

EMORY | eye



Lucky ten ²

Compassionate trial helps patients with retinitis pigmentosa.

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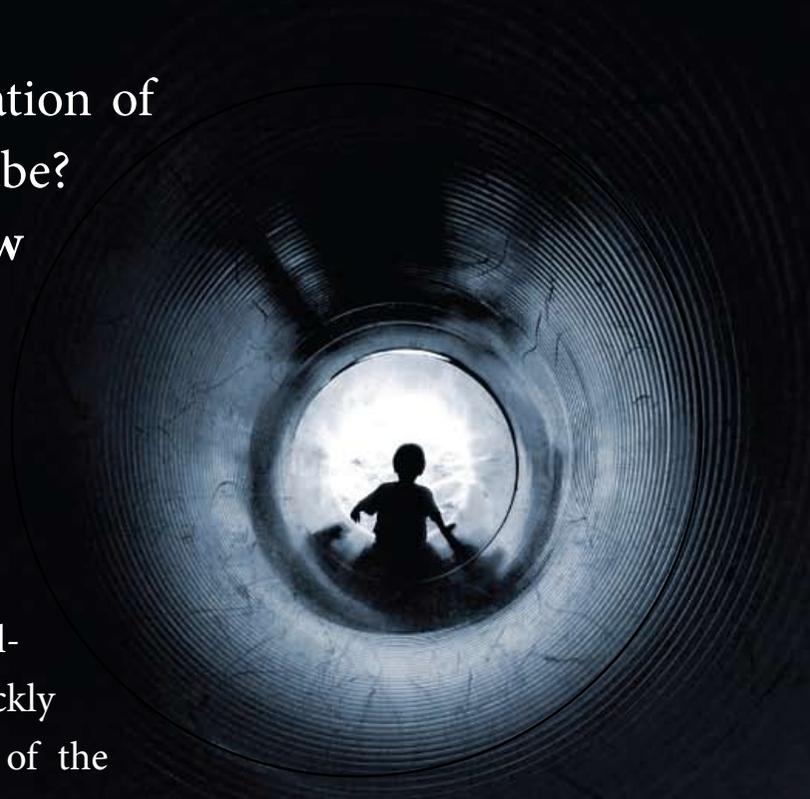
COMPASSIONATE TRIAL HELPS PATIENTS

Remember the long-ago fascination of peering through a cardboard tube?

Your childhood eyes met a new perspective: all the wide, surrounding world reduced to just one small circle.

For a few moments' glimpse, that circle can intrigue and entertain. But as someone's only option—and as a view certain to become smaller and smaller—such “tunnel vision” quickly loses all novelty. Inherited degeneration of the retina, called retinitis pigmentosa (RP), increasingly narrows the field of vision. Night blindness comes first, then a gradual shrinking of the periphery; sight dwindles to the size of a cardboard-tube circle, then to a dot of light like that at the end of a straw, and progresses steadily toward blindness. And there's no known treatment for it. Yet.

This big yet continues to motivate the retinal surgeons and scientists of Emory Eye Center, much to the recent benefit of 10 patients from across the U.S. and Mexico. Starting with a newly invented device and ending with newly aroused hope, these patients' jubilant stories are ones in which everybody—from families to physicians—wins.



Try this: **Before you recycle that next paper-towel roll, take a moment to peer through its corridor to the small circle of light.**

extra mile

WITH RETINITIS PIGMENTOSA by Ginger Pyron

The initial trials

In 2005 the “NT-501,” a one-of-a-kind implant for RP patients, underwent a clinical trial conducted by its maker, Neurotech. The six-month trial was encouraging. Designed to provide long-term release of a therapeutic protein (ciliary neurotrophic factor, or CNTF) directly into the back of the eye via Neurotech’s patented Encapsulated Cell Technology (ECT), NT-501 showed promising results in halting the progression of RP among participants.

The next step: Test the implant again—and again. As Neurotech continued its second and third studies (2006-2007), Emory Eye Center agreed to conduct a separate “compassionate trial” for 10 people with varying degrees of RP. These men and women, selected by Foundation Fighting Blindness and Neurotech, urgently sought help for their condition; a number of them had not been eligible for an earlier trial. Expecting the typical eight- to nine-month time frame for the study, the Eye Center’s trial team later learned that new circumstances dictated a hard choice: Either complete the entire trial before December 20, or wait until the following August.

Compassion in action

From its Latin roots, the word compassion means “to suffer with.” For the sake of the 10 suffering and hopeful patients, and despite a December roster already crammed with appointments, Emory

chose to push ahead with all speed.

Within one and a half months, Emory had maneuvered its way through a university approval process that usually takes six months to a year. And within a highly compressed schedule—during just two short weeks in December—the Eye Center’s team accomplished the almost impossible.

Before receiving the implant, each of the 10 patients had to undergo extensive examinations and testing that involved laborious documentation and spanned many hours each day. Three clinical staff members, working with good will, efficiency, and stamina little short of heroism, engineered the complex processing. If the Eye Center offered an award called “Grace Under Pressure,” the three hands-down winners for 2007 would be clinical trial coordinators Donna Leef, Stacey Andelman, and Alcides Fernandez. From faculty and patients alike, they could expect a standing ovation.

Shouldering the task of performing all 10 surgeries at a stepped-up pace, Eye Center retina specialists Jiong Yan and Daniel F. Martin inserted each implant, one day after another. Neurotech donated the implants, but Emory covered all other expenses of the trial, including the surgical costs.

Jiong Yan observes in retrospect, “Two weeks! That was an almost unbelievable time frame for this trial. But we knew why we had made this decision, and all of us were willing to do whatever

was needed. Everything went perfectly. It was a triumph of teamwork.”

Results: win-win

Ten people, including those featured here, celebrated the end-of-year holidays with the gift of a permanent implant. They and their families entered 2008 with fresh new hope.

At Emory Eye Center, a team of dedicated specialists and staff members enjoyed not only a well-earned rest, but the assurance that their intensive two-week push furthered an ongoing mission: seeking to open the vision and the future of these 10 patients—and of countless others who will come later.

For people who see well, the disheartening progression of RP is hard to imagine. Try this: Before you recycle that next paper-towel roll, take a moment to peer through its corridor to the small circle of light. Then, during your next restaurant meal, look way down to the tiny bright spot at the end of your drinking straw. What if your vision had shrunk that much? And what if you knew that the circle would become even smaller? When you come back to your full vision, notice the rich peripheral details you enjoy. They’re so easy to take for granted—until the day you realize they’ve begun to recede.

Emory Eye Center exists to protect those life-enhancing details. We exist to help preserve vision for people like these lucky 10. In myriad and compassionate ways, we offer our resources to you. 



Linda Maxie, the first person ever to receive the NBT-501 implant, also received a second implant at Emory.

LINDA MAXIE

Emory's compassion: What it meant to us.

“I could see that the computer screen was lit, but that was about all.” That’s how Linda Maxie from Virginia describes the extent of her RP vision—in her better eye—before she received the implant from Emory last December. Now, post-implant, things appear different: she can tell there’s print on the screen and recently has even been able to make out a letter. “That’s so exciting—and it’s also an important change,” Linda says, “because it’s something the doctors can actually measure.”

Linda and RP became involuntary companions back in high school, when Linda received a diagnosis informed by three telling facts: her night blindness, her partial loss of peripheral vision, and her two older siblings’ RP. Central vision stayed with Linda throughout college, though in classes she had to sit close to the blackboard. During her 30s, RP began affecting her mobility, and the next decade brought a new, much more welcome companion: her first seeing-eye dog. Two dogs later, Linda now goes everywhere with “very smart, very brave” Odette, a black labrador.

“I really understand people with visual impairments!” Linda says. This understatement comes not just from years of managing her own vision-related difficulties, but from working—aided by a reader and a specially adapted computer—with appeals for disability, in her complex job as a paralegal for the Social Security Office of Hearing and Appeals.

In the 2003 Phase I trials held at the National Institutes of Health in Bethesda, Md., Linda earned the distinction of

being the first person ever to receive the NT-501 implant. Placed in her poorer eye, the implant seemed to produce some improvement, which has stayed with her. When the opportunity arose to participate in Emory’s compassionate trial last fall, Linda was immediately enthusiastic. Her hope soared.

During the grueling days of pre-testing and documentation that led up to her implant surgery, Linda was amazed by the Emory staff members’ attentive care. “Those were

long, draining days for all of us,” she says. “The potential for stress was really high, but the Emory people never seemed bothered. They went the extra mile with everyone—not just doing their job, but treating us like dear friends, and making everything seem easy.”

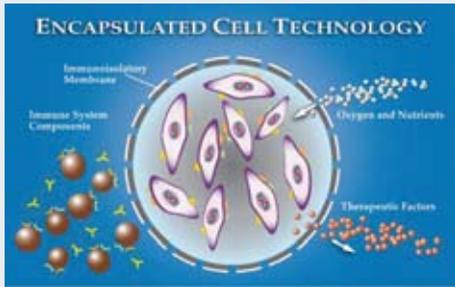
Escorted to each appointment, treated with lunch each day, supplied with staff members’ phone numbers, and shuttled to the hotel and the airport, Linda found that Emory Eye Center anticipated and met her every need. Odette herself came in for special at-

tention, including a well-filled water bowl, dog treats, and walks outside.

Linda will be returning to Atlanta periodically for follow-up checks, and she holds strong hope that her vision will continue to improve. “I won’t ever be able to drive a car,” she says, “but I hope I’ll be able to see color and more objects, so I can get around better. One thing is sure, though: I know I’m in good hands at Emory. On every trip here, I feel like I’m coming back to friends.” *Linda Maxie is a resident of Goodview, Va.*

“Emory staff members went the extra mile with everyone—not just doing their job, but treating us like dear friends, and making everything seem easy.”

--LINDA MAXIE, PARTICIPANT IN THE
RP COMPASSIONATE TRIAL.



A small thing—and a BIG to-do

It may not look like much, but the tiny NT-501 implant raised a quiet hubbub at Emory Eye Center during December 2007. The compassionate trial itself was big deal enough; the necessary logistics, however, tested the efficiency and commitment of the entire Eye Center staff, and found them strong.

Because Neurotech was relocating its offices, no new implants were scheduled for production until summer 2008. To take advantage of the existing implants, the Eye Center chose the compassionate—and expedient—course. Emory staff rallied for a herculean task: preparing the 10 patients according to strict procedural protocol and then performing the 10 successful surgeries, all within only two weeks.

Clinical coordinator Donna Leef recalls, "There was no outside money to back this work, but those 10 eyes warrant the compassionate trial. The doctors said, 'This is important. We'll do what it takes.' Their generosity made me willing to put in all the extra effort."

NATE LIGHT

Helping others to help myself

Back when I was 8 or 10, I had a lot of difficulty in the movie theater; I couldn't find my way around in the dark. My early RP diagnosis didn't keep me from living a normal life, though. I had a long career, and whatever I couldn't read, my wife Pattie or an administrative assistant would read for me. About 15 years ago, I finally stopped driving a car. And in the last several years, my field of vision has narrowed; I now have my good days—which are few—and my bad days, when

blurred or hazy vision causes me to need help.

During my visit to Emory Eye Center for the implant surgery, I didn't realize the project was on such a tight schedule. I did notice, though, that the staff members were literally compassionate, treating us as if we were very important to them. This trial means a lot to all of us patients, too. In the

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past, all we had to look forward to was total darkness. Now, Emory's research gives us some hope of stopping the disease and retaining our current vision. We can't tell yet what the results will be; I just take it one day at a time.

When I started raising money for Foundation Fighting Blindness, my intent was less about helping myself and more about helping other people in the years ahead—perhaps even my own child or grandchild, who may have inherited this disease. A lot of good and promising things are happening now. With all the new developments, we're living in a marvelous time. My wife Pattie is tickled pink to know there's some hope out there. *Nate Light is a retired CEO, Palm Beach Gardens, Fla.*



Nate Light undergoes a visual field test at his June follow-up exam at Emory Eye Center.

KEN RIETZ

Working for those in the future



Dr. Jiong Yan discusses Ken Rietz's chart with him.

Despite my progressive symptoms of RP, I've been able to live actively. In fact, my diagnosis—35 years ago—came from my experience as a tennis player: I could play the game well enough, but after a point was over, I had trouble finding the ball in the court. My career with Burson-Marsteller didn't suffer from my RP, either. Whether I was working in Los Angeles, New York, Washington, or London, the company provided a car and a driver, and my wife Ursula or a staff member always traveled with me.

“Over and above” is how I'd describe the work of Emory Eye Center's staff. In every detail—from our daily schedule at the hospital to our plans for dinner—they were extremely helpful, a pleasure to work with. They were calm and organized, getting people through the whole process in a short period of time. Each one of us felt known and respected. I'm glad to say that since receiving the implant, I can read more letters on the eye chart. My improvement so far has been positive.

Both my wife and I feel blessed to be a part of the Eye Center's work. My main hope now is not for myself, but for people in the future, the ones with RP who are young and following us. I want them to have a future that they can really look forward to. *Ken Rietz is a retired COO, Delaplane, Va., and recipient of the 2008 “Hope and Spirit” award from Foundation Fighting Blindness.*

MEREDITH TYREE

The hope of watching my children grow up

At age 16, with a history of night blindness and fender-benders, I got the doctor's verdict: “You have retinitis pigmentosa, and there's no cure. Start learning Braille, because by the time you're 45, you'll probably be blind.” My dad immediately began raising money for vision research. He told me, “We're going to find a cure, Tiger.”

Now I'm 42, with two young sons, a household to run, and this new implant—which my father's hope and dedication helped make possible. I won't receive a visual field test for another few months, but I can tell that my clarity has improved. For me, that's an extra bonus. I have only 5-percent vision, and if I can hang onto even that much, it's all I'd ask for.

I can't say enough good things about the wonderful staff at Emory Eye Center. They stopped everything else to help us, working long days and all weekend. All of us patients were a little fearful, and they handled us with love and patience. We think they walk on water! By offering this trial, they're giving us such a huge gift—the hope of watching our children grow up, of having independence and freedom. And they do it so humbly.

Somewhere there's another 16-year-old who's just now hearing those shattering words: “You have RP.” I want her to know she doesn't have to live just waiting for the worst to come. There's promise, and there's hope. If my dad were alive today, he'd say, “I told you! We're going to make it happen!” *Meredith Tyree is a mother and homemaker, Midlothian, Va.* 



Tech Stacey Andelman checks Meredith Tyree's vision.