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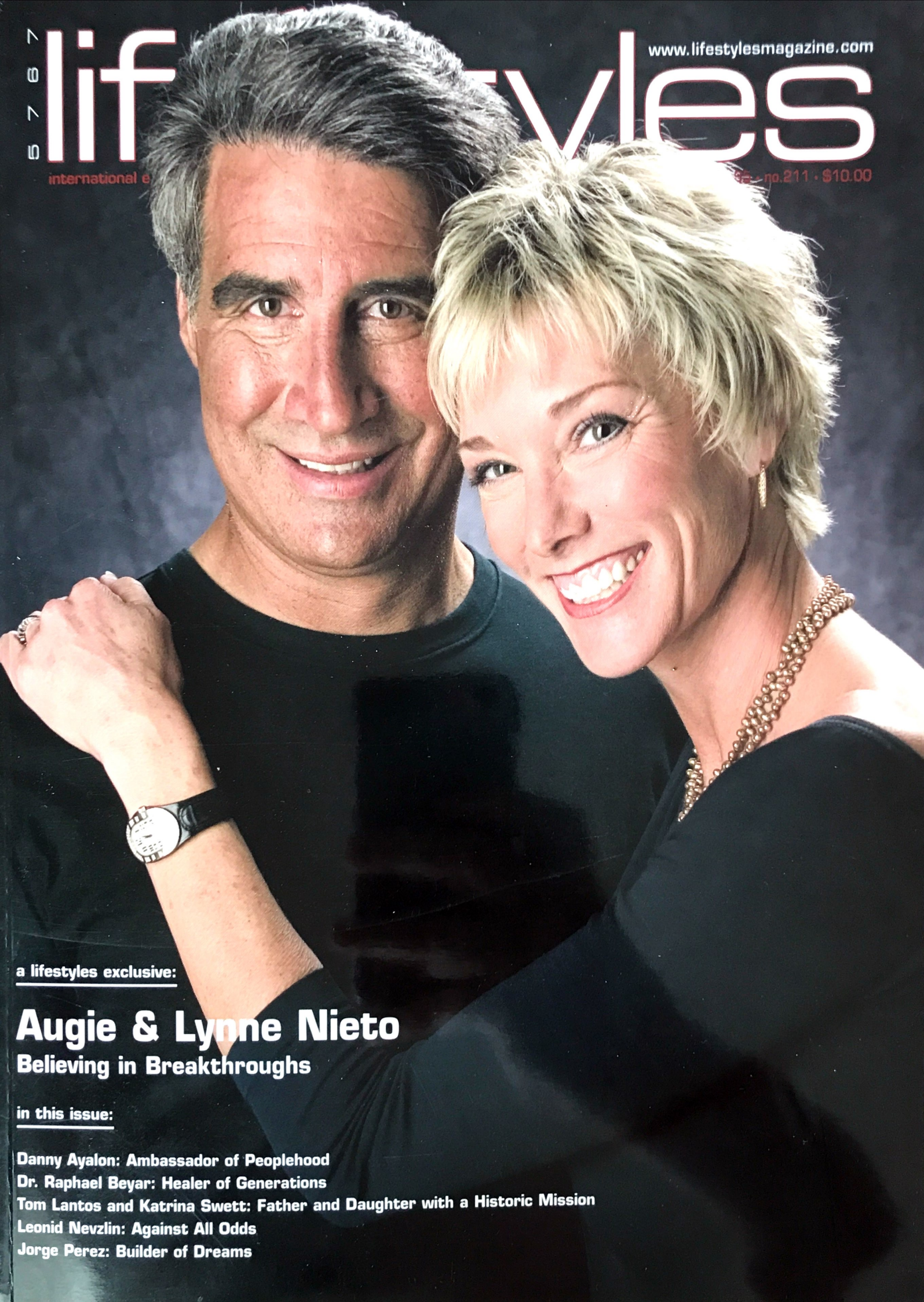
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www.lifestylesmagazine.com

no. 211 • \$10.00



a lifestyles exclusive:

Augie & Lynne Nieto

Believing in Breakthroughs

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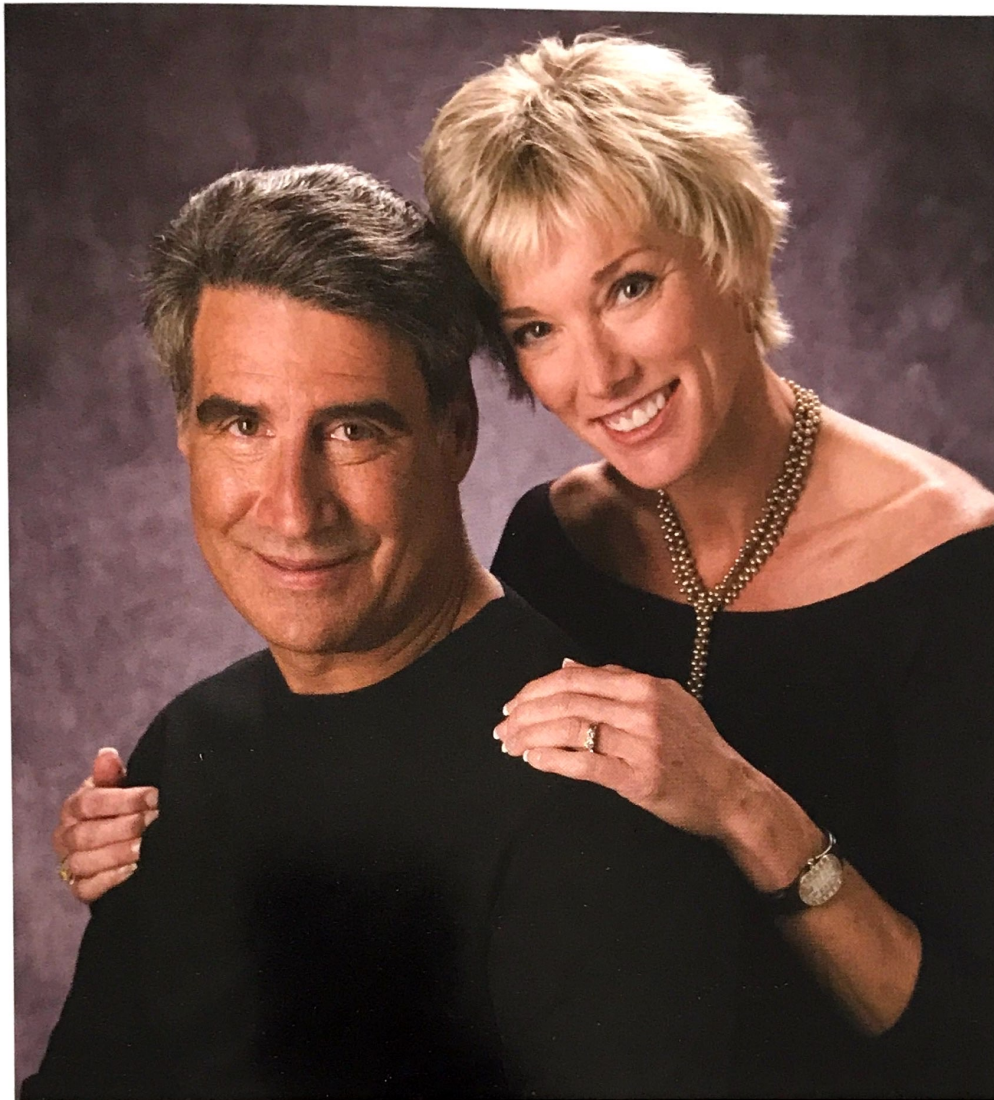


Photo courtesy of Augie & Lynne Nieto

AUGIE & LYNNE NIETO

a championship season

BY ELYSE GLICKMAN

The sunlit garden dining room at the posh Beverly Hills Four Seasons Hotel and Spa is a great, life-affirming backdrop for the Muscular Dystrophy Association's national board meeting in Los Angeles. As the lights dim and a video starts to play showcasing the past year's achievements, raising money for ALS (myotrophic lateral sclerosis or "Lou Gehrig's disease") and muscular dystrophy, Augustine (Augie) Nieto beams with pride. The creator of Augie's Quest, Nieto watches celebrities Robin Williams, Bob Saget, California Governor Arnold Schwarzenegger, Lance Armstrong, and Billy Crystal encourage donations while adding levity and liveliness to the event. Despite the star power on display, the most memorable moment of the day occurs on film, as Nieto says in a self-assured voice, "When I wake up, I have a choice of mourning what I can't do, or celebrating what I can. I wake up every day excited about what I can accomplish."

Near the event's conclusion, Nieto steps to the microphone and immediately captures everyone's attention. Since the video clips of him in action were shot, his condition has changed dramatically. His words are quieter and slower in coming—yet no less powerful. Although many in the room have followed him and his activities over the last two years since his diagnosis, the juxtaposition between “then” and “now” drive home Nieto's unwavering commitment to raising funds and awareness. In spite of everything, he is a man in control, with confidence and inner strength. He also has a much-needed sense of humor, demonstrated by his play “wheelie” demonstration in his motorized wheelchair in the courtyard adjacent to the dining room.

When the crowd has left and he is finally afforded a quiet moment, Nieto

It is the same sense of direction and confidence that propelled Nieto's passion for weight loss and exercise from a class project as an undergraduate at Claremont McKenna College into the Lifecycle empire that dominated fitness centers and home gyms around the world in the 1980s and '90s. After Family Fitness Centers founder Ray Wilson pitched his Lifecycle, a bright yellow stationary bike, Nieto immediately recognized its potential and bought the marketing rights. While early efforts to sell the bike were not initially successful, an undeterred Nieto founded Lifecycle Inc. He jump-started the company, shipping bikes to 50 health-club owners free of charge. The strategy worked, and the bikes started popping up in clubs nationwide. By the time Nieto graduated from college in 1980,

After coming to terms with his ALS diagnosis, Nieto realized he could use the same kind of determination and business acumen to forge a partnership between the MDA and his Augie's Quest charity, which is now part of the MDA. “I believe that in business and in charity alike, people want to know where their money is going first and foremost,” Nieto says.

“I treat the board members (of the MDA organization) as ambassadors for the company, donors as investors, patients as customers, and the research that we do that could result in a cure as the product we sell. When an ambassador sees how fast we were able to move at the rate we were going with our research and support in nine months, they know we're honoring the contract. Every day, I ask myself and answer three questions: 1) Why hasn't

“1) Why hasn't this type of thing been done in the past? 2) Why can it be done now? and 3) Why is MDA/Augie's Quest the best group to do it?”

reveals how the most valuable gifts in life—what can be passed on and shared with others in need—can come from adversity. “If you leverage all your efforts and resources, you are able to move faster than anyone else,” he says. MDA CEO Jerry Weinberg looks on supportively. “What I mean by that is, we needed to put our case forward with an effective message. When you see my logo, you will see ‘Augie's Quest’ on the outside, ‘Cure ALS’ on the interior, and in the very center the MDA logo, as it is the focus of Augie's quest. This sums up how I feel about what I am doing. The design also is modeled after a compass, and when you see it, with the way the words are arranged, this is a way of telling people we know where we are going.”

the company's annual profits had reached \$500,000, and the cardiovascular craze was born. Two decades later, when revenue had reached \$7 million a year, he sold Lifecycle but continued to steer the company as it morphed into Life Fitness. They added stair steppers and treadmills and soon became one of the world's largest makers of fitness equipment. Under Nieto's watch, revenue hit nearly \$200 million by 1997 before Life Fitness was sold again for \$310 million.

ALS is a progressive neuromuscular disease that weakens and eventually destroys motor neurons. It affects 30,000 people in the U.S., including Augie Nieto.

this type of thing been done in the past? 2) Why can it be done now? and 3) Why is MDA/Augie's Quest the best group to do it? When those questions are asked and applied, what one ends up with is irrefutable proof that we're the best charity for a donor to put his money into.”

“It was definitely the personality as well as that of his wife, Lynne, and the straightforwardness of his viewpoint that won me over,” says Jerry Weinberg, recalling their first meetings two years ago. “His insights and perspective in dealing with ALS personally were also enlightening. When we talked about what we could do together, we clicked and we believed, ‘Yes, we can do it together.’ As I know from my experience, it is always tough

to do things alone. But if you have a partner, the two of you can do things more quickly and effectively. He was and is quite a personality. He had a similar effect on the board as well."

Even with her contributions, Lynne Nieto remains humble about her involvement with the MDA and Augie's Quest but is warmly proud of her relationship with Augie on all levels.

Although the two were high school sweethearts and sensed they were soul mates, they broke up before going away to college. Augie and Lynne both married other people, but the friendship remained solid through the years and the pair remained in touch. Fate played a role 15 years ago when Lynne, now the president of a family-owned real estate management company, called Augie up on a lark when she realized one of the company's new acquisitions needed equipment for its fitness room. Three

years after that, the couple, at last, married. They lived in Chicago for the first three years of their marriage, until (ironically) some health concerns of Lynne's prompted them to move back to her native California.

"I am coming to understand the preciousness of life in a way that is so much different than I did before," Lynne notes. "Not only will Augie's life come to end, but all of ours will end as well. But even with that, we all must live as best we can with this knowledge in our hearts as well as our minds. As somebody who has been a planner her whole adult life, this has really taught me to enjoy the moment every day. And then I learned about the joy in asking for and receiving help as well as

having the ability to help others. Before the diagnosis, we were and still are in many ways the most independent people you'd ever meet. However, in traveling the country and asking people to give and help with Augie's Quest, giving and receiving help are equally important, major parts of being alive,

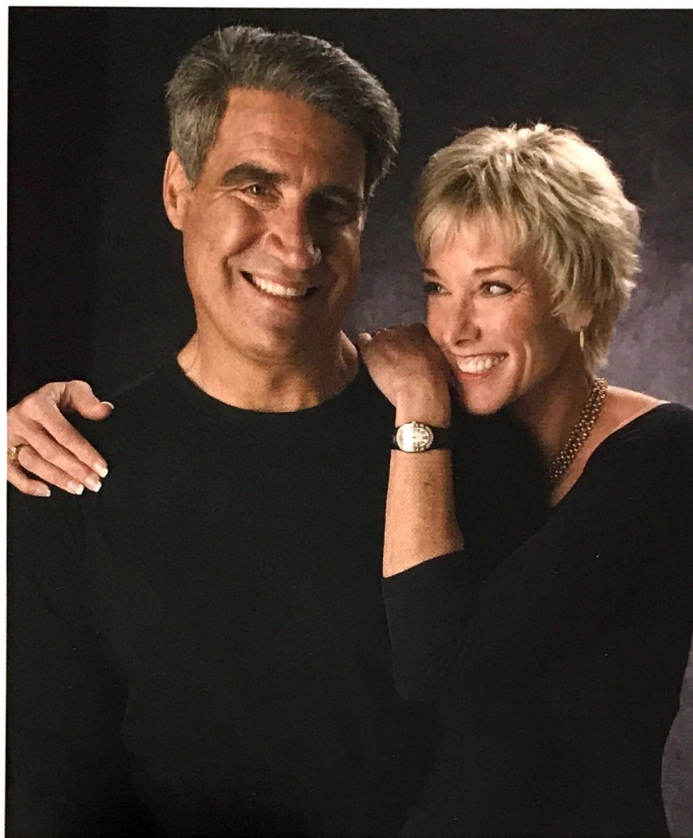


Photo courtesy of Augie & Lynne Nieto

and there is a joy in experiencing both."

Although Lynne's professional expertise is in finance and accounting, she views herself as Augie's physical and mental support first and foremost. Although Augie would say she's a solid part of the team, she plays her role more subtly, explaining that she is a backup player.

"For every good idea I come up with, there may be five that aren't so good, and I honestly don't mind having them shot down. And because too many leaders can be the downfall of the group, I leave most things up to Augie and his MDA team. As for me, I go with Augie everywhere, packing, unpacking, planning the travel arrangements, and the like. I have had to do

public speaking, which was hard at first, as he was the gregarious one and I am the shy one. However, as time has gone on, I have found great value in this whole experience, and speaking has gotten easier."

But before he could come to terms with his condition, Nieto, like many

others who face a life-threatening illness, went through the five states of emotion when first diagnosed.

"I went through denial, going around the country, visiting as many clinics as possible and seeing many doctors only to hear the same diagnosis," he says. "After denial, I became angry, and after anger, I felt sorry for myself and I was in the 'Why me?' phase of my life. And then the worst one, for me, was 'What did I do to deserve this? Is there a God, and if there is a God, how can God be so cruel?"

It was at this point that my wife gave me a book written by Rabbi Harold S.

Kushner, *When Bad Things Happen to Good People*. What Kushner gave me was a new way of looking at things. When an airplane goes down (for example) and there are 300 people on the plane, were they all bad? Of course not! What his message is about is making the choice to react to a bad situation in a positive way."

While Kushner was one major influence, another was Luke Christie, the MDA national goodwill ambassador, who is 13 and has Type 2 spinal muscular atrophy. Nieto marveled at Christie's ability to draw the most out of life and simultaneously inspire and help others like him. The budding friendship, captured in the popular Sunday magazine *Parade*, resonates

"It gave me the empathy and strength to be able to know our body is just the box we are shipped in, and that it is the soul that defines who we are and what matters. I learned... that what some may consider a disability can be a gift."

deeply with Nieto to this day. "Prior to my diagnosis, I have to admit I was judgmental about how people looked because my life was all about helping people lose weight, improve their appearance, and build their muscles," Nieto recalls. "After my diagnosis, I will never forget being in North Carolina at the MDA board meeting in March of last year. I met this incredible young man. My first impression...all I could see at first was the wheelchair. But after I spent hours talking to him, all I ended up seeing was Luke and the courageous way he went about his life. It led to my own transformation. It gave me the empathy and strength to be able to know our body is just the box we are shipped in, and that it is the soul that defines who we are and what matters. I learned from him that what some may consider a disability can be a gift. Luke had so much insight and courage that it seemed as if everybody else was handicapped, because they could never see or experience what he did."

And whether he realizes it or not, Nieto himself serves as inspiration.

"When Augie came to us for the first time, he researched the field thoroughly, and he brought to us an intelligence that we hadn't seen because of his personal experience," adds Weinberg. "He articulated his suggestions and observations so beautifully, that it really helped us both refine the direction of research and fundraising. All we need to go forward as we are now is money. We are working on this together, and we will get there."

"Remember that I said there are always three questions I ask?" says

Nieto. "The first is, of course, 'Why wasn't anything done in the past?' The answer (I found out after lots of hours of research) is often because our government [leaves most of the work and funding] to government agencies and academia. Our combined goal is to find answers and funding, to push things further. In 2006 there were 83 new drugs introduced. How many came from academia? Two! So what I saw was an opportunity to leverage the good work of academia, but also to put our focus on finding [more specific] cures and remedies, and take a closer look at the role of DNA in the illnesses."

In less than a year and a half, Augie's Quest raised over \$10 million for ALS research. In addition to serving as co-chairperson of MDA's ALS Division with his wife, Lynne, Nieto is also chairman of ALS TDI, the world's largest, most comprehensive research program dedicated to developing drugs to treat ALS. This past January, the largest ALS drug discovery project in history was launched in tandem with the MDA. The three-year, \$36 million project endeavors to identify biochemical targets and find their complementary drug.

Another breakthrough at the end of last year, funded by Augie's Quest, was the comprehensive scan of a human genome that identified more than 50 genetic abnormalities in people with ALS. The most common of these abnormalities had never before been shown to play a role in the disease. TGen researchers at an international ALS conference in Japan revealed that the identified differences implicate genes likely to play a role in cell function that con-

trols nerve adhesion, offering a major new avenue for ALS research.



As Nieto did in business, he isn't allowing anything to stop him from attaining the ultimate goal of a cure and treatment. While he has, in a short time, established himself as a role model for many people, his most important students are his children, who are clearly absorbing the lessons. "I want my children to remember that while you cannot control what happens to you, you can control how you respond," he says. "My youngest daughter volunteers at the local MDA office and ran her own fundraiser in her high school. She raised hundreds of dollars among her peers. My second youngest is a pre-med student interning at an ALS/MDA clinic in Irvine. Every day he sees the impact of what we're doing. He came home last week, and said, 'Dad, I saw your file. Looks like you're doing pretty well.' It is so important to me that he can see the message behind the fight I put into it."

For general and comprehensive facts about ALS, visit www.als-mda.org. On September 15th, the MDA will hold a Tradition of Hope Gala in Los Angeles at the Hyatt Regency. The master of ceremonies will be Jann Carl (*Entertainment Tonight*) and John Ondrasik of the band Five for Fighting will preside over a night of entertainment and special tributes. Call (310) 450-9032 for more information. For additional information about the event, other fundraising and research efforts, and how to get involved, visit Augie's website, www.augiesquest.org. **lifestyles**



Photo courtesy of Valerie Sobel

VALERIE SOBEL

nine lives, one heart

BY ELYSE GLICKMAN

The serene, beautiful face of Valerie Sobel quietly masks a lifetime of epic highs and shattering lows. The lows began almost immediately. In 1941, just three days after her birth, Valerie's father was taken to a labor camp in Hungary; she, and the rest of her family, managed to survive by hiding in non-Jewish "safe houses." It took three painful years before Valerie and her family were at last reunited.

The dramatic start to her life—hidden by people operating out of empathy and morality—would foreshadow her life after 1994. At that time,

Sobel had it all—a thriving interior design career, a successful and happy marriage to Erwin Sobel, an eminent trial attorney, and two successful college-bound teenagers. Then, in 1993, her son, André, about to enter the film school at New York University, was suddenly stricken by double vision.

Sobel soon heard the most heart-wrenching news a parent could endure: Her son had a brain tumor and his condition was incurable. In six months, this vibrant, cultured, and energetic boy was almost blind. After he died in early 1995, Sobel decided that she would find a way to use her personal resources and public influence to do charitable work in his name.

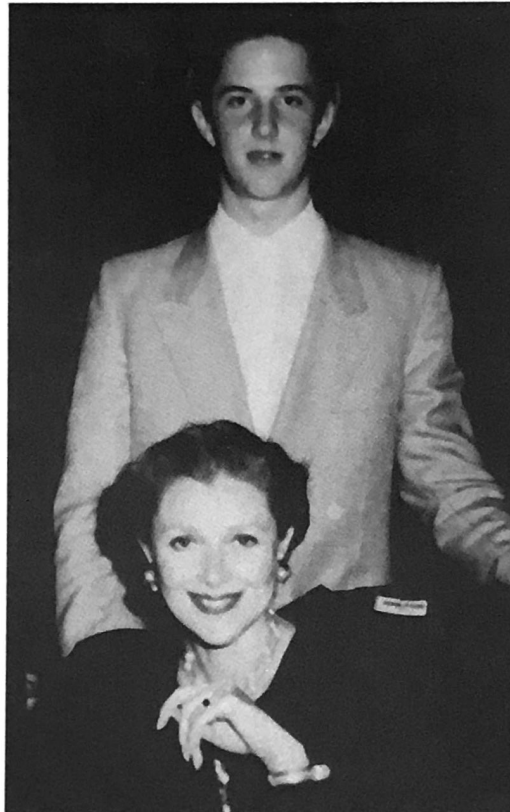
"It is not possible to seek or find God in the truth that others have found, nor without the urgency of catastrophe," Sobel told *Lifestyles* recently while taking a well-earned break from preparations for a forthcoming fundraising and research trip across America for her foundation, The André Sobel River of Life (ASRL). The organization provides for the needs of single parents (and struggling families) with children facing life-threatening illnesses.

"In a pleasant life of complacency, we may practice ritual or be obedient to tradition, but that is not the same as the faith found in praying for a child's life. When you have been on your knees for months, you can find yourself suddenly uttering words from a deep place, 'I will to will thy will,' then you know that you had a glimpse at what faith must be like."

Within a year of André's death, Sobel's faith was tested twice more. Her husband, unable to recover from the loss, committed suicide, saying in his farewell note that he did not wish to live past his son's unveiling. And, just before that, Sobel's mother died of a stroke.

Even with this series of devastating events, Sobel's will to help other families, combined with her resourcefulness, empowered her to begin working on behalf of thousands of families coping financially and emotionally with similar experiences.

"The difficult lessons of my life were learned through surviving a world war where I was separated from my



Valerie and André Sobel.

family (at age 2), the 1956 Hungarian Revolution, the upheaval of living in four countries and seven different cities, the wearing of assorted career hats, and the skills necessary to be married for 25 years," notes Sobel. "These events, if not exactly preparing me for the holocaust of losing a child, a husband, and a mother in the same year, forced me to employ all that I have learned. The resiliency that was required to endure all this was more than I would have suspected I had. It was as if my whole previous life would have been lived to unintentionally prepare me for the spiritual, psychological, and physical battle

fought for André's life. I am in awe to witness the person that emerged."

Although Sobel's family was reunited after the war, the conditions in Communist Hungary prompted her family to flee to the United States in 1957. Despite new social freedoms, the family's financial situation forced Sobel to drop out of high school. However, with her striking looks and innate intelligence, she soon made a name for herself as Valerie Varda, a 1960s Hollywood actress. She appeared on classic television shows, such as *Wagon Train* and *77 Sunset Strip*, and had a few brushes with the day's A-list stars, thanks to parts in *A New Kind of Love* with Joanne Woodward and Paul Newman and *Mr. Hobbs Takes a Vacation*, featuring a cast of Hollywood greats (such as Jimmy Stewart, Maureen O'Hara, Fabian, and John Saxon).

In 1971, she gave up the fast pace of Hollywood life to marry attorney Erwin Sobel. Not only did they share common interests, they shared a past: He also carried scars from the Holocaust. In the 25 years that followed, she raised children André and Simone and became a star in the world of interior design. Her sun-kissed life in Southern California seemed lifetimes removed from the struggles of her childhood. However, those trying days were never far from her mind.

"You don't love a family member automatically for being a family member," she states, "you love them for who they are. There is an instinct learned early on about the preciousness of where you belong. In terms of getting involved in charity in the wake of a child's death, it either bubbles up as a quality of mercy, or is learned like algebra. In my case, it became the ingredient of my personal survival. Structuring the charity was a

Photo courtesy of Valerie Sobel

natural extension of what I have experienced. It became a most natural thing for me in the long run. As an interior designer, I have done some truly beautiful residential projects, but the excitement of design pales by comparison with the work that I do now where we are making a difference collectively, one family at a time. Furthermore, The River of Life carries André's spirit and washes up problems on its shore that deal with the plights of the siblings, the intense challenges of the caregivers, the gigantic divorce rate, and how society deals with its weakest links."

Although the ASRL organization, along with affiliated hospitals, doctors, and

the next day. When a child has something growing in his head or in his spine creating 10 billion new aberrant cells every minute, his mother will not go to work because there is no time to waste. She will take her child to the best place she can get treatment as quickly as she knows how, the best her circumstances can afford. For this reason, we never ask the parent to fill out exhaustive forms. At that point they should not have to deal with the indignity of lengthy and oppressive paperwork. Where there is a treating physician, a critically ill child and a strained single provider, my concern is more for the best and most imaginative solution to the problem rather than worrying about if they are deserving."

Almost half of the foundation's dis-

life-threatening or critical illness of their child?' it is not possible not to go deeper. It is revealed layer by layer, and after six years and almost 6,000 documented cases, a picture becomes apparent. I have become quite stubborn, and all I need is funds to continue this work that started with my family's money. As ASRL's understanding grows, our means decrease. It is an under-investigated problem because the population experiencing it is invisible. People with dying children, balancing emotional pain, finances, and the lives of their healthy children, have no where-withal to demonstrate on the streets or pound the halls of government for assistance. Knowledge about this segment of the population in the field is anec-

"There is no family that has not been touched by tragedy, none that are insured against this worst nightmare of any parent: the grave illness of their child. I cannot think of a greater gift for a sick child than the presence of his parent, and that is what this foundation's work ensures."

donors, have helped thousands of families, Sobel feels that their work has just begun. She monitors the inner workings of the organization, wary of overextending her network and causing families to suffer unduly. The foundation's program now operates at 12 major pediatric medical facilities throughout the country.

By working through social workers' recommendations, the foundation eliminates the barrier of the lengthy application process required by most foundations, not to mention the overhead cost of supporting a large staff. Sobel says emphatically, "By caring for the single caregiver, we care for their child. Our goal is mental health for the caregivers, permitting them to deal with the crisis without worrying about going to work

bursements go to emergency housing, utilities, and groceries for families facing inadequate food supplies or eviction. This has led Sobel to focus her energies on fundraising. The foundation also funds transportation for families going to and from treatments, recreational activities, such as ballet lessons for a patient's siblings, and, sadly, burial costs.

"We try to support what the government or hospitals can never be expected to support: the nonmedical emergencies that accompany an actual medical crisis," explains Sobel, who continues to be shocked and awed by the desperate situations of so many families and their inability to meet basic living needs through other programs.

"Once you ask the question 'How can a single-parent family cope with the

dotal, yet the financial, psychological, and physical problems that result for the extended family and society are worthy of support and a good subject for a think tank."

Sobel encourages everyone she meets to visit the website, www.andreriveroflife.org. Should they have money, expertise, connections, or intellectual property to contribute, she can be reached directly at vsobel@andreriveroflife.org. "There is no family that has not been touched by tragedy," she surmises, "none that are insured against this worst nightmare of any parent: the grave illness of their child. I cannot think of a greater gift for a sick child than the presence of his parent, and that is what this foundation's work ensures." lifestyles