, it did point providers to some valuable nuggets of information that may inform not only future studies, but current care.

Among the different diagnoses responsible for early death, a few stood out as the most common culprits, including leukemia. Brain and central nervous system tumors also seemed to carry significant risk for infants and young children — particularly high-grade gliomas and atypical teratoid rhabdoid tumors, or ATRT.

The study also found critical new information on the causes of death for different types of tumors, potentially keying providers into important

variables to monitor. Children with brain and central nervous system tumors commonly died as a result of tumor progression, while children with leukemia were most impacted by infection. Meanwhile, those diagnosed with solid tumors had more variable causes of death.

The finding that the team expects to influence the most change though, shows that children who experienced early death had a much longer timeline between the onset of their symptoms and an initial doctor's visit. Kids in the early death cohort had an average of 29.4 days between first symptoms and care, while the kids who survived their first 30 days after diagnosis averaged just 9.8 days. Once children in the early death cohort were seen, their timeline to specialist care and diagnosis was typically accelerated, because they were often critically ill.

"That was really novel for us because it makes us think that maybe there's an opportunity there for intervention in the future," Dr. Lind says. "Is there something we could do

to get these kids into the system faster?"

PATHWAYS TO PROGRESS

While this study answered some important questions, it also raised new ones. Drs. Lind and Green are currently working on a new prospective study that they hope will illuminate some of the driving factors of that critical delay in initial care. The study will engage families across the country who lost children to early death from cancer. Dr. Lind hopes that by hearing directly from families, she'll be able to identify barriers to care and ways to address them.

"In our teeny tiny sample size of 45, we really weren't able to dig deep into that information," she says. "Could there be a question with health insurance status? What is the primary language at home? Do you have parents who are working all the time? Do you have a primary care doctor? We just couldn't really get enough information from the retrospective study. So that's one of our major goals of the prospective study."

Dr. Lind and Dr. Green hope to meet with 20 families within six months of their child's passing to ensure details are as accurate as possible. Given the sensitive and difficult nature of the situation and conversation, the pilot study's primary focus will be determining whether these interviews are too heavy a burden on families.

"The first aim is really to make sure that these interviews are feasible and tolerable for the families," Dr. Green says. "There's a good body of literature showing that conducting research with bereaved parents is very feasible, and they actually appreciate the opportunity to tell their child's story and it can be therapeutic, but we want to make sure that in this particular setting that's still the case."

The duo will meet with families via Zoom and have an open-ended conversation about their experience, with a focus on psychological safety. Two weeks after that initial interview, the families will meet with a psychologist and wellness team member



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ADAM GREEN, MD

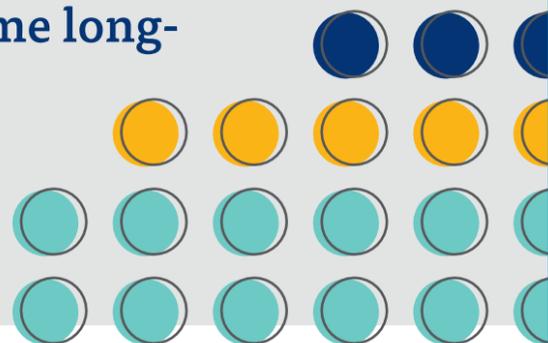
Attending physician, hematology and oncology, Children's Hospital Colorado
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Retracing Steps, Rewriting Stories continued

“Early death has not seemed like as much of a problem as it really is. This is a population that we need to study, because otherwise we’re not going to appreciate the scope and importance of the problem. We need to address these problems to give them that opportunity to become long-term survivors.”

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to ensure the process was positive and productive.

In addition to this new line of inquiry, Drs. Lind and Green are also exploring ways to engage primary care providers in educational opportunities that could lead to quicker diagnosis, particularly for dangerous brain tumors.

“We took a public health outreach campaign from the UK (3) and distilled it into a 30-minute presentation about all the main symptoms of pediatric brain tumors and when to be suspicious,” says Dr. Green, who has already educated more than 500 providers around the state through this program. “I think there’s a lot of excitement about it and hopefully we

can get much larger federal funding and take it to a bigger place.”

This work may take extra effort, extra hours and extra care, but for Drs. Lind and Green, the potential to finally shed light on and prevent the loss of young lives is fuel.

“Early death has not seemed like as much of a problem as it really is. This is a population that we need to study, because otherwise we’re not going to appreciate the scope and importance of the problem,” Dr. Green says. “We need to address these problems to give them that opportunity to become long-term survivors.” ●

1. Green, Adam L et al. “Death Within 1 Month of Diagnosis in Childhood Cancer: An

Analysis of Risk Factors and Scope of the Problem.” *Journal of clinical oncology: official journal of the American Society of Clinical Oncology* vol. 35,12 (2017): 1320-1327. doi:10.1200/JCO.2016.70.3249.

2. Lind, Katherine T et al. “Early death from childhood cancer: First medical record-level analysis reveals insights on diagnostic timing and cause of death.” *Cancer medicine* vol. 12,19 (2023): 20201-20211. doi:10.1002/cam4.6609.

3. HeadSmart Be Brain Tumour Aware. “A new clinical guideline from the Royal College of Paediatrics and Child Health with a national awareness campaign accelerates brain tumor diagnosis in UK children — “HeadSmart: Be Brain Tumour Aware.” *Neuro-oncology* vol. 18,3 (2016): 445-54. doi:10.1093/neuonc/nov187.



Vein Vision

CARDIOLOGY

Pulmonary vein stenosis (PVS) in children has long posed a significant challenge in pediatric cardiology. However, Children’s Hospital Colorado is making strides in treating PVS through the innovative use of optical coherence tomography (OCT), a noninvasive imaging technique commonly used in adult ophthalmology and cardiology. Through high-definition, color-rich views of pulmonary veins, OCT has been instrumental in improving the treatment of children with PVS. The new technology’s high cost has slowed widespread adoption, but Children’s Colorado, supported by an Abbott research grant, has worked to make this technology accessible to patients.

After leading a feasibility study to assess the safety of OCT in the pediatric population, interventional cardiologist Jenny Zablah Alabi, MD, has helped take this technology beyond procedural efficiency and quality and is moving the needle on patient outcomes. Thanks to advancements in diagnostic accuracy, timely interventions and overall efficiency, the Cardiac Catheterization Program at Children’s Colorado has significantly improved survival rates for children with PVS. Before the official launch of the PVS Program, the one-year average survival rate was 80%. Since its initiation in 2017, this rate has increased to 93%. Furthermore, the five-year survival rate has also seen a notable improvement, rising by 7%.

“The efficiency of OCT is attributed to the precision of OCT imaging, which enables more effective interventions and reduces procedure duration,” Dr. Zablah Alabi says. “Procedures that once took five to seven hours now average about two and a half to three hours.”

Dr. Zablah Alabi’s work extends beyond PVS too. She is collaborating with ENT specialists to use OCT for complex airway diagnoses. Looking ahead, Dr. Zablah Alabi is working on integrating OCT with virtual and augmented reality for enhanced preprocedural planning and to help further reduce time under anesthesia, radiation exposure and contrast-agent use.

As a leader in cardiac catheterization, Children’s Colorado continues to share its findings and experiences, influencing other centers to adopt these technologies. With ongoing research and collaborative efforts, Dr. Zablah Alabi and her team are setting new standards for the use of OCT technology in treating and caring for children with PVS, other cardiac conditions and more. ●



JENNY ZABLAH ALABI, MD

Interventional cardiologist, Children’s Hospital Colorado
Assistant professor of pediatrics, University of Colorado School of Medicine



A New Technique Takes Shape

PLASTIC AND RECONSTRUCTIVE SURGERY

An infant's skull contains flexible sutures that allow the brain to grow. In children with unicoronal craniosynostosis, one of the coronal sutures in the skull fuses prematurely, causing a misshapen head and posing neurodevelopmental risks. Traditional treatments for unicoronal craniosynostosis typically involve fronto-orbital advancement, an invasive skull surgery that carries significant morbidity. An endoscopic strip craniectomy may also be used to treat the condition in younger children, though it carries less predictable results and requires patients to wear a helmet postoperatively.

Children's Hospital Colorado Chair of Pediatric Plastic and Reconstructive Surgery Phuong Nguyen, MD, is helping revolutionize treatment for unicoronal craniosynostosis through distraction osteogenesis, a technique that works to slowly stretch

the bone over time. Instead of removing parts of the skull and installing plates and screws — the steps involved in a fronto-orbital advancement — this technique helps the skull gently repair itself. It borrows methods from limb growth procedures, which surgeons might use to help even out a person's legs when they are different lengths.

"It's the same idea: Cut the bone, slowly stretch it and then bone will grow in between," Dr. Nguyen says. "Because we're moving things in a gradual fashion, it gives time for the bone to remodel and reshape."

Distraction of the craniofacial skeleton was initiated for unicoronal craniosynostosis in South Korea 10 years ago, and in the United States, it has only been used in a handful of centers. Dr. Nguyen refined the Korean technique into its

current form by incorporating remodeling of the temporal bone, which improves its shape and better protects the brain, making this a safer operation. He completed one of the first successful distraction osteogenesis operations in Texas, then published a step-by-step report of his technique in 2021 (1).

Dr. Nguyen is bringing his far-ranging expertise to the Rocky Mountain region, helping families near and far facing unicoronal craniosynostosis benefit from a less invasive surgery with more reliable results. ●

1. Nguyen, Phuong D et al. "Distraction osteogenesis with temporal bone remodeling for unicoronal craniosynostosis." *Neurosurgical focus: Video* vol. 4,2 V15.1 Apr. 2021, doi:10.3171/2021.1.FOVID20121.



PHUONG NGUYEN, MD

Chair of Pediatric Plastic and Reconstructive Surgery, Children's Hospital Colorado
Professor, Surgery-Plastic/Reconstructive, University of Colorado School of Medicine



Bringing the Vision to Life

PEDIATRIC MENTAL HEALTH INSTITUTE

Children's Hospital Colorado's Pediatric Mental Health Institute is seeing the direct patient impact of extensive new changes implemented over the past year. Mental Health in Chief K. Ron-Li Liaw, MD, is guiding the team into the next phase of the Institute's action plan, designed to combat the national youth mental health crisis. The team's work is designed to break the stigma against mental health care and provide specialized, unique treatment options by focusing the strategic plan on transforming the hospital's physical spaces, care teams and treatment models, partnering to build a full continuum of care, and implementing innovative, evidence-based care approaches where children and their families live, learn, connect and seek support.

"When I reflect on the past two years since we embarked on a journey to advance a youth- and family-centered coordinated system of care with collaborative partners that ensures equitable access to high quality, evidence-based care and prevention, I am filled with gratitude, excitement and hope at the rapid pace of progress and our new and enduring partnerships across the state of Colorado and the country," Dr. Liaw says. ●



K. RON-LI LIAW, MD

Mental Health in Chief, Children's Hospital Colorado
Professor, Psychiatry, University of Colorado School of Medicine

First year complete at new outpatient location

CHILDREN'S COLORADO THERAPY CARE ON
TELSTAR, COLORADO SPRINGS



Provided access to care for
442 unique patients



Supported nearly **4,000**
visit and treatment days

2023 accomplishments

TRIPLED

Outpatient group therapy offerings by
introducing **15** new groups

33%

Reduction in waitlist numbers since
initiating new stepped-care model

27,000+

Patients screened for depression and
suicide risk through new hospital
initiative with a goal to screen every
patient over the age of **10**

A(:) List

Recent awards and accolades



Asthma Insights
PULMONOLOGY
Best in Pediatrics Award

Emily Skeen, MD, a pediatric pulmonologist from Children’s Hospital Colorado, presented her groundbreaking research at this year’s American Thoracic Society (ATS) International Conference in Washington, D.C. Dr. Skeen’s abstract, “Neighborhood-level Child Opportunity Predicts Exacerbation-Prone Status in a Cohort of Urban Children With Asthma,” not only highlights the impact of social determinants of health on children but also earned the prestigious recognition of “Best in Pediatrics” by the ATS.

Collaborating with colleagues Andrew Liu, MD, and Kate Hamlington Smith, PhD, Dr. Skeen utilized the Child Opportunity Index 2.0 (COI) to analyze the role of neighborhood conditions in asthma exacerbations among children in urban settings. The study demonstrated that a decrease in neighborhood-level opportunities as measured by COI, such as access to healthy food or quality education, significantly increases the likelihood of children becoming prone to asthma exacerbations. This finding was more predictive than traditional, individual-level socioeconomic indicators, such as household income and parental education.

Dr. Skeen’s work shines a light on the critical need for targeted community interventions to alleviate the disproportionate burden of asthma on children in lower-opportunity neighborhoods. The research paves the way for a more holistic approach to pediatric asthma care, emphasizing the importance of addressing environmental and social factors alongside clinical care.



Jonathan Hills-Dunlap, MD, MPH
PEDIATRIC SURGERY

Pediatric surgeon and health disparities researcher Jonathan Hills-Dunlap, MD, MPH, is joining Children’s Hospital Colorado as the latest addition to the pediatric surgery team. His clinical area of focus includes applying minimally invasive surgical techniques to neonatal, thoracic, foregut (anti-reflux, bariatric) and other complex gastrointestinal pathology. Dr. Hills-Dunlap brings a passion for identifying and addressing surgical disparities in children. His research focuses on eliminating these health disparities through dissemination of research findings, advocacy and policy-level initiatives. Dr. Hills-Dunlap hopes to bring equitable care solutions to children and encourage providers to evaluate which of their patients might need additional support to accomplish this goal. As a native Spanish speaker of Peruvian descent, he also looks forward to providing language-concordant care to Latino families at Children’s Colorado.



Cardiology
PEDIATRIC HEART NETWORK ACCEPTANCE

As part of the GATHER Consortium, Children’s Hospital Colorado’s Heart Institute was recently accepted to the Pediatric Heart Network (PHN), a collective of leading hospitals working to improve outcomes and quality of life for children with heart disease. Children’s Colorado joins nine other PHN sites across the country that are funded by the National Institutes of Health and National Heart, Lung and Blood Institute for the next granting cycle, which lasts through 2031. Over the past 22 years, the PHN has brought centers together to collaborate on more than 25 large studies, including 10 trials, to increase treatment options and improve care for patients with heart disease. Now, as a core site, Children’s Colorado will be able to participate in PHN-led clinical studies and have a seat on all PHN committees. The Consortium plans to enhance diversity in research participants and create a shared mentorship model to train the next generation of pediatric cardiology clinical investigators.



Paul Rozance, MD
NEONATOLOGY/PERINATOLOGY
President-Elect of the Perinatal Research Society

Children’s Hospital Colorado neonatologist Paul Rozance, MD, was recently elected President of the Perinatal Research Society (PRS). The Society was first established in 1969 at the University of Colorado and has since grown to include more than 400 members nationwide. Today, PRS provides a space for independent investigators to share their research and findings with fellow researchers in pediatrics, obstetrics/gynecology or

basic sciences disciplines. Dr. Rozance’s areas of interest include neonatal hypoglycemia, intrauterine growth restriction and placental nutrient supply. As President-Elect of the Perinatal Research Society, Dr. Rozance will carry on the tradition of PRS’s Colorado founders, helping to create connections between leading researchers and other experts in perinatal research and developmental biology.



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Sign up at childrenscolorado.org/SpecialtyNews



Hear our view

A podcast from our multidisciplinary specialists that examines the latest treatments for the most common complaints in pediatric medicine

Listen to Charting Pediatrics on **Spotify, Apple Podcasts, Google Podcasts and Google Play**



School of Medicine

UNIVERSITY OF COLORADO
ANSCHUTZ MEDICAL CAMPUS

Connected through care

We partner with neighboring University of Colorado School of Medicine, where many of our care providers serve as faculty. The school's Department of Pediatrics is ranked eighth in the nation by U.S. News & World Report, and is among the National Institutes of Health's top-funded research institutions.

Follow us on X

An X account for pediatric healthcare professionals where we share our latest research, clinical innovations and news

 Follow us [@ChildrensCO_Pro](https://twitter.com/ChildrensCO_Pro)



Exceptional care counts

Here, it all adds up. From the lifesaving studies we design and the boundary-breaking treatments we offer, to the moments we spend brightening a child's day, every extra second we dedicate to improving care for kids makes a difference. This year, those combined efforts have earned us a spot among the best children's hospitals in the nation with four specialties ranked in the Top 10. And we are proud to continue serving as pediatric leaders right here in our own community, with #1 rankings in both the region and the state.

Here, it's different.