

The Blind Visionary

VIRGINIA JACKO



Virginia Jacko speaks to students in Tampa's Hillsborough School District..

In December 2000, Virginia Jacko found she was rapidly losing her sight to *retinitis pigmentosa*, a condition characterized by retinal damage. The discovery prompted her to take a three-month leave from her executive position at Purdue University and enroll in Florida's Miami Lighthouse for the Blind and Visually Impaired. Although she fully intended to return to her work at Purdue after her vocational-rehabilitation program, life soon set the finance expert on a completely new path.

Within four years, Jacko advanced from student to president and chief executive officer (CEO) of Miami Lighthouse. In her book, *The Blind Visionary*, written with entrepreneur Doug Eadie, Jacko uses the concept of blindness as a metaphor for those of life's challenges that narrow a person's vision and constrain his or her sphere of action. Jacko met with *ABILITY*'s Molly Mackin to discuss what inspired her to tell her story.

Molly Mackin: You seem to have a sense of ease both as a CEO, and as someone who has mastered life after losing her sight. It's impressive.

Virginia Jacko: We all have certain traits and talents that make us who we are. I know this sounds corny, but as a result of my blindness I now have more vision, in some ways. Sight can be a distraction. For example, if you're at a restaurant, you start to look around, check out what

people are wearing, see who's sitting with whom, or see if you know anybody there. But if you can't do that, your other senses are heightened: your sense of taste, your sense of hearing.

Sometimes people ask me if it's okay to say something like, "I'll see you again." I tell them, "Oh I say that all the time." It's just that I see you in a different way than you see me."

Mackin: Your book sheds some light on some of the advantages of being blind. For example, you say that during meetings you don't have to look at people's negative body language. That resonated with me. Once I see someone disagreeing with me, even if the words aren't coming out of their mouth, their body language can totally trigger doubt in my own mind.

Jacko: You're right. I haven't recently seen anyone roll his eyes at me. *(laughs)*

Mackin: I imagine you're probably not too caught up into fashion, either.

Jacko: I love fashion. Sometimes people say to me, "Do you miss driving?" and I say, "No, I miss seeing what women are wearing!"

I still try to be fashionable. I'll ask my secretary, Sharon,

“What are you wearing today?” and she’ll say, “Oh that grey suit with the brown stripe in it.” I’ll ask her what kind of blouse, and she’ll tell me it’s the one with ruffles in the front. Then, if I go shopping, I might ask if the store has any blouses with ruffles in the front. (*laughs*)

I was in a style show once. All of the participants were lined up with their dogs, waiting their turn. Donna Shalala, the former Secretary of Health and Human Services, went ahead of me, down the runway. I walked up the steps, and I stood there for a minute. I thought, “You must be crazy, Virginia,” and yet I instructed my dog: “Forward.”

I’d already counted that I had something like 80 steps to walk, so when we got to 80, I told my dog to turn and, as I made the turn, I was so thrilled that I hadn’t stepped off the stage that I raised my hand and gave the audience a big smile and a wave. They gave me a standing ovation.

Mackin: Reading your book made me more aware of all the ins and outs of living with sight. I found myself wondering how I would cope if I lost my own sight. You talk about spilling things in the kitchen and navigating that experience, but I really sensed you were entering a new world, instead of leaving one behind, when you became blind.

Jacko: That’s a great insight. Someone recently said to me, “What was harder: losing your vision or becoming totally blind?” When you lose your vision, you don’t want people to know, at first. You hide it. Of course, this can be applied to a lot of different situations, not just to loss of vision. You want to be something that you can’t be, but it’s an impossibility—so you’re frustrated, on edge, nervous.

Once you learn you’re totally blind, and you’re no longer trying to see, you say, “Okay. I’m just going to do things differently. I’m going to use my other senses. That’s a huge relief.

Mackin: And maybe even a little exciting. Every task becomes an adventure. In the book you tell a story about the first time you walked into Walgreens by yourself, which was something you thought you’d never do again. Once you did it, you had renewed confidence that you would be okay.

Jacko: I remember like yesterday the exhilaration I felt when I got to Walgreens. It was a feeling of, “I did this. I actually did this.” And then I built on that feeling. That’s not to say that I’m not fearful sometimes. But one of the takeaways of my book is never to let fear win. Of course, that’s a struggle for everyone, because having fear is part of being a human being. But the key is to not let fear win.

Mackin: One of my favorite parts of your book is when you describe visiting a restaurant in a department store. You had been told you wouldn’t be allowed to bring your

dog into the restaurant, but you walked in, anyway, and sat down as if nothing had happened.

Jacko: That was a very high-end department store, so when I told the president of the establishment about that embarrassing experience, the business wanted to brush me off onto its attorneys. But when I said, “This is not a litigious matter, but it could become a public-relations matter,” that’s when they thought, “This could really affect us. What if she puts something nasty in the newspaper?”

I suggested the restaurant implement a training program, which they did almost immediately. At the time, I was thinking, I’m kind of an old horse. But what if I had been a young girl on a date? That would have been so mortifying. Maybe I improved the lot for the next person.

Mackin: You changed the perspective of the manager and the hostess, I’m sure.

Jacko: (*laughs*) I have to keep my head, because stuff like that can be really annoying. But if one can think of the proper steps to effect change, it can all work out.

Recently I was at my apartment building, walking by the pool, which is a pet-free zone. Someone had left a dog tied up there. It lunged at my guide dog, which lurched sideways, and I almost tripped and fell into the pool. I found out who owned the other dog and brought up the issue. Of course, the dog’s owner didn’t like that at all. We had an intense discussion about the rules and, in the end, I told the woman I’d get management to send her a letter. I felt so invaded that she would even argue with me about a situation like that! She ended up calling me, apologizing and promising not to bring her dog to the pool again. I tried to end the whole thing on a good note. You’ve got to keep things in perspective while you’re being an advocate for yourself.

Mackin: Pet rules can be tricky.

Jacko: You know, some people get bogus certifications for guide dogs, or they get guide dogs even if they don’t have a disability. But those dogs don’t have the same intensity of training. My guide dog is totally under my control when we’re in public. If you have an animal that is assumed to be a certified guide dog but doesn’t act like one, you’re ultimately affecting the rights of people who actually do have a disability.

Mackin: When the job posting for CEO of Lighthouse opened up, your counselor had told you that you’d never be considered for the slot. Then, when you were chosen, someone quit on the spot. How did you feel about that?

Jacko: People sometimes resent me because I’m a very confident person. I think sometimes they want to patronize me, and sometimes I let them get away with that a little bit. Maybe they’ve never been around a blind person.

Sometimes auditors come to our office for big meetings, and never talk to me at all. They talk to the other board members. I have such a strong financial background that I get a little personal pleasure from letting them totally discount me before showing them I know as much as they do. That always surprises them.

I can read an Excel spreadsheet on my computer, which is something they don't expect. Or they'll say, "I'll send this information to your chief-financial officer. He can read it to you." And I'll say, "Send it to me; I'll read it." So they leave knowing a blind person can do more than they assumed.

Being put down is not easy. My instinct is to be snotty, but I have to control that instinct and be gracious, even when people are being rude to me. There are probably sighted people running private agencies that service the blind who think the reason Miami Lighthouse has grown so successfully is because of its location, not because it's run by someone with great leadership skills who happens to be blind.

Mackin: Do you think people who have never dealt with blindness could possibly know what your world is like?

Jacko: No. Recently my husband and I were having dinner with a couple—a blind attorney and his very recent girlfriend. She said to my husband, "I know all about blind people! I could teach classes about them."

My husband said, "Really? I've been with my wife for years, and I still don't know what it's like to be blind." I think you have to be blind in order to truly understand.

In our job-readiness program, one of the students asked the instructor, "When you're totally blind and you're on the job, how do you go to the cafeteria?" The instructor brushed off the question as being off-topic. That's an example of a sighted person not thinking about what the situation would really be like for someone with vision limitation. If you had sight, you would pick where you wanted to sit, in part depending on whom you know in the room. But when you're totally blind, you're just thrilled to find a seat and grab the first one.

Mackin: What are your plans for the Institute?

Jacko: Miami Lighthouse is becoming recognized as a national center of excellence. We're expanding our mobile eye-care program for needy children. We just brought our eye-care unit to Naples, FL, where 92 percent of the children we saw needed prescription glasses, but had no way to get an eye exam or glasses because they didn't have Medicaid or any form of insurance.

With the recent contract from the Florida Department of Health, we've been able to expand our program to all of Florida's counties. We're also expanding Braille literacy as, unfortunately, Braille is being used less and less. If a

totally blind child wants to become an attorney or an executive here in Florida, he needs to pass an exam in either print or in Braille. If he doesn't have good Braille literacy skills, he will not be able to get a standard diploma.

Expanding low vision services to seniors who may never be classified as legally blind is also a priority for us. They should be able to remain independent in their homes and not a burden to their families or moved into assisted living. They need to learn how to do things differently, with the right lighting, with the correct lenses, with the right shading of the lenses, with the right magnification and other assistive devices.

We have a plan to collaborate with professionals in academia, as well. We purchased a house across the street from Miami Lighthouse and we'll use it to house people who need continuing education units, occupational therapists and physical therapists. So we'll provide all of that. The population of people with low vision is exploding, and medical professionals need to know how to work with people with low vision.

Finally, we've begun a residency program with the Bask and Palmer Eye Institute: a collaboration between this nation's number one eye-care institute and the number one leading vision rehabilitation center. These collaborations create a synergy of excellence.

Mackin: What is your national or international vision for the Miami Lighthouse?

Jacko: Miami Lighthouse has a national reputation. Articles in peer-review journals highlight our ceramics program, in which the blind can "see" using their hands and create beautiful art. There's an article about our music production program, which is a program enabling the blind to find mainstream employment through what we call our Better Chance music production program. That's been trademarked and the curriculum has been copyrighted. I also have an article about our free eye-care program in optometry, published in the *Journal of the American Optometric Association*. That organization is featuring us as a model for other states to adopt.

Mackin: How were your children affected by your experience going blind and moving to Miami?

Jacko: My children are used to having a mother who is highly confident and who sometimes goofs and spills her coffee. They are very independent, as am I. It's just that I have another way of doing things, and I need to rely on their sensitivity, in certain situations.

In other situations, I'm no different than any other mom. I know they're proud I didn't let blindness get me down. It was my daughter, who was teaching here at Florida International University, who said, "Mom, you have to relocate to Miami and get your vision skills at the Miami



Left: Jose Feliciano, Virginia and Miami Lighthouse musicians.
Right: Virginia Jacko, Gibney and Doug Eadie at a book signing.



Lighthouse.” That was some time ago. To relocate here for the purpose of vision rehabilitation, stay on in Miami, get on the board of directors, and finally become the first totally blind president and CEO of the organization is more than any of us could have ever asked for.

Mackin: So your daughter stepped up and said—

Jacko: She saw me struggling with the computer, and her PhD is in human interaction with the computer. She wrote a proposal to the National Science Foundation and, under President Clinton, received one of 20 very distinguished awards called the President’s Early Career Awards for scientists and engineers. She used a grant of a half-million dollars to develop software whereby the blind and visually impaired get a computer designed for their specific eye diseases. My daughter has published research on macular degeneration and accessibility issues for people who are visually impaired.

Mackin: What kind of message do you hope to send through your life and work?

Jacko: I’ve noticed that sometimes people handicap themselves by saying, “Oh, I can’t do this,” or, “I can’t do that.” Of course there are certain things people with a disability can’t do. If you are legally blind, you’re not going to be piloting an airplane. Someday, maybe, technology will evolve to a point at which that becomes possible. But in the meantime, there are so many things that blind people can do. It’s a shame how many handicap themselves. This Thursday I’m meeting with a teenage boy who just learned he has Stargardt Disease, which is typically the early onset of macular degeneration. People with

this disease very seldom go totally blind, but they do have to learn how to use their vision differently. My goal is to help this boy and his family understand that, once you know why your child is having trouble seeing, you can deal with the circumstances. You can still be a high achiever and have academic success. Maybe when you take your exams you’ll need to have a little more time, but that’s not going to be a mark against you. It’s going to be a way for you to have the test scores you deserve.

Mackin: What do you want people to glean from your personal and professional experiences?

Jacko: *The Blind Visionary* is for anyone, not just for the blind community. I hope this book has four take-aways, each of which can be remembered under the acronym “RANK.” “R” is for “Reach out aggressively to find stakeholders, colleagues, and advocates.” “A” is for “Act on opportunities because they are always in front of us.” “N” is for “Never let fear win.” And the “K” reminds us to “Keep things in perspective.”

Throughout the week I’ll often ask myself, “Virginia, how did you RANK?” That’s always a question worth asking, no matter who you are. ■ **ABILITY**



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