



Duke Eye Center patients Sara and Sadie Edgcomb talk with Duke women's basketball coach Joanne P. McCallie

## TWINS BATTLE RARE FORM OF GLAUCOMA

First grade is a bittersweet transition for kids and their parents; it's the beginning of a new era of childhood. When Stacy and Jay Edgcomb watched their excited twin daughters scamper off to the first day of first grade, they knew the year would be significant. Little did they know they were about to embark on a voyage that would make them see the world differently.

The journey started when a teacher noticed that the twins were having difficulty seeing the chalkboard, and the school nurse verified a vision problem, initially identified as myopia (near-sightedness).

A quick trip to their local ophthalmologist revealed seriously elevated eye pressure, and he realized the problem was beyond his expertise. Within days, the family packed up and drove 400 miles from their home in Fort Fairfield, Maine (population 3,400), to Boston to see a world-class expert—the first leg in a many thousand

mile, four-year journey that eventually led them to the Duke Eye Center.

In Boston, the Edgcombs discovered that Sara and Sadie have a rare form of childhood glaucoma called spherophakia, a congenital abnormality in the shape of the lens which creates intermittent blockage of normal drainage and causes dangerously elevated eye pressure.

"There is a one in one million chance that both twins could have this condition, so at first we were in denial—we just couldn't believe it," says Jay. "Nobody on either side of our families has anything like this."

The experts in Boston said the only option was to remove the twins' lenses and fit



them with extremely thick "Coke-bottle" glasses. "Our girls are so athletic, so young! We knew we had to exhaust every possibility before going this route. We started with laser iridotomies [creating a tiny opening in the outer rim of the iris] with hopes of decreasing the chance of the drainage angle closing, and this seemed to work for a while," Jay explains.

Continuing their quest to quickly find more acceptable options, since elevated intraocular pressure can cause permanent damage to the optic nerve, the Edgcombs made several calls to doctors in New York City and Philadelphia continued on the next page

"There's more here than medicine. Duke is a leader in technology and research, and the team of specialists is willing and able to look at new treatments."

JAY EDGECOMB

One of Silver's research mentors is Scott Cousins, MD, vice chair for research in the Department of Ophthalmology. "Dr. Silver is an enthusiastic clinician-scientist in training who has an extremely good rapport with her patients and colleagues. She has novel ideas for her research, and I am expecting great things from her," he says.

Silver is making use of a mouse model of glaucoma developed by Stuart McKinnon, MD, PhD, associate professor of ophthalmology, to investigate the exact role that immune system cells—monocytes and macrophages—play in the pathology that leads to glaucoma. "Right now I'm investigating how monocytes and macrophages may be involved in the loss of retinal ganglion cells and optic nerve axons in glaucoma," she says.

She's looking for pathways in that process that could be possible targets for new treatments, and also markers that could be used to diagnose disease and predict progression. "In addition to not having a whole lot of treatment options for glaucoma, we still don't have a lot of precision in our ability to predict which patients have aggressive disease and are really at risk for vision loss," she says.

A singer who once performed professionally, Silver has performed with the Duke Chapel Choir. She doesn't have much time for music these days, between her research and seeing patients on the comprehensive service at the Eye Center in Durham. But she does take advantage of the Triangle's proximity to all things outdoors. "It's been nice to have easy access to white-water rafting, hiking, and rappelling," she says.

Horne also performs cataract surgery, lectures medical students who are completing ophthalmology rotations, and provides instruction to a resident who sees patients with her in her clinic once a week.

"Duke is an excellent place to not only have a chance to teach but also to learn, myself, as a new ophthalmologist," she says. "There is great support in building your practice, following your clinical and research interests, and finding your own niche."

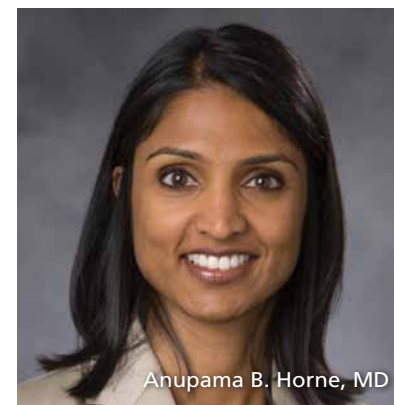
"Dr. Horne's enthusiasm, compassion, skill, and work ethic were immediately apparent when she joined our service," says Robin Vann, MD, chief of the comprehensive ophthalmology service. "Our patients, our staff, and I are happy that she has joined the Duke comprehensive family."

Horne's husband, Philip Horne, MD, is a second-year orthopaedic surgery resident at Duke, and they have a two-year-old daughter. "It's nice to be part of the Duke family again," Horne says.

## A CLINICIAN-SCIENTIST LANDS AT DUKE

After living in seven different states, Frankie-Lynn Silver, MD, MHS, landed in North Carolina because of a fellowship program at Duke that's offered at only a handful of places. That fellowship, funded by the National Institutes of Health (NIH), moved her closer to her goal of not only treating patients with glaucoma, but also discovering new therapies for them.

"The K12 fellowship was a unique opportunity to train as a clinician-scientist and become a bridge from the research to the patient communities," says Silver. "Because of that training, I was awarded a different type of NIH research grant, which broadened those opportunities here at Duke. Duke is establishing itself as a unique translational incubator, creating an environment that fosters novel observation and development of new ideas."



Anupama B. Horne, MD



Frankie-Lynn Silver, MD, MHS

## RETURNING TO THE DUKE FAMILY

As an undergraduate art history major at Duke, Anupama B. Horne was also completing premed requirements because she knew that she wanted to be a doctor. It wasn't until her third year of medical school in her hometown in Ohio that a rotation led her to the field of ophthalmology—and back to Duke.

"Once I started interviewing at the Duke Eye Center, I quickly realized that, especially for being such a renowned department, it was very down to earth and welcoming to new faculty," says Horne, now an assistant professor of ophthalmology.

As a physician on the comprehensive ophthalmology service, Horne helps a wide range of patients. She practices at the main Duke Eye Center in Durham three days per week and sees patients at the Southpoint office one day a week.

"I see all comers," she says. "I'm a true general ophthalmologist. It's great to be involved in the initial management and diagnosis but also know there's always specialty support here for further help."

## AESTHETICS WITHOUT INCISIONS

HELPING PATIENTS FEEL BETTER ABOUT THEMSELVES

When she's not helping patients with orbital tumors, blocked tear ducts, and other painful eye problems, Julie Ann Woodward, MD, chief of Duke's Oculoplastic and Reconstructive Surgery Service, finds artistic satisfaction in helping patients feel better about themselves through minimally invasive aesthetic procedures. "I use my creativity in helping bring back the look of youth for my patients in a way that looks natural and not overdone. It's very important for me to have my patients look natural," she says.

Some of the most effective tools at her disposal are facial fillers, such as Juvederm, Restylane, and Perlane. "Fillers are really the most important thing to create youth in the face, even more so than a face-lift," says Woodward. "After the late 20s, the human face loses almost a teaspoon of volume every year. That is what produces wrinkles and sagging." Newer options offered at Duke include Radiesse, a longer-lasting filler for deeper areas of the face.

Woodward has specialized training in laser surgery, including laser resurfacing, which uses an intense beam of light to refinish damaged areas and shrink fine wrinkles. She also offers fractional CO<sub>2</sub> laser resurfacing, which allows for a more rapid healing process and less redness after the procedure. Other offerings include vascular laser treatment of rosacea and broken capillaries on the face, nose, chest, and chin.

It's important to have such procedures performed by a surgeon specially trained in laser surgery, according to Woodward.

"The learning curve is so great. Each patient heals a little bit differently. It takes experience to get the patient a good result without complications," says Woodward, who has performed laser procedures for 13 years.

New aesthetic options on the horizon at the Eye Center include skin care products as well as a procedure called Ulthera, which is akin to a nonsurgical face-lift. It uses ultrasound to tighten the skin and soft tissue. "Ulthera provides a minimally invasive way of lifting the jowls and neck without using any incisions," says Woodward.



Julie Ann Woodward, MD, chief of the Duke Eye Center Oculoplastics and Reconstructive Surgery Service, performs a ptosis repair. She specializes in natural-looking cosmetic procedures using facial fillers and laser skin treatments.

"It's very important for me to have my patients look natural."

JULIE ANN WOODWARD

## PIONEERING RETINA SURGEON RETIRES

Epstein, MD, MMM, chair of the Eye Center.

“He is the gold standard,” adds Eric Postel, MD, associate professor of ophthalmology. “Dr. McCuen has led the field in terms of understanding processes and therapies for many different diseases.”

McCuen spent nearly 19 years as chief of the Duke Vitreoretinal

at Duke and as far afield as Japan, Egypt, and Europe.

In Postel’s case, he came to Duke as a resident and then did his retina fellowship in Wisconsin. McCuen was instrumental in bringing him back to Duke. McCuen similarly mentored Prithvi Mruthyunjaya, MD, assistant professor of ophthalmology, who performed both a residency and a fellowship at Duke under McCuen.

“Dr. McCuen encourages and fosters people’s interests in retinal surgery, both by the example that he sets and in collaboration in research and clinical care,” says Mruthyunjaya.

A true team player, McCuen also has used his decades of experience to help colleagues improve their own work, such as when he helped Mruthyunjaya and Cynthia Toth, MD, professor of ophthalmology, write a paper describing a new surgical concept called macular translocation.

“As we were formulating the paper, Dr. McCuen gave us some parameters for how to best present our outcomes visually so that ophthalmologists reading the paper could see, in a tangible way, how to apply this surgery to their patients. If it weren’t for Dr. McCuen doing that, it would have been harder for us to convey the importance of Dr. Toth’s groundbreaking work in this field,” says Mruthyunjaya.

Glenn J. Jaffe, MD, who in 2008 took the helm as chief of the Duke Vitreoretinal Service, says, “When Dr. McCuen directed the service, rather than just imposing his will, he solicited opinions from all members of our vitreoretinal faculty. Whenever possible, he tried to get buy-in on decisions from the whole group. That’s a philosophy that has been very helpful for me as I direct the service.”

Now, as McCuen pursues his other passion, boating, he and his family will spend the next year traveling along the Inland Waterway, likely flying a Duke flag. For us, he will always represent the very best of Duke Ophthalmology. ■



A pioneering ophthalmologist known as “the retina surgeon’s retina surgeon” retired from the Duke Eye Center in March. But the influence of Brooks McCuen II, MD, will continue through his legacy of all the accomplished surgeons he has trained at Duke and beyond.

McCuen, the Robert Machemer Professor of Ophthalmology, advanced and evolved the technique of vitrectomy, an eye surgery that removes diseased vitreous and scar tissue, enabling the repair of detached retinas and restoring sight.

“Retina surgeons from all over the world who have a difficult case will send it to him,” says David

played indoor hockey and hide-and-go-seek with six friends. They eagerly anticipate skiing and more basketball, and their only regret is that the eye-related trips have botched their perfect school attendance record.

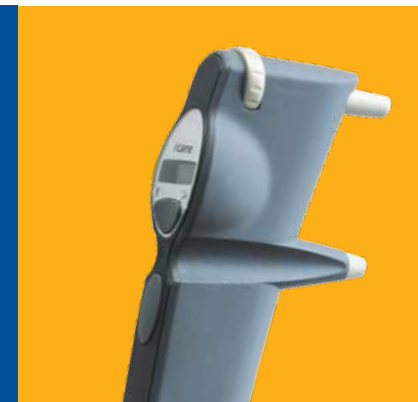
How has their condition impacted their daily life? “The main impact is that the twins have to wear sports glasses when playing basketball, soccer, or participating in other physical activities. We found great-looking sports glasses, so they aren’t embarrassed to wear them,” says Stacy. Their school has been exceptionally accommodating, and their friends are very helpful. By looking at Sara and Sadie, you’d never know they have an incredibly rare disease.

When asked if traveling so far was a burden, Jay says, “The distance doesn’t matter—it’s worth our peace of mind to come to Duke and have a doctor we can trust and who listens to us. There’s more here than medicine. Duke is a leader in technology and research, and the team of specialists is willing and able to look at new treatments. The fellows are amazing, the staff is unbelievable, and the facilities and equipment are world-class. We feel so lucky to have found Duke Eye Center.” ■

behind-the-scenes tour of Duke’s Cameron Indoor Stadium with ACC Coach of the Year and Duke women’s basketball head coach, Joanne P. McCallie, who coincidentally spent her early coaching career at the University of Maine at Orono, not far from the Edgecombs’ home.

The outcomes of Sara’s and Sadie’s treatments are good, considering how rare and serious their condition is. Sara recently had a procedure to further reduce her eye pressure in the right eye, which had a standard drainage implant but continued to run high pressure. This exact procedure for pressure was conducted on Sadie last fall, and Freedman anticipates the frequency of the Edgecombs’ visits will decrease moving forward. “[Jay and Stacy] will continue monitoring the girls’ pressures, and their wonderful local ophthalmologist will monitor their recovery and watch their drainage implants, lens implants, and retinas—and if all goes well, we’ll just see them once a year,” she says.

At their most recent visit, exactly one year from their first trip to Duke Eye Center, Sara and Sadie were recovering from their eye surgery and preparing to go to the Virginia Tech vs. Duke women’s basketball game. With the telltale remnants of surgical tape still on their cheerful faces, the fifth-grade twins recounted the fun they had at their recent 11th birthday party, where they



The newly approved portable tonometer from Icare Finland Oy, used by the twins to check intraocular pressure.

twins sometimes woke up with headaches, nausea, and vomiting—all likely effects of transient high eye pressure. Jay and Stacy suddenly understood that all the times the girls were unexpectedly ill in the mornings probably weren’t due to food allergies, the flu, or anything other than symptoms of their glaucoma. “The alarming thing about this is that they never once complained about their eyes or their vision,” says Stacy.

Working with Freedman, the Edgecombs recently proceeded to petition their insurance company to purchase their own Icare tonometer at home, which they did after almost a year. The twins are pioneers; they are among the first in the United States to use this device in a home setting.

### THE ROAD AHEAD

The Edgecombs make the most of their trips to Duke Eye Center. The drives are long, so they break up the trip with educational and discovery-oriented stops along the way, including Washington, D.C., and the Shenandoah Valley. Once in Durham, the family enjoys trips to Duke University women’s basketball games. Both girls are avid basketball players, and through connections at Duke Eye Center, they got a

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approved portable tonometer from Icare Finland Oy, a medical technology company that specializes in intraocular pressure measurement devices. Her hope was that the tonometer could allow parents to safely monitor the eye pressure of their children with glaucoma—at home and outside office hours. Freedman and her fellow, Nandini Gandhi, MD, were using the Icare tonometer in a study approved by Duke’s Institutional Review Board, and they enrolled the Edgecomb twins. On the first visit the Edgecombs made to Duke Eye Center, Jay texted Freedman early in the morning to let her know that Sadie’s eye pressure had topped 50 mm Hg (normal is usually under 22 mm Hg).

The multiple eye pressure checks at home revealed the fluctuation in Sadie’s and Sara’s eye pressure which was being missed with routine office visits. It confirmed that their highest pressures, in the 60s and 70s, were occurring in the early mornings. This seemed to explain why, for years, the

in a hotel room and trying to get them treated. It’s the least I can do.”

Unfortunately, this particular procedure did not help Sara and Sadie with their glaucoma because there was too much permanent damage to the drainage pathways in both eyes of both girls, according to Freedman. But over the course of a year, they had additional surgeries and multiple treatments—most recently the insertion of a drainage implant. They have had other procedures to further reduce eye pressure, including endoscopic laser treatment to some of the ciliary body processes in one eye each, to reduce the amount of fluid the eye makes.

### NEW TECHNOLOGY REVOLUTIONIZES TREATMENT

Much like diabetics who need to track their blood sugar levels throughout the day, Sadie and Sara needed to keep close tabs on their eye pressure. Tonometers, which can measure eye pressure in the home setting, would be needed to avoid frequent trips to the ophthalmologist’s office or a stay in the hospital to get multiple eye pressure checks.

Fortunately, when the Edgecombs found Freedman, she was studying a newly



Duke Eye Center pediatric glaucoma specialist, Sharon Freedman, MD, with Sara and Sadie Edgecomb

## TWINS

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for second and third opinions; each time they were referred back to Boston, and all the specialists said implanting new lenses wasn’t an option. Meanwhile, their local ophthalmologist continued contacting specialists to see if the girls could have intraocular lens implantation at the time of their cataract removal to avoid having to wear glasses or contact lenses.

In the winter of 2010, the Edgecombs found Duke Eye Center’s pediatric ophthalmologist and glaucoma specialist Sharon Freedman, MD, professor of ophthalmology and pediatrics at the Duke Eye Center. She offered to examine the twins immediately to determine the feasibility of lens removal with intraocular lens implants, in hopes of making more room in the anterior chamber (the space between the iris and the cornea) and thereby possibly improving their glaucoma. They dropped everything, packed up their suitcases, and flew 1,250 miles to Durham to make the first of six trips to Duke Eye Center.

“We felt so welcomed and comfortable at Duke, and over time, we’ve come to view the staff as members of our extended family,” says Stacy, a branch manager at a local credit union. “Dr. Freedman and the whole staff communicate so well and involve us in every aspect of the decision-making process. And when we’re back home, it’s really comforting to know that Dr. Freedman is just a call or text away.”

“I am passionate about my work and I become very close to my patients and their families. We’re dealing with very serious conditions, so we commit to each other to work together; I make myself available. Access and communication are critical,” says Freedman. She has been known to bring fresh fruit, home-baked cookies, and goody baskets to the Edgecombs during their weeklong stays. “I just know how I’d feel if I were on the road with my children, living

### EDITORIAL

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