

# Augie Nieto Faces Off With ALS

## Never Give Up: The sports-machine exec won't let the disease beat him

BY TRANG HO

INVESTOR'S BUSINESS DAILY

Severely depressed, Augie Nieto gulped a fistful of antidepressants.

At 47 years old, the self-made multimillionaire didn't want to be a burden on his four kids and wife, a high schoolsweetheart.

Diagnosed with amyotrophic lateral sclerosis in March 2005, the tall, muscular fitness guru couldn't even lift his hand to his chin to shave.

Talking had become a challenge. Soon he would be completely paralyzed and unable to speak, breathe or eat on his own.

It was a twist of fate for the face of health who brought exercise to the masses as the co-owner and CEO of Chicago-based Life Fitness.

The ripe athlete ran marathons, lifted weights, went scuba diving and traveled the world preaching the virtues of diet and exercise.

Nieto grew up in a lower-middle-class family in Anaheim, Calif., and was a fat teenager. But not for long. Dubbed the Henry Ford of the fitness industry, he went from selling a stationary bike out of a second-hand RV home during college to building the largest fitness equipment maker in the world.

Life Fitness bulged to \$550 million in sales, with orders coming in from 54 countries. Nieto sold his stake in



Nieto, with wife Lynne, has a disease that hits brain and spinal-cord nerve cells.

the company in 1997 for \$330 million.

### Back From Depression

Nieto woke up from a coma in the hospital surrounded by his family and friends. He felt overwhelmed by their unconditional love.

"That was the turning point for me," he told IBD.

The disease that commonly kills victims within three to five years of diagnosis gave him a greater will to live than ever. He read everything he could about ALS. In seeing how so little money was devoted to disjointed research for the malady, Nieto founded his own ALS foundation, Augie's Quest. He rebranded himself as the face of the affliction to spearhead the counterattack.

With the spirit of an entrepreneur, Nieto runs Augie's Quest like a goals-driven company rather than a bureaucratic nonprofit. He views donors as investors and patients as customers. He approves all research. All donations go completely to research and none to overhead.

Augie's Quest works with the Muscular Dystrophy Association to coordinate ALS research. Nieto appears regularly on the Jerry Lewis telethon and other fundraising events.

Nieto has drawn celebrities, business leaders and Major League Baseball to the cause. In four years, he's raised \$24 million in the ALS battle.

"I'm more proud of what I've done after ALS," he said. "I have never been happier in my life."

ALS is commonly known as Lou Gehrig's disease, named for the New York Yankees star who died of it in 1941. "But it will one day be known as Augie's cure," his wife, Lynne Nieto, said.

In 2006, Augie's Quest and the MDA funded breakthrough research that found 50 differences between the DNA of people with ALS and those without. Pinpointing these genetic distinctions was paramount in searching for treatments.

In 2007, the MDA and

### Nieto's Keys

- Co-founded Life Fitness, the exercise-equipment giant; founded Augie's Quest, an ALS foundation that's raised \$24 million for research.

- "I wake up every day excited about life! There is so much to do and so little time!"

Augie's Quest teamed up with the world's largest ALS research center — the ALS Therapy Development Institute — to biochemically dig for a cure. This past March, something promising emerged at ALS TDI. The biotech firm, based in Cambridge, Mass., announced it had discovered a drug, ALS TDI 00846, that slows ALS progression in mice.

With other drugs in the pipeline, Nieto says he's "100%" hopeful that researchers will beat the illness in his lifetime.

Paralyzed from the neck down, Nieto cannot speak or control the bodily functions that healthy people take for granted. He relies on a machine to breathe, a nurse to inject liquefied food into his stomach and a tube to drain his urine. He can only blink his eyes and move his toes.

Although he has lost such physical abilities, his mind is sharper than ever. He works at least 10 hours a day. In addition to running  
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Augie's Quest, he serves as chairman of the MDA's ALS Division, ALS TDI and Octane Fitness, an exercise equipment firm. He's also on the board of **DynaVox**<sup>DVOX</sup>, the leading developer of speech-generating equipment. Meanwhile, he has written two books: "Reciprocity Incorporated" and "Augie's Quest."

In an interview at his six-story, oceanfront home on a beach aptly named

Inspiration Point in Corona del Mar, Calif., Nieto said: "I'm insecure. Most successful people are. That is what drives them."

He responded to questions by typing on his customized computer: "Celebrate insecurity. It's a good thing. It keeps you motivated and drives you to do better."

### **Still Communicating**

Sitting in a wheelchair

equipped with two monitors, he uses the computer with a foot-controlled track ball. With TypeRight, a software program developed just for him by tech entrepreneur Troy Jurgensen, he can type as fast as 40 words a minute. His responses appear on a screen half the size of a steno pad.

And using iControl, a program Jurgensen and his staff at Computer DX made to adapt iPhone applications, Nieto sends text messages, looks at Web sites, at-

tends conference calls and writes e-mails. He receives an average of 120 a day.

He manages to give speeches and even toasted his daughter's wedding in Sun Valley, Idaho, in August with a DynaVox machine.

The device reads what he's written aloud with the voice of artificial intelligence commonly heard on customer service lines.

Now 52, he has a clear aim: "I have to redefine normal every day! I'm preparing to live 20 more years."

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