

GOING DEAF AND BLIND IN A CITY OF NOISE AND LIGHTS

Rebecca Alexander has a condition that is robbing her of her sight and her hearing.

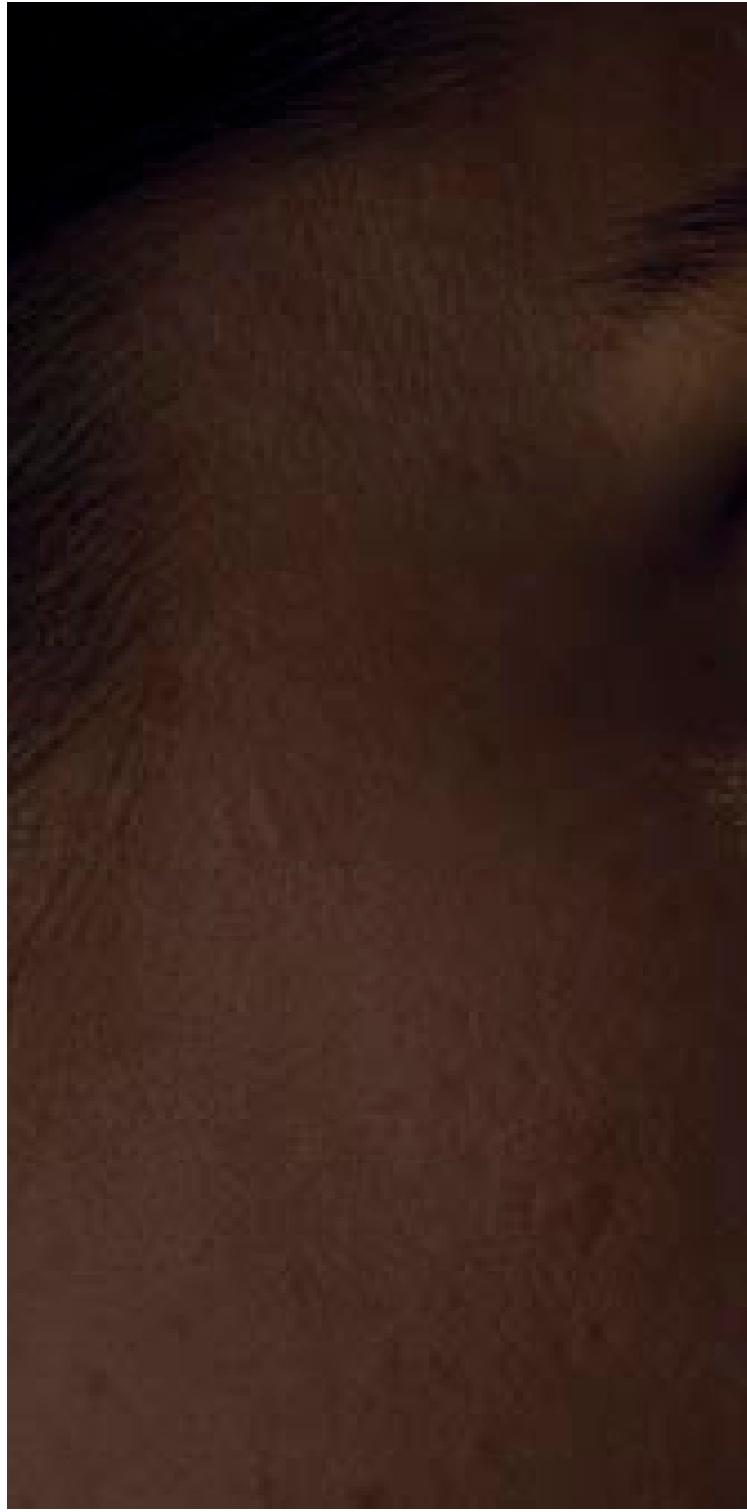
But she can't stop moving at 100 miles an hour.

By **Arianne Cohen**

WHEN REBECCA ALEXANDER walks into the party at a Hell's Kitchen condo, it's like someone turned on a 10,000-watt lightbulb. The room migrates toward her, absorbing her aura, a raw, happy energy. She had sold the party to me as "a regular event where young blind people meet somewhere that's well lit." It looks like any other party: loud music, appetizers, a dozen twenty- and thirtysomethings mingling in a room devoid of furniture to trip over. Most everyone in the room has retinitis pigmentosa, the progressive death of photoreceptor cells, which can lead to blindness.

Alexander, a pretty 29-year-old brunette who is also losing

her hearing, grins hello. The Kanye West song that's playing sounds to her like an auditory blur, and she views everything through two small holes called "doughnut vision," which is like if you squeeze your hands into little circles in front of your eyes. A typical person can see 180 degrees without turning their head; Alexander can see less than 15 degrees. Her pupils dart back and forth, to figure out who's there, scanning to compensate for her brain's unfortunate habit of wrongly filling in blank spots, putting empty space where there's a person. Her condition is known as Usher syndrome type III, a recessive genetic mutation causing her retinal cells and ear-hair cells to die, an ailment shared





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by fewer than a thousand Americans. A typical sufferer is blind and completely deaf by his forties.

Within moments of entering the party, she's in a clique, seamlessly shifting so that the voices come toward her good left ear and her back is against a wall, cutting down her scanning area. Her hearing aids are hidden by silky, dark hair. She's in hyper mode, which is how she gets when she can't see or hear much. To conceal this, she talks up a one-way storm, in a superloud voice, blue-green eyes flashing happily at you. She's now telling her friend Lis Perry, a sales manager with retinitis pigmentosa, about how she balances her psychotherapy practice (she specializes in eating disorders) with the fifteen weekly spinning classes she teaches.

Others join the circle around her, and the conversation turns to Governor David Paterson. The consensus is that perhaps the public will begin to understand that most legally blind and deaf people don't live in a cloak of total darkness or silence. But Alexander is not listening. She spots crackers and cheese mashed into the carpet. "Uh-oh! No one step over there." She rushes off to find paper towels, like a guest at any other party.

A FEW WEEKS LATER, Alexander breezes into a midtown diner on a Monday night. She likes diners because they're not dark and loud like the nightclub in Southampton where she spent Saturday night. "Alan [Pinto, her on-again/off-again boyfriend of four years] had to lead me around all the dark stuff on the floor," she says. "I always hold close to someone. People see me and say, 'Hey! Rebecca!' And having to find them, and then know who they are in the dark—it's all so annoying." She plops down in the booth across from me and announces, "You know, I really think that the people around me have been hindering my independence. I know they do it because they care, but I just drove from the Hamptons to here."

I barely conceal my instinctive sense of alarm at the idea of a driver with such limited vision on the road.

"I was fine," she continues. "I can see. And I felt so free. I did the Long Island Expressway and came right in over the bridge. During the daytime, it's okay! I can go where I need to when I need to. That's so important for me." The waiter appears next to her and asks her what she wants. He's alongside her right ear, and she doesn't see him. I lift my finger into her eye line and point at the waiter.

Alexander moved to New York from Los Angeles because her inability to drive at night left her stranded and dependent. Not long before she moved, driving home on Wilshire Boulevard, she hit a homeless man who had wandered into traffic. "I heard the thunk. It seemed like he was really injured, and I was freaking out and crying." It turned out he was okay. Horrified by the thought of her behind the wheel on the L.I.E., I suggest that what she needs is a driver. Her face drops, and she changes the subject. (Later, I text her friend Josh Swiller about the driving. He texts back, "OMG. How many people died?")

To improve her hearing, Alexander will also eventually get a cochlear implant. It's not a save-all—they can mangle the texture of natural voices and music into a mechanized sound, like a bad

answering machine. But she'll be able to continue her psychotherapy practice, much like Rush Limbaugh continued his radio career after getting an implant in 2001.

Alexander and I chat for a while about her personal life. She spent her mid-twenties in therapy, ardently addressing her sensory loss, which is especially hard for someone so physically wide-awake, so literally pulsing with energy. She has always found great solace in sex; touch is her most meaningful sense. But when she was younger, her reliance on sex as a lifeline backfired. "I used to find myself in very compromised positions with guys. I would hide my hearing aids under the bed. I remember hooking up with a guy, without hearing aids or contacts, and he wanted to start fooling around again. And it was so dark, and I wasn't familiar with his place, that I ended up going along with it when really I wanted to be left alone. That's the worst feeling in the world, to feel so helpless."

She worked hard in therapy and picked up master's degrees in social work and public health from Columbia, in addition to her bachelor's from the University of Michigan. "I challenge you to find anyone who accomplishes more in a day," says her brother Peter Alexander, 32, an NBC correspondent. "She texts me, and she's like between her third and fourth spinning classes, about to do a counseling session."

I begin to understand why everyone uses the adjectives *amazing* and *awesome* to describe her. I find that I adore her, too. Which makes it painful to imagine her slowly closing world. "It's really the isolation," says Swiller. "Most people wake up and the first thing they do is turn on the radio, and the last thing at night is turn off *The Daily Show*. We input all that noise to blast out thought. She doesn't have that. She's alone with her thoughts, in her own world, in a way."

Whatever keeps her up at night is not something she talks about. "Well, we all have our shit," she says. "One of the things that's so unique and wonderful about this is that you're forced to use other senses. It makes you creative. For example, I was meeting a friend at Houston's on 53rd, and it's

really dark on the stairs. I wanted to put my name on the list, but I wasn't gonna break an ankle over it. So I watched people exiting and counted how many times their bodies went up. Sixteen stairs, then turn, then five more."

The next day, I ask Alan about the driving. I can practically hear him wince over the phone. "I think it's impossible for anyone to put themselves in her shoes," he says. "She sees a difference over time, and she's scared about what the future holds for her. This is me getting into her head more than she'd want, but I think she keeps going 100 miles an hour to not have to process it all." He pauses. "Which, I guess, is the best way to do it. It's sort of the idea that everybody has their cross to bear. Hers is just more defined."

Disability is not easy anywhere, but Alexander suggests benefits to being deaf in Manhattan. "Whenever there's a fire truck or whatever, I just turn my hearing aids off and I'm in my own world," says Alexander. Her ex-boyfriend Sam Swiller (brother of Josh), a deaf banker and economics professor, says that when he's walking on the street, "my favorite thing is to

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**‘WHOA! WHERE
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Alexander conversing with her deaf friend Josh Swiller at a party; her on-again/off-again boyfriend Alan Pinto is far left.

turn off my cochlear implant. In the city, there's a rhythm to everything. It's like poetry in motion."

The New York area is home to 6 percent of the country's legally blind, creating a subculture of roughly 80,000. The young flock here for the opportunity to play on a level field, where everybody is dependent on public transportation, cabs, deliveries, and Internet ordering. "It's very attractive that most of New York is on a grid system," says Matthew Sapolin, the city's disabilities commissioner, who as a young blind man came here to attend NYU. "If you can count, you can get around."

Taxis are essential to Alexander, though they're hazardous too: Her tally of lost taxi items includes wallets, cell phones, bags, shoes, very important papers, and her favorite black pullover. "When I turn to see if I left anything, it's black-on-black. I can't see crap." Pinto keeps buying her portable flashlights, but she doesn't use them because they're not bright enough.

Her doorman, Tony, is her link to the outside world. I call him to find her when she's late to meet me at Bloomingdale's, since she doesn't always pick up her phone. Tony buzzes her apartment. "She's either not there," he says, "or she took out her hearing aids." We chat, and I realize that he doesn't know about her vision problems. He thinks she's just deaf.

She appears at Bloomingdale's fifteen minutes later, gripping her finger; she has just been sideswiped by a biker, no big deal. We go in search of a can opener. Alexander doesn't browse. She goes shopping only for specific items. As we slowly make our way up to the household-goods area, she fixates on my face, lip-reading. That's the way her New York is: one thing at a time, focused.

Her main strategy is pretending that she knows what's going on, which she's quite good at. Her facial expression never reveals discomfort—you have to look at her eyes to see them flash disorientation. She nearly walks into a low central table of glass perfume bottles. If she can't see ahead, she naturally slows so that I

walk ahead, and then she imitates. We walk through a nexus of mirrored escalators, luggage, and kitchen supplies, with a checkered black-and-white floor. She nearly walks into a center-aisle perfume display and stops. "There's a lot of glare. And the black-on-black with mirrors look like an optical illusion." I point in the direction we were going, but she doesn't see. Her doughnut vision cuts me off at the shoulders. She reaches up to feel which way my arm was going. "I see pots!" Bingo, kitchen area. She scans until she sees the word GADGETS high on a wall. She moves toward the wall, a can opener hanging just past her right shoulder. She scans the wall, moving to the left. "A mango splitter? Really? A cherry/olive de-pitter?" She grabs interesting items as she moves farther away from the can opener. "Maybe they don't carry them." A minute later, she backtracks. "Jar opener! Wait, no, that's different." And finally she sees it. "Success!"

Alexander's saving grace is an excellent sense of directional memory, developed by necessity. She easily directs me out through the maze to the right exit. "I rarely get all turned around. If I came from there, I can get back there."

ONE OF THE TWO New Yorkers with Usher syndrome type III that Rebecca knows is a woman named Cindy who lives in the East Village. Her family has devoted significant funds to researching a way to find a cure. The two are friendly but until recently didn't talk much about their condition. Pinto, who has battled lymphoma in the past, keeps up with Cindy to discuss developments. "Rebecca's kind of attitude is, 'I'm living my life, let me know when you have something,'" he says. "She still goes about her life as if she doesn't have Usher's."

Which is why, for her, the Hell's Kitchen party is a sea of potentially ugly things to come. She glimpses Marc Grossman as he's led into a chair by his wife. "I've seen him so many times," she whispers, "but it's hard to imagine" (Continued on page 79)

yourself like them until it happens to you. Two years ago, I couldn't imagine being like I am now." Grossman is the hero of the group, happily married and gainfully employed (the blind have a 70 percent unemployment rate). He began his twenties sighted and ended them blind. When I strike up a conversation with him, he describes his commute. Each morning, he takes the subway to midtown. "On the platform, I just kinda bang my cane on the subway until there's an opening. If there's no floor, I know I'm between cars. Sometimes I get discombobulated and say, 'Someone help me find the door!' and people are cool." He disembarks at 34th Street and Eighth Avenue, a particularly arduous platform with trains on both sides. He runs his cane over the bumps on the edge to orient himself and follows the crowds to the stairs. The station is fuzzy, punctured by lights and "high visibility yellow," the color painted along subway platforms that many legally blind people can see. In bad weather, he navigates himself across Penn Station to the Seventh Avenue exit by "shorelining," running his cane along a wall or edge. New Yorkers can be overbearingly helpful. "They often grab you," says Grossman. "It's just not cool to be grabbed. The best thing is to say, 'Hi, can I help you?' Because most of the time, I don't need help."

As Grossman talks, Alexander zones out. She rarely encounters situations like his—she eschews her cane so no one knows she's blind. "People constantly come into my vision through blind spots, and I'm like, 'Whoa! Where did you come from?' It's annoying, because people are constantly coming too quickly. People on cell phones, walking too fast, walking too slow. It's the way this city rolls. On the other hand, it's not so bad, because everyone here runs into people."

It doesn't always work out so well. Recently, she ran chest-first into a guy, and the contents of her open backpack flew across the crosswalk. She couldn't see her stuff, and the traffic began to move. The guy called her an idiot. Pinto says she came home crying. To prevent these incidents, she always takes the same neighborhood routes, down to the step. "You have to be so careful of those open cellar doors at night," she says. "They're known as death traps."

The Upper East Side's broad, clear sidewalks and grid system are particularly popular among the blind. Grossman is brave; he often trolls new neighborhoods solo. He figures that if he gets lost, he'll just call a friend to come find him or wait until he hears footsteps. This, everyone agrees, is a built-in security system of New York: You're

never alone. Any time of day or night, someone will pass within a couple minutes. And it's always pretty safe. "I've been on subways where there's rough kids talking crap, and then I hear, 'Yo, let the blind guy through!' It's like a moral circle." I ask if he's ever been hit by a car. "One time, I felt myself stray in a major crosswalk," he says. "I knew I was in the middle of the intersection. So I just said, 'Yo, someone help me!' and someone ran out and grabbed me."

Alexander watches as Grossman's wife leads him to the bathroom. I ask if she's doing any other planning ahead. Her blue-green eyes look at me plaintively. "How do you plan ahead for going blind-deaf?"

Alexander was raised to have high expectations. "My mother is totally perfect. She writes perfectly and sings and plays the piano and is beautiful." The numerous collaged family photos in her apartment resemble Ralph Lauren ads, an intensely attractive clan with dark eyebrows and piercing blue eyes. Her father and twin brother are lawyers. When Alexander was 12 and first experiencing vision problems, she was diagnosed with retinitis pigmentosa; not until she was 20 was it understood that she had Usher's. The carefree life she had known, which had included scampering around Yosemite as a child, was no more. But her mother, Terry, a school administrator, instilled in her the belief that she could still live a very full life and should never pity herself. "What's her alternative?" says Terry. "She could be part of the wild world that everyone else is immersed in, or she could succumb to a quiet, dark world."

First came a series of bruised knees from banging into open drawers. Then the tinnitus started in college, a persistent ringing in her ears that presaged hearing loss. Alexander responded by joining the wildest world possible, with a rash of teen partying and slew of eating disorders through college. "So much of my eating was about not being able to control things," she says. Just after college, her vision took its first serious dip. She coped by dating. "I don't want to say promiscuous, but I used to think it was easier to just make out with someone if I couldn't hear him. They didn't know that the real me wore hearing aids."

Almost everyone I interviewed found a polite way to mention her ease at attracting men, but potential boyfriends don't tend to respond well to Usher's. Sam Swiller, who is still close to her after their failed romance, gamely explained his hesitancy. "The unfortunate thing about her disease is you don't know how quickly it's gonna get bad. And while things were perfectly great then, I was always think-

ing about the future, and it didn't give us enough time to develop the present. You ask yourself, 'Am I going to be able to get what I need from this individual?' I was idiotically overcome by a relationship where neither of us could make restaurant reservations by phone."

Her family members have found themselves in an emotional wash cycle, but "they treat me like I'm normal," says Alexander. "Kevy [Kevin, her twin brother] mumbles on the phone. The other day, I didn't hear Peter ask me something, and he goes, 'I said, "What ... are ... you ... going ... to ... eat ... tonight, fuck-er?"' He just gets it. Honestly, it would be much harder for me if my brother had it and not me," she says. "In some ways we've coalesced around Rebecca," says Terry. "I don't know that I would be involved with anything that [my ex-husband] is doing were it not for us following research. We're not in the same social circles, but we're very close with the kids."

HEARD ONE PHRASE repeatedly at the Hell's Kitchen party: You play the hand you're dealt. It's an attitude of getting on with things. One night, I watched Alexander shimmy into tight jeans in her East Fifties studio, getting ready to go out. All eighteen lights in her apartment were on. She expertly applied makeup under three bright bulbs. In three weeks of hanging out with me, she'd yet to really delve into her feelings about going blind and deaf. It occurred to me to try the past tense—how does it feel to have already lost so much of two senses? She sank into her bed. "I miss walking into a store and saying, 'Oh my God, do you hear this song?,'" she says. "And it's terrible to remember that I used to sit at my cabin at camp and whisper. I could never do that now. Or I remember being little, in my room, and hearing the creaking of the door in the kitchen."

Then she snapped out of it, pulling on a thick headband, obscuring her brown hearing aids. I try to gently coax her back into reflection, asking how she copes with the loss. "Yoga is really great."

No, I mean, cope.

She pauses, purse in hand, and looks at me. "If you were in my shoes, you'd do the same thing. If these were the cards you'd drawn, you'd play them. You would." She grabs a scarf and waves me out the door, past her cane. Tony loudly yells good-bye. While she hails a cab on the corner, I tell her about a poll that says Americans are more afraid of blindness than of AIDS, cancer, and heart attacks. She looks dumbstruck. "Cancer? For real? I don't get that. Really, it's not that bad." ■