

THE MIAMI HERALD

APRIL 21, 1991

TROPIC

THE INHERITANCE

Bill and Priscilla Carlebach gave their seven beautiful children everything: love, wealth, status. And something else. Something fatal.

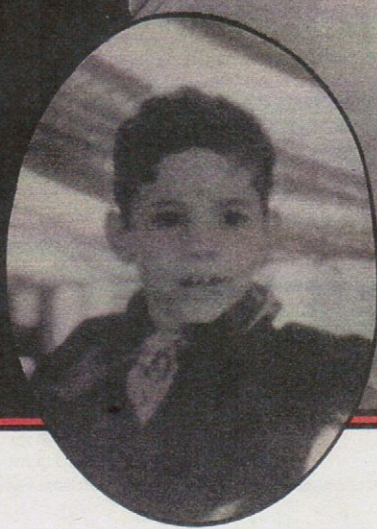
The last portrait ever made of the late Elisabeth Carlebach, with her baby daughter.

THESE PHOTOGRAPH'S COURTESY OF THE CARLEBACH FAMILY

PHOTOGRAPHY
BY MICHAEL
CARLEBACH



The Carlebach family from top: Steve, Priscilla, Lis, Michael, Katie, Bill and Matt. Doug (left, inset) and Melissa died before the family portrait was made.



A SURVIVOR'S STORY

After watching an inherited disease brutally squeeze the life from four of his brothers and sisters, Miami Photographer Michael Carlebach was left numb with horror. For years, he fled from his ghosts. Now talk of a cure has given him new strength, and he is facing his family's tragedy the best way he knows how. With a camera.

Michael Carlebach opens a file cabinet in his office at the University of Miami and fingers through the manila folders filled with the thousands of negatives that are his life's work. He gets to the heading "personal, 1970-1980." The 10 worst years of his life. He starts pulling out negatives, slowly, deliberately. He has dreaded going back to this. But it is his decision — something he has to do.

No one else is in the building. It is quiet as a crypt. He goes into the darkroom and switches the radio to classical music. His sister Lis will be first, with her baby. Lis was the third to die. Michael watches the white paper in the pan. Lis is appearing under water. Her hair comes in first. Her hair was so beautiful that day. Everything about her was. The print says what Michael wants it to: that his sister was resolute, bold, and yet so vulnerable. That she had this child that looks so much like her. This beautiful, *healthy* child.

Instead of working faster, Michael works more slowly. Matt will be next. Matt, his little brother, was the fifth to die. They were in Matt's house in The Grove when Michael took the picture. Michael got as close as he could to his brother's face. His concerns had been to catch the light stubble on Matt's chin and even the eyelashes under his eye. He studies his brother under the liquid in the developing pan. He is so delicate. So full of life, and yet so delicate. He moves the print to the drying rack.

Katie is next. She will be the hardest. Michael's breathing is wheezy in the silence, that double breath that connects him to the family illness. Katie looks sick. In her, he sees most clearly the transition from health to sickness, the change he saw take place in all three of them.

There is a certain looseness about Katie, but her fingers are clenched in tension. She throws her head back in defiance, but her eyes are dark and clouded. Like Lis and Matt, she is on the verge of adulthood. She is on the verge of death.

Michael leaves the photos on the drying rack, and returns the next day, Sunday, to look at them again. Again, he is alone in the building as he spreads the photos out on his desk. The light streams in through the high window. He holds the pictures up to it again and again. He has not looked at these photos since they were taken, since Lis and Matt and Katie were alive. When he can't look at them anymore, he stares at the floor. There is no getting around it. This is the closest he can get to them. He stares at the floor for the longest time. When he gets up, the light has drained from the room.

The Carlebach family has decided to talk. It was Michael's idea. Which is a surprise to everyone. Michael, says Steve, his one remaining brother, is not known for letting it all hang out. In fact, no one in the family is. Priscilla, their mother, says she can't see what good it will do. Their tragedy is no one's business. Bill, their father, says he's not exactly comfortable talking about it, either. But both parents have agreed to give it a try, after all these years, because Michael has asked them to help him deal with it. It's about time, Steve says. Talking will help all of us.

And it's about time, too, because the doctors and scientists who let the Carlebachs down again and again have finally cornered the killer. It won't be long before the horror Michael's family lived will be as archaic as small pox.

"There's not the sense of doom now," Michael says. "We can look it in the face."

The Perfect Family

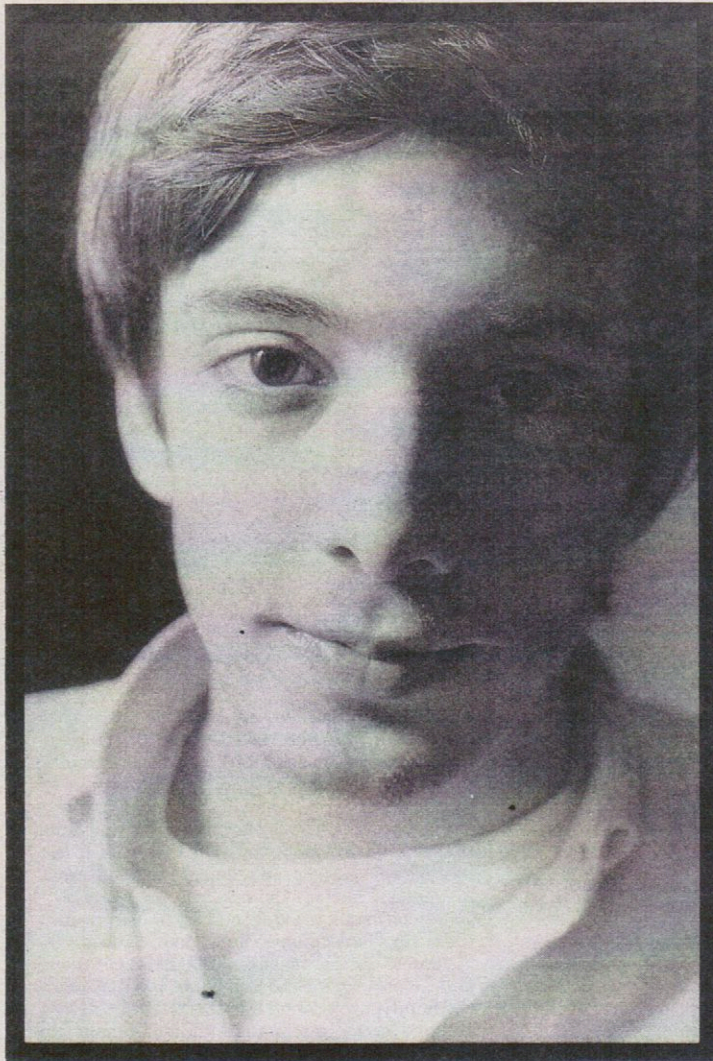
Between 1945 and 1958, Bill and Priscilla Carlebach had seven children, three girls and four boys. Most of that time, they lived in a huge stone farmhouse in Westchester County, New York. The address was Hard Scrabble Road, but their life was anything but. The kids went to the best New England prep schools. They wintered in Naples, Fla. Spent summers at the home in Cape Cod. Took the Queen Mary to Europe in the spring. The children had a nanny and a governess. Adlai Stevenson was their godfather, and Louis Auchincloss, the famous writer, was the family lawyer. And like their friends the Kennedys, the Harrimans and the Lehmans, the Carlebach parents were dedicated to a life of service in the New England liberal tradition.

As the director of trade missions for the U.S. Department of Commerce, Bill's main concern was the Third World. He arranged trade agreements all over Africa, Central America and the Caribbean, always with an eye toward improving the lot of the poor. He and Priscilla were active in church projects, rebuilding a cathedral in Harlem and feeding the homeless. Bill constantly ran for local political office, and he and Priscilla worked for Democratic Party candidates.

The Carlebachs of New York. Two parents and seven kids. Nine privileged, intelligent, compassionate human beings. A great American family. This is the story of their struggle, their decimation and their search for grace.

When Bill Carlebach got out of his maroon Chrysler convertible in his Army uniform, Priscilla Wardwell thought her heart would stop. It was 1942. She was 17. He was 24. And so suave. So all-knowing. So impressive. They drove from

B Y M E G L A U G H L I N



Matt Carlebach, Michael's little brother, was the fifth to die. By that time, what was left of the Carlebach family could no longer stand to gather for a memorial. "It reminded us too much of who was missing," Michael says.

A SURVIVOR'S STORY

her house in Chappaqua, N.Y., to the Glen Island Casino on Long Island Sound. He loved her blue eyes and her auburn hair blowing in the wind, her petiteness, and the way her dimples dented in and out. She ordered a Singapore Sling to impress him, and it did. He was utterly amused by her. She, on the other hand, loved his calmness and his wry cynicism. She kept noticing his hands and his build. He was so manly. In a year, they were married.

They had three nights in L.A. before he was shipped overseas. They would have lots of children, they decided. They would have the family that neither of them had

had as kids. Bill, an only child and adopted, wanted a lot of kids, his own kids. Priscilla, the youngest of five daughters of a divorced woman, wanted a family with a father who lived at home and supported them. A typical American family.

"It never occurred to us," says Priscilla, "that we wouldn't have what we wanted. We were so naive, so ridiculously naive."

When Bill got back in '44, they went to Havana for a two-week honeymoon. Nine months later, Doug was born. A year after Doug came Michael. Then Elisabeth, a year after that. In 1947, when the kids were 1, 2 and 3 years old, Bill and Priscilla sent one of Bill's black and white photos for a Christmas card. In the photo are three adorable dewy-eyed toddlers. Doug and Lis have their mother's curly hair. Doug and Michael are sloe-eyed like their father. Lis has her mother's dimples. But there is something else the children got

from their parents that is not visible in the picture. Something hidden deep in their genes that would remain a secret for another 10 years.

Bill: "If I had it to do all over, I would. We got great delight from our children."

Priscilla: "If I had known, I would never have had them."

Seven Little Indians

The Hard Scrabble Road house where the children would spend the early years of their childhood was a 19th Century Dutch farmhouse in Chappaqua. It was a place with a sense of the past and a place where the family could grow into the future. These were the days of Eisenhower and Stevenson, of Roy Rogers and John Cameron Swayze, of postwar prosperity and deceptive simplicity. The children rode the bus to the private school, played war games and cowboys and Indians in the woods, had dinner with their parents, then did their homework around the dining-room table and watched TV before bed. It was the ideal 1950s family life.

But when Priscilla was pregnant with Katie, their fourth child, Doug, 7 years old, started getting sick a lot. The two other children — Michael, 6, and Lis, 5, — had lots of sniffles, but Doug's lasted longer and recurred more frequently. No matter what they did, colds turned into bronchitis and bronchitis became pneumonia. In 1953, by the time Katie was toddling around and Matthew had been born, Doug was chronically ill.

Priscilla took him all over New York and New England to specialists. Each recommended something different. She tried it all: Oxygen tents. Steam. Sleeping with his head down. Sleeping with his head up. With the window open. With the window closed. Staying still. Getting more exercise. Coughing more. Coughing less. Priscilla was dizzy with instructions, none of which seemed to be making Doug well.

Doug's oxygen canisters became a regular part of the household. Michael would lie in the twin bed across from him at night and listen to the hiss of the machinery superimposed on his older brother's breath. Sometimes, Doug felt so lousy he didn't even want to watch Gene Autry on TV, much less go to a Jerry Lewis movie with his little brother.

Doug's fingers changed. They fanned out and became rounded. And, like his lips, slightly blue. He got dark circles under his eyes. A lung specialist recommended a year on a health ranch in Flagstaff, Ariz. But it did no good. Neither did trips to Florida for the warm sea air. Doug just kept getting worse. By the time he was 11, one lung was so scarred and dysfunctional that it had to be cut out.

Michael was being crowded from the bedroom he shared with Doug by ventilators, oxygen tents, pill bottles, doctors and nurses. He remembers packing for camp, feeling Doug's resentment as he watched from his oxygen tent. When Doug started lapsing in and out of consciousness and it was obvious the end was near, Michael went to a friend's house to stay. He remembers when the phone call came: I'm so sorry Priscilla, his friend's mother said. Then the woman turned and looked at him.

"The news always came that way," says Michael. "To this day, I cringe when

the phone rings."

Michael came home to a small blue coffin in his and Doug's bedroom. He made great circles around it, his mother says, and showed no emotion. What Michael remembers is that the signs in each room — No Smoking/Oxygen in Use — were still there. Somehow, that quelled his panic. It was as if Doug were still breathing.

After the funeral, Michael left for camp. He was glad that the camp was so full of life and activity — all the canoeing and archery and hiking. But when it came time to lie on his cot in the tent, he couldn't sleep. He'd lie there and think about his brother.

That same year, the lung specialists recommended tests for everyone in the family. (By this time, all seven kids had been born.) They would have to take sweat tests: lie in bed under rubber sheets with the heat turned way up until they were dripping wet. Then, rush sweat-blotted towels to the lab. The tests were for something called "cystic fibrosis," a mysterious genetic disease that the doctors suspected had killed Doug. Priscilla and Bill were told that it sometimes ran in families.

Cystic fibrosis had first been diagnosed in the '30s. But diagnosing it was tricky. Its symptoms always looked like something else. The test, which was not a direct test for the disease but an attempt to track it indirectly through one of its symptoms — high salt content in the sweat — was notoriously inconclusive. In the Carlebachs' case, the tests were repeated ad nauseam: The children kept coming up positive one time and negative the next. Except for baby Melissa, who got all negatives. And Michael, who got all positives.

Bill and Priscilla went through all this numbly. It seemed somehow beside the point: The medical testing and advice hadn't saved Doug. They had lost faith in doctors. As Priscilla puts it: "It taught me never to trust authority again."

Because it was all so uncertain, they decided not to tell the children who had the disease and who didn't. And besides, for the time being, everyone was healthy.

The Healthy One

Michael was 12; Lis, 11; Katie, 6; Matt 4; Steve, 1, and Melissa was an infant when the family moved upstate to Old Chatham, in 1957. For Michael, it was a tremendous relief. He was no longer known at school as the brother of the boy who died. No one at the new school had seen him burst into tears in class. What a glorious year it was. There was nothing about death anywhere.

The Old Chatham house, set in rolling hills, was big and sprawling. It had a kidney-shaped swimming pool surrounded by a flagstone patio. They were a happy family again. A normal family. Or at least as happy and normal as a family that has lost a child can be.

Besides Bill's work with the Department of Commerce, the family owned a hardware store where Michael could lose himself among the screws and bolts and tools, just like he could lose himself at night, reading books that were not assigned for school, books about bacteria and microbes and Pasteur and Leeuwenhoek, all the villains and heroes

of science. He had decided to become a doctor. He had decided to find a cure for the thing that had killed his brother.

Michael was working at the hardware store when the phone rang again. Melissa, the one child who had always tested negative, the only one who seemed completely safe, was dead. The gate to the swimming pool had not locked shut. She had toddled in. Bill spotted her on the bottom of the pool. He dove in after her. It was too late. She had drowned.

Priscilla Carlebach, 67, and Bill, 74, are less than halfway through their story.

Bill: "If I had it to do it all over, I would."

Priscilla: "If I had known, I would never have had them."

It is late February of this year, and the Carlebachs are visiting their 46-year-old son, Michael, in Miami. They are sitting on the front porch of his house in Coconut Grove, where he lives with his wife, Margot. It is the second day of talking to a reporter, and, though Michael has asked them to be candid, Priscilla has made a decision. She has no more to say on the subject.

"Losing your children is the ultimate failure," she says. "People air their sadness, and for what? It is no one's business. I simply don't believe in it."

There is a disarming openness to Priscilla. But when it comes to the deaths of her children, she shuts down. No one has a right to their lives, to their intimate suffering, to what she lost. If she keeps talking, she will have to tell about Katie next. Then Lis. Then Matthew. It is more than she can bear.

Priscilla continues to embroider a pillow for a church sale. There are berries on it and birds and vines, a whole world to get into. She holds it out from her lap and admires it. She turns the conversation to other things. But as she talks, big red welts form on her face and neck.

Priscilla gets hives when the kids' deaths comes up. Her niece, Vee Wardwell, recently observed in a letter to her cousin Michael: "The expression 'swollen with grief' comes to mind."

For eight years after Melissa died, everything was fine. At least, the Carlebachs managed to persuade themselves it was. There were colds, and flu, and bronchitis, but who could say things were worse than normal for a house filled with children? And no matter

how sick the children got, they always got better.

Then Katie stopped getting better. Katie. Laughing Katie. Incandescent Katie. The colds never let up. There was a constant wheezing, a chronic shortness of breath. Just like Doug. In the decade since her older brother had died, new antibiotics had been developed, new physical therapies. The family spent hours every day pounding on Katie's chest and back to jar loose the mucus in her lungs, sending her into coughing fits to clear them.

But despite everything, Katie got sicker. Her body stopped absorbing food, so thick was the mucus in her digestive system. She got excruciating headaches from the lack of oxygen to the brain. Her lungs hemorrhaged.

In 1970, at the age of 20, she drowned in her own phlegm in a big four-poster bed at the top of the stairs.

The Killer

They call it cystic fibrosis because of the way the lungs look in an X-ray. Near the end, there are big fibrous welts of scar tissue and bubbling holes that look like cysts. The name comes from the result, not the cause. People with cystic fibrosis are born with the inability to regulate the water in their own cells. Too much is drawn into the center of the cell, and too little is left in the membranes, leaving unusually thick mucus in the respiratory and digestive systems. The lungs never clear. They become a hotbed of infection, nurturing the bacteria that cause recurring pneumonia that eventually makes breathing impossible.

When Bill and Priscilla Carlebach planned a big family, they had never heard of cystic fibrosis. They were healthy, unaware of the deadly genes they both carried.

Since 1989, genetic testing has been able to identify CF through a tiny chip in the DNA on the long arm of chromosome seven. A person with the disease will have two defective genes — one from each parent. A carrier will only have one. If two carriers have a child, there's a one in four chance that the child will inherit the disease, and a one in two chance he will be a carrier. An estimated 30,000 Americans have CF, and many times that number are carriers.

But most people have no reason to be tested because they don't know it's in their family. For generations, deaths from cystic fibrosis were chalked up to pneumonia or tuberculosis or some other lung disease.

"Sometimes," says Michael, "I go through old cemeteries and look at family plots. There are so many children who died in their teens. It was obvious something went on."

After Katie died in 1970, Lis and Matt started having more and more lung problems. That's when Bill Carlebach went in search of his real parents. Back then, the genetic intricacies of the disease were still unknown. All Bill knew was that it had to have come from someone, and because he had been adopted, and his heritage was a mystery, he was sure it was he who, as he puts it, "was to blame."

It took him a year to track down his biological mother. He found what he had feared: Bill's grandmother had died of wasting lung disease — a dead ringer for cystic fibrosis.

Despite all his success, Bill had spent his life feeling that his adoption was a secret stain. Now, he thought, here was the proof that he had been right all along, and that his imperfection had brought this plague to his family.

Although scientists have known for decades that it took a gene from both parents to get cystic fibrosis, somehow, neither Bill nor Priscilla was aware of that. Instead, they dealt with their loss by seeking or avoiding blame for blameless deaths. Bill took it on himself alone. Priscilla was only shocked into accepting that she, too, was a carrier in 1982, when her sister's 7-year-old grandson, Elisha, was diagnosed with CF.

At the time Katie died, Michael, then 25, was living in Miami with his wife, Diane, and their 3-year-old-son, Adam. They had talked about having a second child, but decided to be tested for cystic fibrosis first. They had to wrap themselves in rubber sheets and sit in their car in the hospital parking lot with the windows rolled up until they got dizzy and nauseated from the heat. The child cried hysterically. They got so weak and dehydrated, they could barely make it back to the doctor's office.

But the tests were inconclusive. The first set of results said that Diane had the disease and Michael didn't. The second said Michael had it and Diane didn't. They decided to have another baby anyway.

As it turned out, they were lucky. Neither of their children has the disease,

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Dody Tokarsky, shown here with her mother, has just spent 50 days in the hospital battling CF. After a month to detoxify, she will go back in for more IV antibiotics. (Page 16)

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though they could possibly be carriers.

Paper Ghosts

Michael Carlebach, well-known photojournalist, Ph.D., and director of the photography and journalism programs at the University of Miami, sits in his dining room with his arms wrapped around the back of his chair as if he does not trust himself to stay put. In front of him, on a sturdy wooden dining table in his airy old Florida house, are the three photographs he has just printed at his office: A dark-haired young woman in a Mexican skirt, leaning back with a knee up. Another dark-haired young woman holding a baby who, like her, stares wide-eyed at the camera. A young man with light hair and fuzz on his chin who looks to be on the edge of puberty.

Katie. Lis. Matt.

Michael came to Miami in 1967 when he married Diane Golding. Lis followed him a few years later, about the time Katie died. Then Matthew moved to Miami in 1972 to live near Michael and Lis. Matt went to the music school at UM and played keyboards for a local band. He was 20, already chronically ill, and — unlike anyone else in his family — talked openly about the disease, and his impending death. He had been reading about genetic research, and he predicted that a cure would be found. Just as confidently, he predicted it would be too late for him.

Lis was living with her baby in the Coconut Grove house where Michael now lives. She, too, had been sinking into chronic illness. It had started before her pregnancy, and the doctors had told her not to have the baby: Childbirth would complicate her breathing problems and shorten her life. But, in true Lis fashion, she told them to butt out. If Lis was anything, her mother says proudly, she was headstrong and independent.

Her daughter, Cilla, was 2½ when Lis died.

At Lis' memorial service, Pat Agnew, a member of the extended family, remembers that Priscilla stared at Matthew the whole time.

"She knew," says Pat, "that he would be next."

At the end, Lis, bitterly angry that this unstoppable force was taking the life from her body, stealing her from her baby, pushed her family away. She didn't want them at the hospital to see her die. But this was not the case with Matt. Instead of withdrawing as Lis had done, he hung on and on, game for anything that would give him a few more days. He agreed to the respirator, the tube feedings, the tangle of plastic that took the place of body functions. And when he was too sick to talk he spelled out words with his hands to communicate with the people he loved.

But Michael could not be there for him. He had had enough of cystic fibrosis. He had been relieved when Lis had barred

family from her sick room. With Matt he had no excuses. So he invented them: photography jobs that took him out of town.

Thinking back, Michael suspects it is no coincidence that most of his work during that time was for medical magazines. He took a lot of pictures of people being helped or cured by the latest technology. Matt wasn't going to be cured. Michael spent less and less time with him.

"I could always play the fool, crack jokes, try to cheer him up," Michael says. "But when things got too bad for that, I just couldn't be there. I couldn't nurse him."

When Matt died, Michael got the phone call in the middle of the night.

He called his parents early the next morning to tell them they had lost another child. This time, the survivors in the Carlebach family did not assemble.

"Matthew's death completely did us in," says Michael. "We couldn't bear family gatherings. It reminded us too much of who was missing."

A Separate Peace

"It's such a shame," Michael says. "They were all such good people, and they drowned. They all drowned."

The Carlebach family — two parents and seven children — was reduced, by 1977, to two parents and two children, four people, numb with grief, each searching for a separate peace.

Priscilla's quest has been mainly spiritual. From Unitarianism to the Episcopal Church, via 12-step programs and psychotherapy. At 64, she got a B.A. in religion from Manhattanville College and now, at 67, is completing an M.A. in humanities. In the family, she is known as "the explorer."

The church has offered her a community of love where death can be talked about. It is also a place, she says, for getting outside herself and helping others.

"You never recover," she says, "but you do learn to forgive yourself."

Bill's way of forgiving himself — for not being able to save his children, for passing on the disease in the first place — has been through community service: church administrative work, work for historical preservation, and, mainly, political work, like running for the New York State Assembly.

He has just returned from Budapest, where he set up a program for students in Eastern Europe to learn the latest in U.S. computer technology.

In recent years he has taken up painting — colorful family scenes, primitive Norman Rockwells. One is a scene in a dining room. The table is set and a Christmas tree is in one corner. All his children are there. Doug and Steve are sitting at the table. Lis is standing near them, swinging a Hula Hoop around her waist. Melissa is on the floor playing with an electric train. In another, they are all around the swimming pool. Michael is holding a fishing rod and Matt is on a tractor. Katie is on the swing. Priscilla is pregnant with Melissa.

Steve, 36, Michael's only surviving sibling, found sanctuary in theater, getting an M.F.A. in directing from Boston University and then becoming head of the drama department at Connecticut College. From Aristotle's

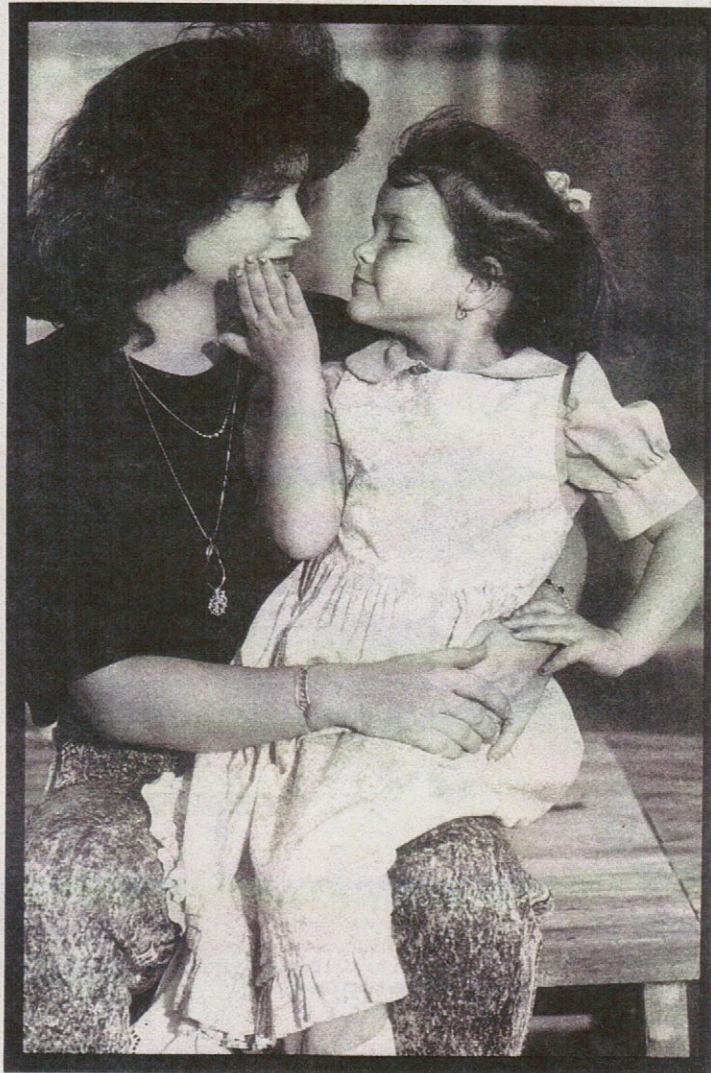
time, drama has been a way to turn tragedy into catharsis, and that is not lost on Steve. Things he can not bring himself to say directly he can express in the language of the theater:

"Our *Long Day's Journey into Night* has left us all emotionally repressed. . . . Just like in the beginning of *Rosencratz and Guildenstern Are Dead*, my parents kept flipping a coin and coming up tales. . . . It's like Christopher Durang's play, *The Marriage of Bette and Boo* — Bette keeps having babies and they keep dying. . . . You learn not to talk about it, to talk in a coded language like the characters in *The Dining Room* by Gurney."

Being There

Dr. Moises Simper, the head of pulmonary medicine at Miami Children's Hospital, became friends with Michael Carlebach four years ago, when Michael volunteered to work at the Miami camp

"The news
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Five-year-old Megan Shade with her mother, Trina. "I couldn't go on without her," Trina says.

camp for kids with breathing problems.

All kinds of breathing problems, that is, except cystic fibrosis. There is a summer camp in the Keys for kids with cystic fibrosis, but Michael never goes there.

Instead he spent his vacation at the Miami camp on Bird Road snapping away, offering photos to the kids and their parents. Simpson admired Michael's ability to catch emotional essence in his photographs. But he had no idea why Michael came to the camp every year.

"He lost five brothers and sisters?" asks Simpson incredulously. "He has never mentioned anything about cystic fibrosis in his own family."

"I spent the last 25 years in denial," Michael says. Just as he dealt with Matt's last days by getting assignments out of town, he dealt with all the death in his family by throwing himself into his work and studies, traveling as a photojournalist in the late '70s, going to Florida State for an M.A., then Brown for a Ph.D in American studies in the early '80s.

While at Brown, he took a course called "Death and Dying" and studied lung disease in 19th Century America. One of his recurring photographic subjects is cemeteries.

There was a heavy price for not being able to face his tragedy directly. "I think all the kids resented it very much that I was not there when they were really sick, and I will always regret that."

The emotional distancing was hard to turn off. While he was fleeing from loss, he ended up fleeing from his family, too. "I avoided the deaths of my brothers and sisters, and I also missed an important time with my own wife and kids. In the 1970s — even when I was in town — I wasn't there."

Through A Lens Darkly

In January of this year Michael Carlebach approached Tropic and suggested a story on cystic fibrosis. It was an odd request for someone whose work is usually characterized by irony and humor.

He did not mention his own family.

In February he was back, suggesting the story from another angle: "You can write about my family. But it can't be a sad, voyeuristic story. It's to show people, who have it in their families, the profound changes that are taking place."

And, one more thing, said Carlebach. He'd supply the photos. We could use the ones he'd taken, of his own family, the ones his dad had taken, and some more portraits of South Floridians who suffer from the disease. He'd go out and get those. He did not say that taking photos would be another way, besides talking, of facing what he'd run from for 15 years.

A couple of weeks ago, when he walked into the Clewiston home of 5-year-old Megan Shade to take photographs for this story, Michael came in contact with cystic fibrosis for the first time since Matt's death in 1977. But even when he heard the child wheezing and saw the ventilator in the corner, in his usual phlegmatic way, he showed no reaction.

"When I'm taking pictures," he later said, "I enter another world. The camera protects me from feeling emotion."

He took pictures of Megan in her bedroom on her water bed, and down by the lake behind her house. He took pictures of her in her Little Mermaid costume and nodded when she talked about wanting to be the "Little Mermaid," the child who can breathe under water. He took pictures of her playing with her mother and nodded noncommittally when her mother whispered, "I couldn't go on without her."

But when he put his camera away, the job behind him, his apparent ease vanished. He didn't stay to chat, as he usually would after working. Instead he silently packed his equipment and headed to the car. With the door closed behind him, he let out a deep, trembling sigh that was part groan, an

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in
The Sunday Magazine of
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Every spring, Michael Carlebach volunteers at a Miami camp for kids with breathing problems. He takes pictures of kids with all kinds of respiratory ailments. Except cystic fibrosis.

A SURVIVOR'S STORY

expression of sorrow 35 years in the making.

The next day, when Michael got to Scott Chait's house, he arrived in time for Scott's afternoon clapping treatment. The monotonous hitting on the back and chest to jar the mucus loose is a sound he knows all too well. It was not something he wanted to see or photograph. Instead, he sat in the living room and waited, seemingly as calm and easygoing as ever, except for a foot shaking back and forth, at 90 miles a minute.

At 17, Scott Chait is beginning to show signs of the disease. He is getting taller and taller but not gaining weight. Still, except for the maddening routine of taking 50 pills and having two clapping treatments a day, Scott leads a fairly normal life. But as time goes on, he is getting more and more wary. He knows

about the medical breakthroughs; his parents keep the clippings taped to the kitchen cabinets. He also knows that he keeps losing his friends with cystic fibrosis and that the clock keeps ticking.

When the coughing fits subside, Michael takes Scott's picture in front of the posters of beefy men in Dolphins' uniforms — Scott's heroes.

Dody Tokarsky's house is a few miles away. It is her second day home from the hospital, after a close call with hemorrhaging lungs. She has already had part of one lung removed, and her doctor is talking about a double lung transplant — usually a last-ditch effort. After 50 days in the hospital, she's taking a month break with her mother and her dog, Spot, before returning to a regimen of IV antibiotics. At 32, Dody now spends more time in the hospital than out. Like many adults with chronic illness, she's having trouble with insurance.

"They refuse to pay for the clapping therapy here at the house," she says. "And if I don't get that, I'm sunk."

In Dody, Michael comes closest to seeing his sisters Katie and Lis. Like them, Dody is petite, with big brown eyes. Like Katie, she is very close to her mother

and, like Lis, she is fed up. She has K vulnerability and Lis' rage.

But it is not only sadness he feels meeting Dody or Scott or Megan. To people, these *alive* people, are his chance to right a wrong. They are his hope. They are his opportunity to honor the brother and sisters he lost and couldn't face. They are people with cystic fibrosis who do not have to die.

Jesus On A Donkey

In September 1989, scientists found the gene that causes CF. Researchers from Toronto Hospital for Sick Child and the University of Michigan had been wading through the DNA of CF patients and their parents for four years, ever since they had discovered that what caused the disease was located on the seventh chromosome (humans have 23). They had expected their search to go on for decades: Each chromosome carries about 100,000 genes, and each gene is made up of tens of thousands of unimaginably tiny "bases" — each of which must be examined individually and compared to the same genes from cells of people who do not have the disease.

Bob Dresing, president of the National Foundation for Cystic Fibrosis, says that researchers told him it would take at least 100 years to find the gene. They'd never find it in the lifetime of his son, who has cystic fibrosis.

But something incredible happened. On the fourth gene, at the 6,500th base, gene researchers spotted a gap. Three bases were missing. This was it. This was the chip that causes cystic fibrosis. The incomprehensibly tiny flaw was it. Right there, so soon.

Nat Tripp, Michael's cousin and the father of Elisha, who has cystic fibrosis, remembers standing in the kitchen of Vermont home with his 14-year-old son when the news was broadcast. It had been a difficult summer: Elisha never wanted to take his pills or have the clapping treatments, Nat hovering over the boy constantly nagging. The demands of a chronic illness had made them both testy and impatient. Besides, they both knew that no matter what they did, there was really no hope.

They were fixing dinner on this night and the radio was tuned to National Public Radio. The commentator said there had been a major breakthrough with cystic fibrosis. Both father and son stopped what they were doing and turned and stared at the radio. When the explanation was completed, they simply looked at each other.

Nat spoke first: "Well," he said, "There it is."

Eli said nothing, and both father and son returned to their chores.

"But later that night," says Nat, "each went to separate corners of the house and cried."

The news traveled quickly through the Carlebach family. Here was something to rally around. Something that meant life instead of death. They telephoned each other and sent articles through the family letter chain letters. There was hope for Eli. There was hope for all children with the disease.

The cure will come in the form of something you sniff. It will ride into the lungs on a vaporized fat globule like Jesus on a donkey and spread the word: Cell heal. The genetic signal that will conv

Drugs to control

the symptoms

should be

available in two

years. The catch:

People have to

stay alive that

long.

unhealthy genes into healthy ones will invade the lung cells and, instead of damaging them, repair them. They will begin to process water normally, the mucus will thin, the wheezing will stop.

But first, the kinks must be worked out, the medicine must be tested and adjusted. Moises Simpson, chief of Pulmonary Medicine, Miami Children's Hospital: "This cure will be available in the next 10 years."

Richard Hubbard, chief of Pulmonary Medicine, The National Institute of Health: "I don't think it's being overly optimistic to say it will be ready for distribution in the next five years."

In the meantime, there is more good news: New drugs to effectively control the symptoms should be available to patients in the next two years. Again, testing. But doctors believe that unlike antibiotics — which merely fight the infections engendered by the basic cause of CF — the new drugs will strike directly at the cause itself. They will thin the mucus, restore the water flow. The net effect will be virtually as good as a cure.

The only catch: People have to stay alive long enough to take the new drugs.

It was after cystic fibrosis could be genetically detected that Luanne Carlebach told her husband, Steve, Michael's only surviving sibling, that she wanted to have a baby. They'd been married for three years. They were both in their mid-30s. It was time, she said. No way, Steve told her, thinking about Luanne's lung problems and his own cystic fibrosis gene, which could make him a carrier.

Steve, with Diane — Michael's first wife — had taken care of Matthew when Michael couldn't. He had watched his brother's steady decline up close, and he was not about to bring a child into the world who might be born with the same death sentence.

OK, said Luanne, they would go for genetic testing to make sure they were not both carriers of the cystic fibrosis gene. They ended up at Yale University School of Medicine. It turned out that their answer was not as easy as yes or no. Some people have the classic gene defect that makes them clearly carriers of the disease. Some people are clearly not carriers. But others fall somewhere in between, and face varying degrees of risk that they will pass CF on to their children. To sort it all out, the researchers took blood samples from everyone in both families to use as a baseline for comparison.

But before Steve and Luanne got the results, Luanne announced that she was pregnant.

A month later, the results came. Steve was a classic carrier and Luanne had a mutation on the gene that put her in the high-risk category. Steve "freaked out." He didn't want Luanne to go through with the pregnancy. But Luanne remained adamant. She was going to have the baby, no matter what.

Steve and Luanne's baby is now a year and a half old. She is named after her Aunt Katie. She has blue eyes like Priscilla, her grandmother, who calls her the miracle baby. She has been sweat-tested three times, and does not have cystic fibrosis. Along with the three other healthy Carlebach grandchildren, and the medical breakthroughs that will save Elisha, Katie has brought the Carlebach family to a place of hope.

Carlebach family gatherings are once again something to look forward to. Bill and Priscilla are planning a 50th wedding anniversary for next year. "It will be wonderful," Priscilla says. "We'll all be together."

"They're an amazing family," says Meg O'Brien, a longtime friend. "That they reach out to people, that they're compassionate, that they function so beautifully after what they've been through... it's remarkable."

The Inheritance

Lately, Priscilla keeps having this dream. She and Bill are in it with all the children and the grandchildren. Michael's two sons, Josh, 16, and Adam, 23, are there; so is baby Katie, and Lis' daughter, Priscilla, who is now 20. In the dream, she says, something is being

Continued on Page 20

CF FACTS

- Cystic fibrosis is the most common fatal genetic ailment in the United States.
- Number of people born in the U.S. with cystic fibrosis every year — 2,000.
- Number of Americans living with CF — 30,000.
- For information about cystic fibrosis contact the Cystic Fibrosis Foundation, 800 344-4823 or 301 951-4422; 6931 Arlington Road, Bethesda, MD 20814.
- Local office numbers: Miami — 947-4243; Fort Lauderdale — 739-5006; Boca Raton, Deerfield Beach and Delray Beach 426-3918; Palm Beach and West Palm Beach 407 655-9577.

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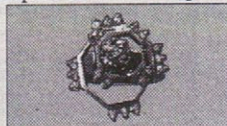
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A SURVIVOR'S STORY

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passed to the children and through them to the grandchildren, something intangible, something of great cosmic importance. Priscilla cannot say exactly what it is, but it is something that makes her wake up refreshed and hopeful.

Diane Carlebach, Michael's ex-wife, who has known the family for 25 years, thinks she knows what it is: "It is the inner strength that Bill and Priscilla have passed on. It is in all of the Carlebachs."

Michael is still uncertain whether he has CF. At 46, he has lived twice as long as most people afflicted with the disease. At least twice in his life, a series of tests has indicated he did. His lungs never seem quite clear. He is prone to bronchitis and

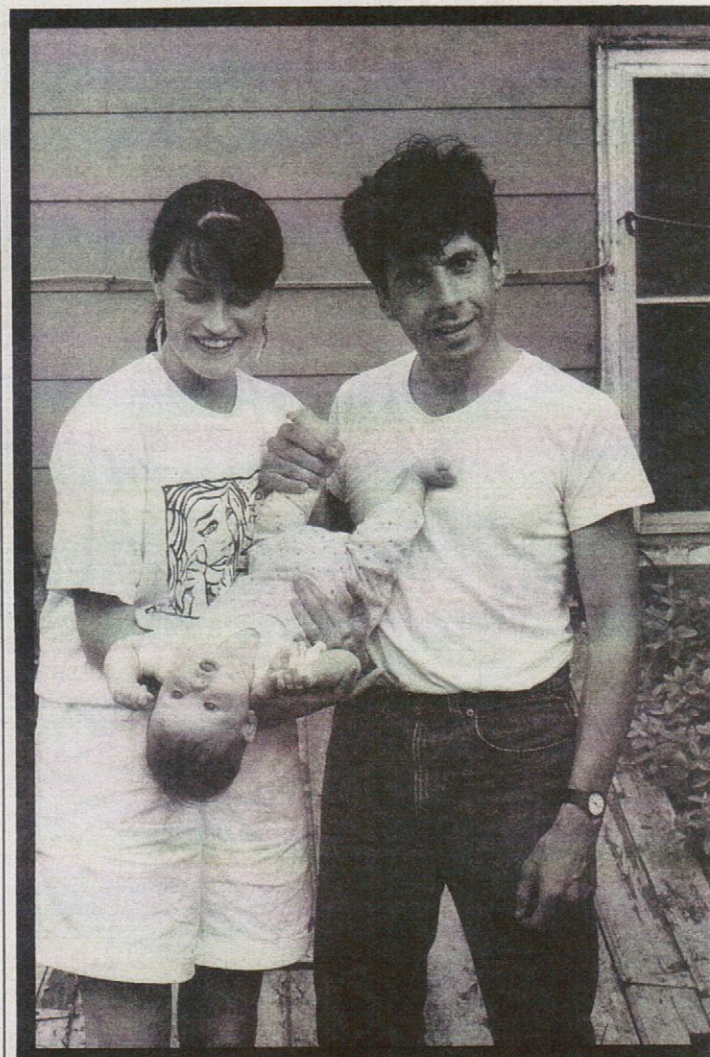
pneumonia, and has allergies and asthma. Recently, when his genes were analyzed to help his brother Steve decide whether to have children, Michael could have finally gotten a definitive answer. He elected not to.

"I don't think I have it," Michael says. "Maybe I'm just on the line of having it. At this point in life, it's better not to know. It doesn't do any good. I've got better things to worry about, like getting a raise and writing memos."

He's joking, of course. But he is busy — running the journalism department, teaching, finishing his forthcoming book on the history of American photojournalism, putting together writing conferences, presenting papers, keeping up with his sons, being with Margot, working at the Children's Hospital summer camp, and, as always, taking photographs.

"You know," Michael says. "Just do everything I can to keep my head above water."

MEG LAUGHLIN is a Tropic staff writer. Her most recent story was about a school for young criminals.



The family calls Katie, the daughter of Steve and Luanne Carlebach, their "miracle baby." Though her parents are carriers, Katie does not have cystic fibrosis.