

DOUG SILVERMAN JR.

Lyn Frederickson's book, *Confronting Mitral Valve Prolapse*, sold 15,000 copies in 10 days.

MVP

A feisty nurse named Lyn Frederickson has become a most valuable player in the fight against the heart/nervous system disorder, Mitral-Valve Prolapse. She even wrote the book on the disease.

BY MELANIE LeMAY

It was 1984. Becky Work was a certified nurse midwife and an assistant professor in the School of Public Health at UAB. "As much as I knew about physiology, I couldn't explain it. I'd just recovered from an ectopic pregnancy, and I was overwhelmed with strange symptoms my doctors couldn't explain. Sometimes my heart would suddenly begin to race up to 160 beats per minute. My chest hurt and I couldn't catch my breath. I felt like I was trapped in a car with the accelerator jammed. Several times these attacks occurred while I was in the grocery store, and before long I found myself avoiding any kind of shopping. I cut back on my work and stopped delivering babies altogether. Eventually I became home-bound. I didn't want to commit suicide, but I wanted to escape from my body."

Three years later, 17-year-old Delanne Vincent was checking in late for still another morning at Homewood High School. No matter how much sleep she got at night, she felt lethargic when she awoke. Sometimes she could hardly move her arms and legs for the first few hours of the morning.

Throughout the day she would feel exhausted and vaguely depressed. Sometimes, inexplicably, she'd feel a sudden rush of warmth, and then the sensation of smothering. Her fingernails would turn purple and she'd begin to hyperventilate. Panic-stricken, she'd burst into tears. "I thought I was dying, and no one understood. It was my senior year in high school, I had a steady boyfriend, and I was happier than I'd ever been in my life. Everybody kept asking me what was wrong with me, and I didn't know what to say. My grades fell from A's to D's. Everything was falling apart."

In a strange twist of fate, the work of a cardiovascular nurse named Lyn Frederickson touched both Becky Work and Delanne Vincent, and today the lives of all three women are vastly different.

In 1984, Frederickson was running an autonomic testing center in the cardiovascular unit at UAB. A single parent with a teenaged son, she was pouring her energy into her work. "At that time in my life, my work was my security and self confidence. When I started seeing patients like Becky Work, I wondered and worried about them, and it became a personal mission to find some answers for their problems. Thank God I wasn't the only one worrying. Dr. Cecil Coghlan was seeing those same problems, and was beginning to think those symptoms were connected with a relatively minor heart abnormality called Mitral Valve Prolapse, along with dysautonomia, which is an imbalance of the autonomic nervous system. Dr. Coghlan thought

the symptoms could be triggered by physiological or emotional stresses; in Becky Work's case, the ectopic pregnancy.

"We struggled with Becky's treatment for months, changing her diet and trying one medication after another to slow her heart rate and calm her anxiety attacks, which she referred to as 'autonomic storms.' Finally she began to respond. There's no doubt the medication helped, but most of all, it helped Becky—herself a medical professional—to know there was a physiological reason for her problems."

It is largely because of progress in clinical research made by UAB's Coghlan and other physicians like Dr. Andrew Gaffney at Southwestern Medical School and Dr. C. F. Woooley at Ohio State that Delanne Vincent was able, by 1987, to obtain even more sophisticated diagnosis and treatment from Dr. Richard Russell at a

I felt like I was trapped in a car with the accelerator jammed

Birmingham center entirely devoted to treating Mitral Valve Prolapse and dysautonomia. With increasingly sophisticated diagnostic techniques, doctors were seeing many cases of Mitral Valve Prolapse and a center devoted solely to its treatment could be justified. Lyn Frederickson is director of that center at Baptist Medical Center-Montclair, which boasts four physicians and a staff of seven. The center currently sees about eight new patients a day.

"I'm thankful that by the time I needed help, Lyn Frederickson had started the Mitral Valve Prolapse Center at Baptist Montclair and MVP had a higher profile," Delanne Vincent says. Because doctors were seeing so many cases of MVP and dysautonomia among well-educated, high achieving young adults, the syndrome was touted as the Yuppie disease of the '80s.

Doctors found that in some women and men, the heart's mitral valve (which separates the upper and lower left heart chambers) was floppy. Instead of closing neatly like hinged doors, the leaflets in the valve would balloon out when they closed. Although the condition appeared to be harmless as

far as coronary disease was concerned, it did seem to be linked to abnormalities in the autonomic nervous system. Doctors hypothesized that since the mitral valve and autonomic nervous system develop simultaneously in a fetus, an abnormality in one might point to problems with the other. Symptoms associated with the conditions included rapid heartbeat, chest pain, shortness of breath, severe fatigue, numbness, dizziness, cold hands and feet, migraine headaches, panic or anxiety attacks, loose joints (including in the jaw), difficulty concentrating, sleep problems, and gastrointestinal problems.

The medical community was sharply divided in their opinions about the disorder. To further complicate the issue, not all the people who tested positive for MVP had debilitating symptoms.

"One of my teachers had been diagnosed with MVP," Vincent says, "but she had no symptoms and was skeptical about the symptoms I attributed to the disease. If I'd had open heart surgery, everyone would have sympathized, but since I didn't look sick, Dr. Russell really had to go to bat for me with the school." Russell believed Vincent, whose mother had also suffered symptoms from MVP, had first weakened her autonomic nervous system with years of caffeinated soft-drink consumption. A case of "walking pneumonia" triggered the more serious symptoms.

By eliminating caffeine and sugar from her diet, faithfully following an aerobic exercise program, and using medication to calm her autonomic nervous system, Vincent's condition improved dramatically. Her energy improved, and she was able to make up her school work. She entered beauty pageants and wrote poetry, and today is planning a career in child psychology or physical therapy.

And what role did Lyn Frederickson play in founding the diagnostic and treatment center for MVP which has helped Vincent and some 4,000 other patients since the spring of 1987? "I was lucky," Frederickson says simply. "I was in the right place at the right time, and I was working with some of the best medical minds around. Many of our patients were articulate high achievers like Becky Work and Delanne. When we heard them describe symptom after symptom, and when we saw them respond positively to treatment, we knew we were on to something. Each case is different, of course, and we had to try a variety of treatment combinations to achieve results."

When she felt the time was right to establish a center specifically designed to treat MVP and dysautonomia,

Frederickson approached several local hospitals. BMC Montclair seemed to support the concept most enthusiastically. "Montclair was trying to build its women's services, and Dr. Philip Watkins here lent me his support and political influence. I remember telling them my projections for the center, how I was going to release a book about MVP and how they needed to be prepared. I told them Dr. Watkins (medical director of the center) and I would probably be doing national TV appearances within the year and that people would be calling in droves. When I suggested they get an 800 number and staff the phones with at least 10 people, everyone found it hard to believe."

In the beginning, Frederickson saw each MVP patient personally. "I spent a good hour and a half with each patient, and it was hard for each one to assimilate that much information at one time. They constantly called me back with other questions or clarifications about what I'd told them. Finally I decided to write down everything I knew and just hand them a booklet. I planned just to photocopy it for patient information."

Instead, the booklet evolved into a full-length book for the lay person, describing in clear, illustrated terms the physiology behind MVP and listing concrete suggestions for diet, exercise, and medical treatment to eliminate or ameliorate symptoms. Frederickson called the book *Confronting Mitral Valve Prolapse* and submitted the manuscript to 48 publishers. Forty-six rejected it summarily. "One wrote back and offered to print it if I'd send \$495," she laughs. "The 48th publisher was Slawson Communications, a medical publishing house. The editor was getting ready to send me a rejection letter when his wife happened to see the manuscript lying on his desk. She had just been diagnosed with MVP, and could find no literature about it on the market. She devoured what I'd written and then informed her editor husband that he would publish the book. It was pure luck."

In medical publishing, where sales of 2,000 copies constitute a best-seller, Frederickson's book was an overwhelming success. "We sold the first 15,000 copies within the first 10 days and went into a second printing immediately. In the first six months, we sold 70,000 copies nationwide." The book is in its third printing.

When Frederickson began making public appearances on radio and television talk shows to support the book, Montclair's phones rang off the hook. "The hospital was putting in 800 lines and beefing up the staff to handle queries from all over the country," Frederickson says. "I began to write a

quarterly newsletter, (45,000 circulation) produced and funded by Montclair, to send to our callers. We always encouraged them to find a local physician because proximity is important in this kind of treatment, especially when medication is involved. At one time we had at least a three-month waiting list at the Center."

Frederickson no longer sees every patient at the Center. Her schedule is too hectic, what with publicity and administrative demands. She and Dr. Watkins appeared on Cable News Network's *Sonya Live* talk show in Atlanta earlier this year. As a result of the show, CNN fielded some 10,000 phone calls and the Center received hundreds of written inquiries.

More public appearances are planned in Houston, Chicago, New York, Los Angeles, San Francisco, and Seattle. Frederickson is currently working on a set of three MVP

Before she was treated for MVP, Delanne Vincent thought her life was falling apart.



videotapes dealing with general information, a Jane Fonda-type workout session which will be filmed at the Botanical Gardens, and a special tape devoted to management of panic attacks. As another weapon against panic attacks, she's producing audiotapes which employ imagery, relaxation techniques, and biofeedback to speed recovery.

In the face of such notoriety, Frederickson has polished her natural poise to a relaxed and professional confidence. "I love speaking to groups because they're so hungry for information. Many members of the audience—or their friends or relatives—have been doctor-hopping for years. They send me cards and letters about their improvements, thanking me for what I've done. It's a tremendous boost."

Not all of Frederickson's audiences are so supportive, however. Many physicians believe the symptoms ascribed to MVP are psychological in nature and that the condition has been blown out of proportion. For Frederickson, the critics can be hard to bear. "My personality is such that it

hurts a lot. Basically, I'm a flower child and I want everyone to like me." To help her field questions from sometimes hostile critics, Frederickson endured a grueling two-day media training session in New York where instructors taught her to counter verbal attacks that could damage her credibility. "One of the trainers was incredibly harsh. When he got through with me, I could honestly say that if I could live through that experience, I could handle anything."

Some critics ascribe supposed MVP symptoms to other conditions. "I suspect there's some crossover with other diseases.... But the problem reminds me of the classic analogy of the elephant and the blind man. How the elephant feels to you depends on where you're standing. How you define these symptoms depends on your point of view. In years to come, I hope we'll all be able to stand back and look at the whole elephant. Right now we're just

scratching the surface of what's out there to know. If I revised my book right now, I could make it twice as long. All kinds of new information—like the relationship between panic attacks and REM sleep—is emerging every day."

Although she continues to direct operations at the Center, Frederickson is frequently on the road. "In the coming years, I hope to help other interested hospitals establish Mitral Valve Prolapse centers. Here at Montclair, we have no desire to be the Mayo Clinic of Mitral Valve Prolapse. Geographic proximity to a doctor is important for MVP patients."

Ironically, Frederickson, who remarried three years ago and has a one-year-old daughter, does not suffer from MVP or dysautonomia, but years of experience with chronically ill patients has given her an empathy few can match. And how have her contributions to MVP affected her life? "It's one of the accomplishments I'm most proud of," she says, "but you have to admit I was incredibly lucky. After all, how many people in this world get the chance to write the very first book of its kind?" **B**