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*A family's journey to
overcome disability.*

'We Were Relentless'

Inside: Camp Section



'We Were Relentless'

A family's journey to overcome disability.

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Senior Writer

All Jordan Levin's parents ever wanted for their profoundly deaf son was for him to experience life like anybody else. They knew they were headed in the right direction when they discovered that, at age 8, Jordan didn't even know he was hearing impaired.

"No one had ever told me I was different," Jordan said. "One day I watching a show on TV and the words 'closed captioning for the hearing-impaired' came across the bottom of the screen. I went to my parents and asked them, 'If I'm watching this show, does that mean I'm hearing impaired?'"

From the start, Mollene and Dr. Martin J. Levin of West Bloomfield were determined not to allow their son to be treated any differently from a hearing child — at home, in school or in other activities.

At 32, Jordan, who lives in Keego Harbor, holds a bachelor's degree in business administration from Michigan State University, is a certified personal fitness trainer at Fitness 19 in West Bloomfield, an avid hockey player and an inspirational speaker. "I talk about pursuing dreams," he said knowingly.

All of this is chronicled in the book *We Were Relentless: A Family's Journey to Overcome Disability* (2009, Xlibris, \$19.95), written by Martin Levin. A reception to launch the book will take place on Sunday, Feb. 15, at the Janice Charach Gallery inside the Jewish Community Center in West Bloomfield.

Jordan weighed a mere 31 ounces when he was born three months premature. His hands were the size of a man's fingernail, his limbs about the width of a pencil and his chest circumference not much larger than a banana. He spent his first four months in the hospital, almost half that time on a respirator. In the early days, he was given only a 10 percent chance of surviving. But, in spite of his premature birth, surgeries, infections and complications, he grew to 4.6 pounds and went home.

"He had been born four months earlier, but we were told developmentally it was as if he was just born," Mollene said. "He was zero."

Staff photo by Angie Baan



Jordan Levin and his parents, Mollene and Martin

A Devastating Diagnosis

"Jordan could have been blind or had brain damage or serious lung problems," Mollene said. "But he didn't, and he just moved along developmentally — but slowly." Jordan was always active, "a wild man who never, ever, ever sat still," said his mom. As a preschooler, he escaped his parents' watchful eye, once starting a gas-powered lawn mower and another time the family car. Before he could walk, he was able to climb out of his crib.

When he was about 2½, Jordan was diagnosed as being profoundly deaf, which the Levins believe was caused by a combination of his prematurity and medication.

He was fitted with hearing aids, which give him about 30 percent hearing. Before he had the aids, he could hear low frequency sounds, but not speech. His origi-

nal, cumbersome body aid — a pouch on his chest connected to each ear with speaker cord — has since been replaced with clear, barely noticeable aids that go inside and behind the ears.

"We were told Jordan would never speak; that he needed to learn sign language and that he would only be able to communicate with other people who knew it," Mollene said.

While researching possible alternative options, Mollene met families whose children spoke clearly and didn't use sign language. The Levins attended the Voice Conference in Toronto, sponsored by a group advocating teaching deaf children to speak. "There we met Dr. Ciwa Griffiths from the Hear Center in Pasadena, who pounded her fists on a table and told us, 'Don't let anyone tell you your profoundly deaf child can't do

something,'" Mollene said.

"We were told to treat Jordan like any other child who can do anything."

At the conference, they learned about the auditory training method developed by Dr. Griffiths to help hearing-impaired children gain speech through amplification and learning to listen. "Just because a child had a hearing aid on didn't mean he could hear a sound," his father, Marty, said. "Jordan needed to learn to use his hearing."

The Levins went to Dr. Griffiths' center, returning home in search of a tutor trained to teach auditory training. They found Karen Pawlick of Bloomfield Hills, who at first declined to work with Jordan because she had young children at home. Perseverant and resourceful, Mollene suggested she watch the children while Karen met with Jordan for an hour, three days a week. The arrangement continued for nearly half the 12 years Karen tutored Jordan.

At home, Mollene and Marty continued the lessons with Karen's guidance.

"We found there is so much more to teaching speech than we ever imagined," Mollene said. Hearing children learn to speak by listening and repeating. "We couldn't teach Jordan to hear, but we could teach him to listen," Mollene said. By concentrating only on what he needed to hear, Jordan was able to make out sounds and later words and sentences that were directed at him, and to speak them himself.

Now he is able to hear what is said to him even when speakers cover their mouths — to avoid lip reading — because he is listening.

The process was tedious, with Mollene leaving her teaching job to be with Jordan and Marty working a reduced schedule in his Northville optometry office.

"First we had to figure out how sounds were made and then how to teach them," Marty said. "For the 'L' sound, we had Jordan reach for peanut butter on his palette with his tongue and he learned the 'P' sound by blowing out a candle."

Understanding Jordan

The Levins were determined not only to teach Jordan to pronounce each sound, but for him to speak like a hearing per-

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Special Report

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Jordan at 2 months



Jordan, 5, in his Superman costume



Jordan, 13, speaking at his bar mitzvah at the Birmingham Temple

brother, Brian, 27, of Miami Beach. "And I always felt a part of things, never, ever neglected. And I know Jordan wouldn't have the listening skills he does if our parents didn't hone in on them his entire life."

School Days

When it was time for Jordan to go to elementary school, the Levins resisted pressure from the school district to put him in special education classes. "He belonged in a regular classroom," Mollene said, explaining their understanding that being with hearing peers would give him a better chance to succeed in a hearing world. "I also assured them that the extra help Jordan would need would be our job, not theirs," Mollene said. "I told them, 'Treat him like everyone else. He actually doesn't realize he is different than the other kids.'"

At the end of each school day Mollene met with Jordan's teachers. "I had a notebook to write down the concepts that were done that day so we could do them at home," she said. "He wasn't a problem at school, but we worked at home endlessly to make up for what he missed in school."

Jordan had no idea what Mollene was going through. "I didn't know she was doing anything different," he said. "I thought all parents picked their kids up from school and talked to the teacher."

Throughout his school career, Jordan worked with his parents in study sessions.

"Maybe the stars were aligned for Jordan and my parents," Brian said. "It's lucky my mom's a teacher and that my dad's a damn smart guy to be able to redo middle school and high school. Jordan is the product of a lot of hard work."

When Jordan was a senior in high school he was diagnosed with attention-deficit hyperactivity disorder (ADHD) and began taking the drug Ritalin, which boosted his concentration level.

Along the way, Jordan also had the obstacle of ulcerative colitis to combat.

Making It All Work

"Jordan is a phenomenally accomplished athlete, with phenomenal coordination," his mom said. "He is an amazing snow and water skier. He played hockey in high school and still plays. And he is incredibly strong."

The many activities and sports were blended into his days along with the lessons. "One spring, baseball and hockey overlapped, so Mollene would drive Jordan between the games and I would sit in the back of the car with him and we would do homework," Marty said.

Of course, there were concerns.

"When Jordan first started taking driving lessons we worried about how he would watch the road if he needed to turn

son. "We wanted to make sure Jordan was understandable, and we didn't want him to have flat, deaf speech," Mollene said. Jordan learned breath control and his parents taught him to speak with the rate, rhythm and intonation of a hearing person. "I played the piano up and down the scales and he listened and repeated the intonations," Mollene said. Today Jordan's speech reflects all of that.

Jordan also learned non-speech sounds, like the whistle blown during a hockey game and the ring of the telephone.

Jordan's parents also worked with him on language development. "We taught him five words every day," Marty said. "And one idiom, because the hearing impaired don't understand the nuances of the idiom, taking everything very literally."

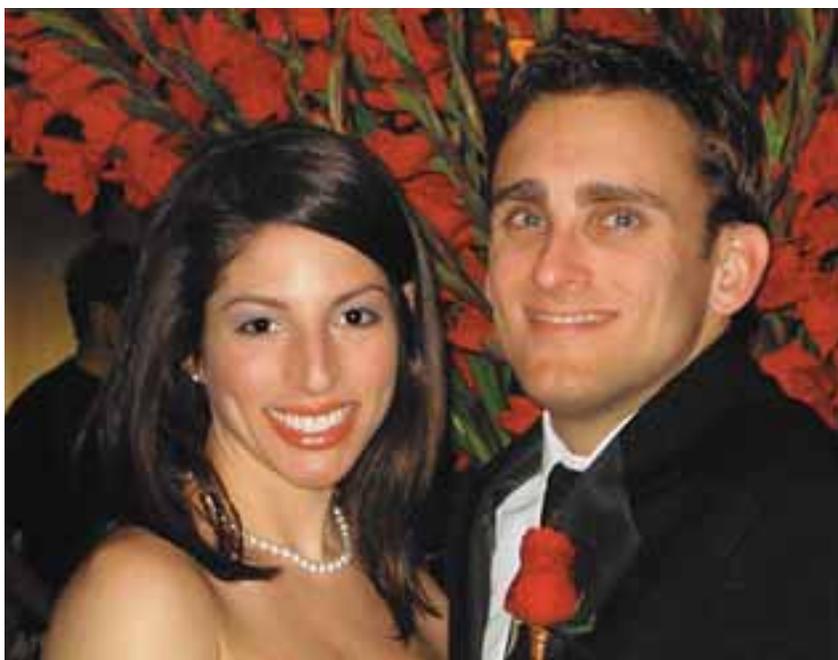
Whatever Jordan did became a lesson.

"Traveling, sitting down to dinner, going to the grocery store were games for Jordan, but lessons to us," Marty said. "He practiced listening to peripheral noises and people talking. Brushing his teeth was a 10-minute experience."

The couple created "language experience" books for Jordan. If they went to a farm or Cedar Point, they took pictures and put them into a book along with vocabulary words and sentence structure lessons.

To make the studies more fun, Mollene and Marty often found themselves crawling on the floor, singing, dancing and jumping up and down.

All of this was normal in the Levin household. "The way we lived was just a way of life for all of us," said Jordan's



Hillary Fisher, 26, will wed Jordan, 32, this June.

his head to read the instructor's lips," Mollene said. Sending Jordan off to overnight camp brought the worry of lost hearing aids.

Never embarrassed by the hearing aids, Jordan just wore them. Although when he was little he wore them with the help of double stick carpet tape.

Not only didn't Jordan try to hide his hearing loss, at times he flaunted it. "At Michigan State hockey camp, when I was 11 or 12, I would stand down the hall in the dorm and the guys would see how far they could move and still have me read their lips," Jordan said.

That was an indication of Jordan's comfort level and confidence, according to his dad. "A lot of people with handicaps are somewhat reticent," Marty said. "We wanted to create an atmosphere where Jordan was able to speak for himself."

Even though he didn't know it at the time, Jordan grew up dependent on his parents' intervention.

"I first realized this when I called my parents and asked them to switch me out of a college class because the professor's full beard kept me from reading his lips, which I have to do in large settings," Jordan said. "They told me, 'You're a big boy, take care of it yourself,' and I did. I learned not to take 'no' for an answer."

His mom added, "Now he gets people to do all kinds of things. First we were the ones who were relentless. Now it's Jordan who became relentless."

Writing It Down

Through the years, Mollene said, when we'd tell our story, people would say, "You really should write a book." Now

that Jordan's dad has written the book, Mollene said, "I'm hoping people who don't know Jordan will be touched by him through it."

Jordan's dad — who co-produced the *My Kids 1st Coach* video about preventing childhood obesity — wrote *We Were Relentless* as an inspiring account of Jordan's rise above disabilities and challenges. But it is also an informative, often humorous, honest portrayal of the frustration, love and relentless encouragement and drive of his parents.

Jordan has turned his experiences into a secondary occupation as an inspirational speaker, talking about overcoming challenges and making positive life changes to groups ranging from adult professionals to school children.

"I speak about how to be relentless in pursuit of your dreams, and help teach how to succeed in ways never thought possible," Jordan said.

He began his speaking career after comfortably enjoying talking in front of a crowd at his bar mitzvah celebration at Birmingham Temple in Farmington Hills. Soon after, he volunteered to speak at the Toronto Voice Conference, the same program where Mollene and Marty first met Dr. Griffiths.

"It's hard to explain my brother," Brian said. "If I say he's profoundly deaf, people assume he's in special ed and that he signs. They never imagine he has a job and lives a normal life."

When Hillary Fisher first noticed Jordan on JDate.com, she didn't know

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Special Report

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Jordan flanked his brother Brian and father, Marty

he was deaf. By the time they had their first date, she knew but she didn't care. Even from the first meeting, she said, "I didn't think about it. I didn't have a problem whatsoever understanding Jordan." As Fisher, 26, of Keego Harbor, got closer to Jordan, she became enamored with his parents as well.

"Mollene and Marty didn't dwell on anything negative," she said. "They didn't make him feel different and let him function like everyone else."

Fisher is an artist and assistant director of the Janice Charach Gallery in West Bloomfield. Engaged to marry Jordan this June, she said, "Mollene, who is a doll maker and a funky avant-garde fiber artist, taught me to knit. Together we are making the chuppah for our wedding."

The Way Of The Future

Jordan has taken advantage of new, helpful communication technology. He has a CapTel (Captioned Telephone) that provides word-for-word captions of telephone conversations.

"The way people use e-mail for texting and Blackberry messaging has made Jordan's life so much easier," Brian said. "It is a great equalizer because everybody does it. Jordan and I live in different cities but we text or e-mail every single day, usually many times."

Fisher, too, has learned about technology that assists those with hearing impairments. "I went to hear Jordan speak at a conference in Ann Arbor and while I was there I learned about a device that wakes a hearing impaired parent to tell them their kids are up," she said. "And Jordan's alarm clock is like an earthquake; it shakes him."

Jordan and Fisher often rent movies, but they have been to a theater

in Livonia that provides closed captioning projectors that fit into the seat's arm rest-cup holder. "Nothing has been an issue with us because of Jordan's hearing loss," Fisher said. "Jordan loves music. He has listened to some songs so many times with his parents, he can hear the beat and he knows when the lyrics start. And he's a natural dancer — better than me."

"Jordan is not part of the deaf community because he communicates like a hearing person by listening and speaking."

Brian hopes others will be inspired by Jordan's life. "I hope the book motivates any parent to do everything in their power to get every possible benefit for their children, no matter what the challenge," he said.

Jordan wants readers to come away with a new perspective on life.

"If there's something they dream about doing, they have to go for it," he said. "I want people to look at me and know that nothing is impossible." □

A reception to launch *We Were Relentless: A Family's Journey to Overcome Disability* will take place at 4 p.m., Sunday, Feb. 15, at the Janice Charach Gallery inside the West Bloomfield JCC. To RSVP, e-mail info@wewerelentless.com or call (248) 851-9757.

Books will be available for sale and signing. Books are also available by accessing the Web site at: www.wewerelentless.com.

To contact Jordan for speaking engagements, e-mail: Jordan@jordanlevin.com; call (248) 683-4826; or access the Web site: www.jordanlevin.com.