

FAITH VALUE

as a daughter suffers from the same puzzling and protracted disease that has already taken their two sons, a Trabuco Canyon couple's extraordinary strength is derived from an inner peace and powerful belief in God

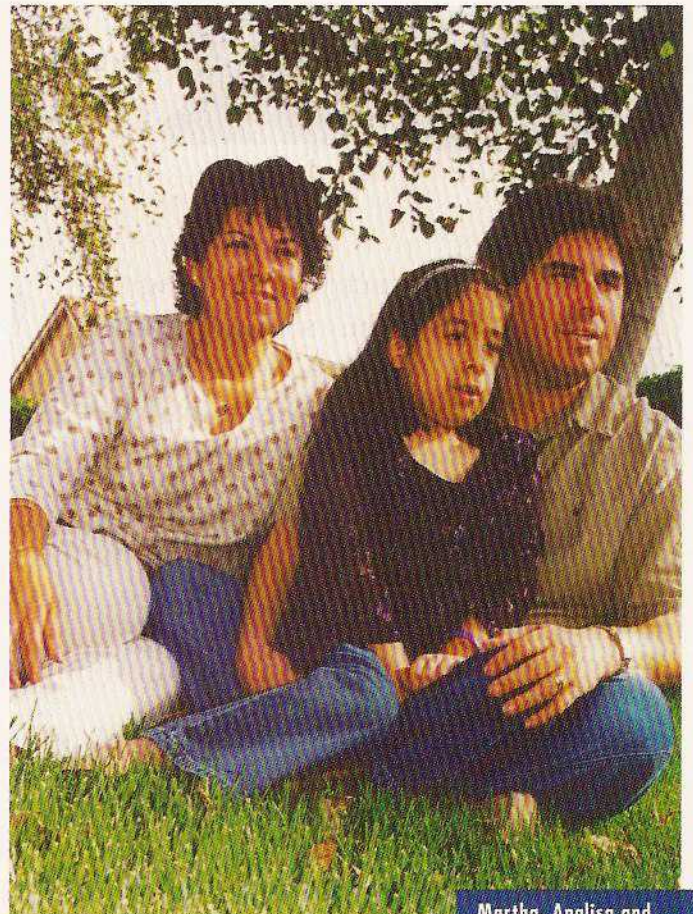
text and photography by William Campbell



In the 32-inch Sony television in the living room of their Trabuco Canyon apartment, Arnold and Martha Ontes are enjoying a 1992 home video of their son, Andrew, as he clowns around for the camera.

From their reactions to the boy's humorous antics, it's easy to believe that this might be the tape's first showing. Amid the smiles and laughter generated by Andrew's onscreen frolicking, what isn't easy to believe is that this boy is dead.

But it's been more than three years



Martha, Analisa and Arnold Ontes

since Andrew finally succumbed to the ravages of a complex and perplexing disease never before seen that left his doctors scrambling for answers until time ran out.

Also watching the video is 8-year-old Analisa, Andrew's younger sister. Five when he died, she misses her brother, choosing to remember him in unique ways. One of her favorite memories of Andrew is when he would get mad at her and scratch at her with his fingernails.

"I didn't like it when he was here," she says, "but now that he's gone, I do."

Arnold and Martha exchange a smile and a knowing shrug. They understand.

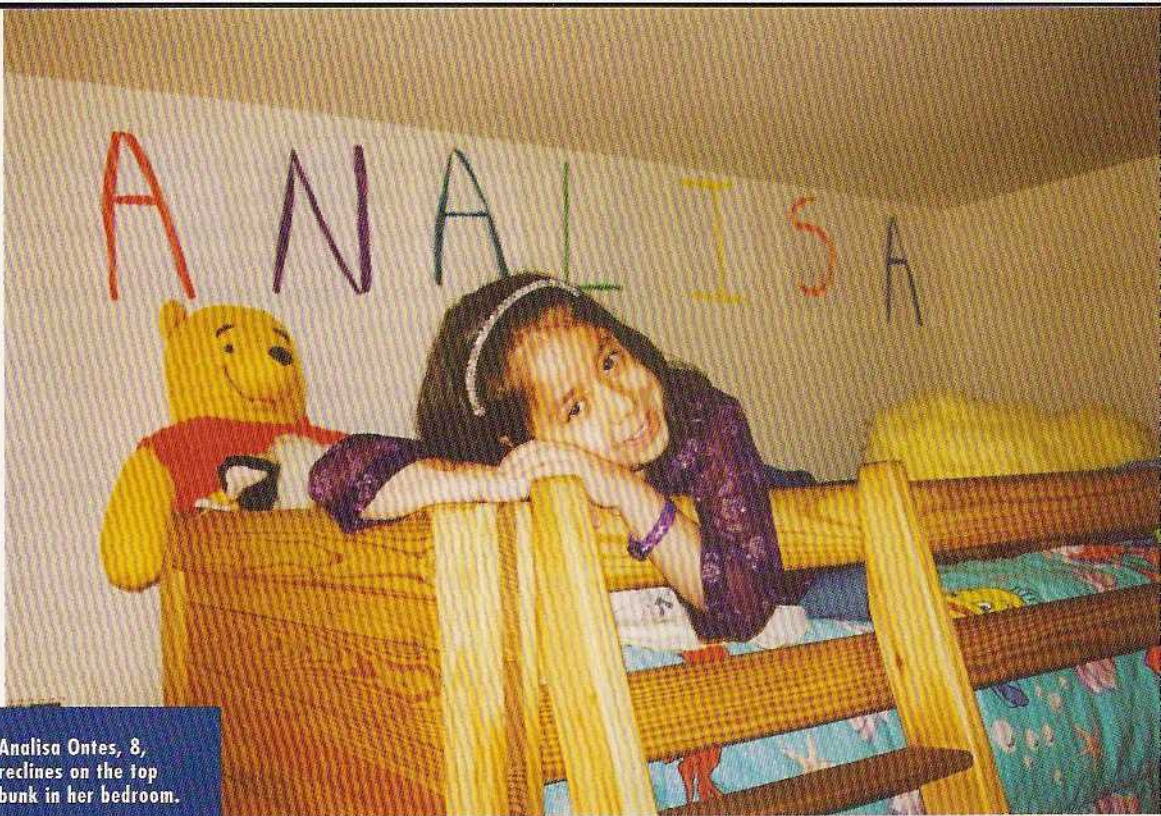
But while mom and dad openly rejoice and revel in this video flashback of their son, their daughter basks quietly in the glow from the screen as the scene changes from a boisterous Andrew to one whose attention is focused on what his father is holding: a baby. As Arnold kneels down with Analisa in his arms, Andrew approaches his 3-month-old sister and carefully plants a kiss on her forehead.

"That was the first time that they were together outside of a hospital, July 4, 1992," Arnold says.

Analisa smiles. Next she watches herself and Andrew in her crib. This is her favorite part, she whispers. Surrounded by stuffed animals, Analisa never takes her eyes off her brother. Andrew, on the other hand, alternates between staring back at Analisa and turning to look at the camera. The love in his eyes and the smile on Analisa's face are priceless, almost as priceless as the next moment when he lays down next to her and starts patting her softly on the back.

The ensuing silence is punctuated by a nasty cough from Analisa. It's the same cough her brother had, because she has the same vexing terminal disease her brother had. Her doctors are still unable to get a secure grip on what's causing her deterioration.

In other words, Analisa is going to die, like Andrew—and like Arnold III before him, Arnold and



Analisa Ontes, 8, reclines on the top bunk in her bedroom.

... it's been more than three years since Andrew finally succumbed to the ravages of a complex and perplexing disease never before seen that left his doctors scrambling for answers until time ran out.



Andrew Ontes in October 1997, two months before he died.


Martha's first son, who was stillborn in 1988.

Yet having journeyed through enough tragedy to rip apart most families, the Onteses have remained steadfast and strong in a life together buoyed by an abundance of love and bonded to an unshakeable personal relationship with God.

BORN IN EAST L.A.

Arnold was born in 1963 in East Los Angeles. An only child, he moved with his mother and father to El Monte in the San Gabriel Valley when he was 3. Educated

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at Catholic schools all his life, he graduated from Bishop Amat High School and attended Los Angeles Trade Technical College, where he studied graphic design.

"I had ambitions of doing something on my own eventually," he says. But in the meantime Arnold worked at a top design firm in Los Angeles and stayed involved with the Imperials in East L.A., a lowrider car club he joined after high school. The club would prove to be the link that would lead him to Martha.

"At that time, Jerry Zapata joined the car club and we became really good friends—really tight. He was getting married to his girlfriend, Alma, and asked me to be best man at his wedding. Martha, who was Alma's friend, was to be her maid of honor."

Born in La Puente in 1962, Martha is the youngest of five siblings. After high school, she attended Mt. San Antonio College "for about a year and a half and got bored."

She was working at Catalina Swimwear in the City of Commerce when she met Arnold.

"We both knew each other's friends, but not each other," she says. "That wedding basically brought us together."

Arnold and Martha started dating in July 1985. They were married less than a year later, June 28, 1986.

Martha said what most impressed her about Arnold was that he knew what he wanted.

"He talked about the future and his vision of it—how could I miss with that? He wasn't just working to work. We talked about having a house and a family and stability," she says.

"Basically, we wanted to have what our parents had," he says. "Her mom and dad were married 49 years before her dad passed away. My mom and dad just celebrated their 39th anniversary. Divorce is not in our vocabulary."

About a year after getting married, they moved into their first home, a two-bedroom, one-bath house in Monrovia in the San Gabriel Valley. Early in 1988, Martha found out she was pregnant with Arnold III.

BOO BOO BEAR

With a baby on the way, the Onteses did some remodeling,

which included new windows, new carpeting and a nursery for their new child.

"We were excited," Arnold says. "Martha was getting checkups at the doctor. Everything was perfect. She was healthy. We never smoked or drank—no drugs. We were normal."

But two days before her due date in September 1988 Martha noticed something was not normal. "I got a phone call at work from her saying that she didn't feel right," Arnold says. "She didn't feel the baby moving and I remember praying for there not to be anything wrong."

"It felt like a tight contraction that didn't go away," she says.

Arnold raced home, picked her up and took her to the hospital, where ultrasound was used to pick up the baby's heartbeat. Fifteen minutes later they hadn't found it.

A doctor was called out of surgery to assist.

"The doctor said if he's not moving and he can't find a heartbeat, then our baby's passed away," Arnold says. "He checked for a couple of minutes and then looked at us and said he was sorry, but he didn't hear a heartbeat."

The official cause of death: natural causes.

"We thought it was cord death," Arnold says, "lack of oxygen."

Martha delivered Arnold III after labor was induced, and Arnold recalls that he saw himself in his dead son's peaceful face.

"We got to hold him and kiss him, and put his little hat on him," he says. "He looked like me when I was a baby. He had fat cheeks and looked just like he was sleeping. This was my son still."

They nicknamed him Boo Boo Bear. He was laid to rest in a tiny, baby blue casket.

MAKING A CHANGE

But not buried were a number of questions, and Arnold and Martha wanted answers. Though both were raised Catholic, they considered themselves to be some of the most unreligious people on the face of the earth.

"We're not big on tradition," Arnold says. "When we would go into church we were used to statues, we were used to genuflecting, but after our baby's death it all seemed kind of empty."

But they reached out to their local church anyway. After the Mass, Arnold asked his wife, "Did you get anything out of that?" She said she hadn't. Neither did he.

"I remember going to the priest who said the Mass afterward and introducing ourselves with 'Hello Father, our baby died,'" Arnold says. "He just hugged us and said 'Oh, I'm so sorry,' and talked to us for a few more seconds and then turned away."

"We were looking for some support or guidance and he didn't give us any," Martha says.

In October 1988 came one of what Arnold likes to call his "answered prayers." By chance he heard Diamond Bar Calvary Chapel Pastor Raul Ries on the radio. "He was talking about things I could relate to—unlike the priest," Arnold says. "And something in his message touched me so much that I called Martha from there and told her she should tune it in on the radio in her cubicle."

They decided to go check out the



Analisa wears a portable IV unit, which allows her hospital stays to be shorter.

nearest Calvary Chapel in West Covina. At the service, Arnold and Martha were amazed. They had never seen so many different types of people—young people, old people, bikers, people wearing Raiders hats—and all of them with Bibles in their hands.

"I'd never seen so many people hungry for church," he says.

By the end of the service, the Onteses were crying. Something touched them in the message they heard in that converted Safeway store. It was a message they weren't getting anywhere else and they knew they'd found a new home and the beginnings of a rock-solid faith.

"Going to our new church, we just felt fed," Arnold says. "We felt a relationship with Jesus that we just didn't have with Catholicism."

PANDA BEAR

Three months after losing Arnold III, Martha was shocked to learn she was pregnant again. "There had never been any talk about not having another baby," she says. "We never said, 'No, we're not.' We never said 'Yes, we are.'"

"We just practiced," Arnold says with a laugh. The end result of which was Andrew, nicknamed Panda Bear, who arrived Sept. 5, 1989, three weeks earlier than expected.

Leading up to her delivery, Martha said doctors watched her closely to make sure that what happened with Arnold III didn't happen again. To say the least, it was a stressful time for the Onteses. In the last trimester, Martha found herself doing a lot of clock watching between the baby's movements, while friends and family were constantly asking if everything was going well. It was, despite early contractions in the 28th week that led doctors to put her on medication.

While Andrew cried when he arrived, Arnold and Martha rejoiced. "He was moving and he was crying and we got to hold him and it was awesome and he was my son," Arnold says.

The relief was palpable, but it also was short-lived. Leaving

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Martha to recover at Kaiser Permanente's Los Angeles Medical Center on Sunset Boulevard in Hollywood, Arnold drove home to Monrovia to get some rest. The phone call from Martha came early the next morning telling him to get to the hospital—and quick.

At first the doctors and nurses considered it nothing more than jaundice, but tests soon revealed that Andrew was very anemic, his blood cell levels dangerously low. A few hours after a transfusion, his blood levels had dropped again. Thus began a cycle of transfusions that continued for a month while doctors worked to diagnose the baby.

"It seemed like every doctor within Kaiser told us that Andrew had every disease under the sun: tuberculosis, cancer, leukemia, lupus, cystic fibrosis—AIDS!" Arnold says. "Well, we were gullible. If Andrew had AIDS that meant we had AIDS—and how had that happened?"

It hadn't. The AIDS diagnosis was wrong, as were all the others. Andrew didn't have leukemia or lupus or cystic fibrosis. The truth is, Andrew's doctors didn't know what he had or how to cure him of it. What they did know was that Andrew suffered from a disease they had never seen before.

Dr. Michael Kaplan, chief of allergy and clinical immunology at Kaiser's L.A. medical center, supervised Andrew's treatment during the course of his life. "We couldn't put a name on it," Kaplan says. "It didn't fit any particular syndrome. But what we did know was that he had a disease that was very much like cystic fibrosis, with a lot of thick mucus and respirato-

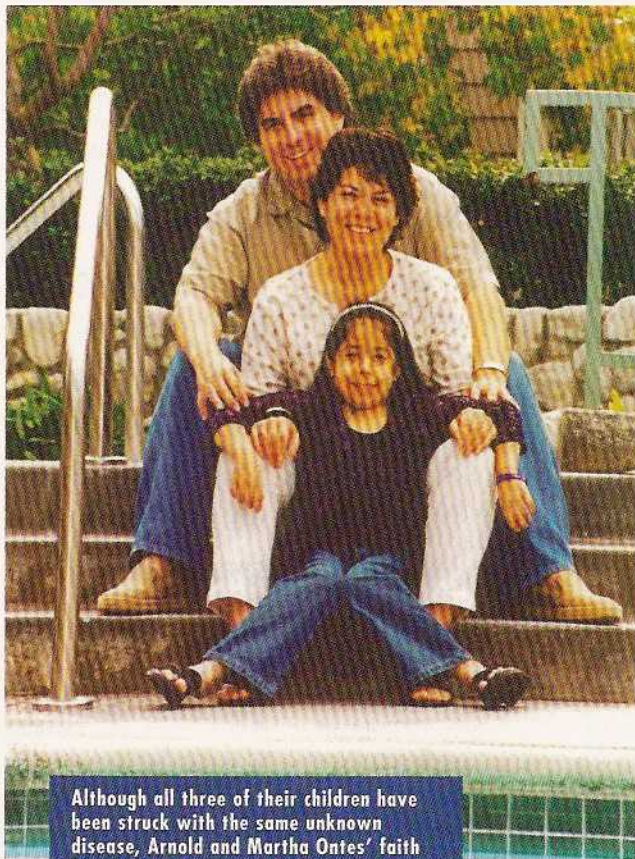
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ry obstruction and hyper-inflated lungs. He had trouble exhaling all the air and wound up just like a cystic fibrosis patient; prone to infection, having respiratory difficulty." But he was never diagnosed with cystic fibrosis. "All the tests—even the sophisticated genetic tests—came out negative," Kaplan says.

The trouble with Andrew's blood was a different matter. Not only did he have the lung disease, but he had low gamma globulin levels—he didn't



Although all three of their children have been struck with the same unknown disease, Arnold and Martha Ontes' faith keeps them optimistic about the future.

make antibodies well—and his spleen was doing too good a job of filtering out his red blood cells and making his hemoglobin low.

Ultimately, Andrew would have his entire spleen removed, which corrected the hemoglobin problem, but affected his ability to fight infection.

"He received gamma globulin regularly to compensate for that," Kaplan said.

The doctor also says Andrew was evaluated by a hematologist immunologist who thought Andrew had a mi-

cro bacteria in the tuberculosis family, but that it wasn't the regular kind of tuberculosis that immune-compromised patients might get.

"So he was being treated with an agent to boost his immune system and also being treated with antibiotics against the TB-like organism," he says.

It was akin to the medical equivalent of "pin the tale on the donkey"—in this case, the disease. "I never quite felt comfortable that we had a handle on what was going on with him and what we could do to prevent further deterioration," Kaplan says. "I never got into that comfort zone, so we wound up trying to do things preventatively, but we were limited."

The frustration Kaplan experienced in trying to help Andrew was compounded because of the personal rapport he developed with the boy over the years. To Kaplan, Andrew was much more than just another patient. "This was a good kid," he says. "Even when he was sick he was always bubbly and we had some special inside jokes between us. It was a very personal thing."

Asked if it is a case of Arnold III and Analisa having the same thing Andrew had, Kaplan replies, "It's the same, I'm quite sure."

It's mindboggling to consider. Not just the appearance of a new disease—but the fact that the three Ontes children are the only three cases reported.

'THIS GUY KNOWS GOD!'

Dale Goddard was another of Arnold's answered prayers. A pastor at Calvary Chapel in West Covina at the time, Goddard was presiding over the wedding of Arnold's friend, Tom Diaz, which was taking place a week after Andrew's birth.

"I was supposed to be in his wed-

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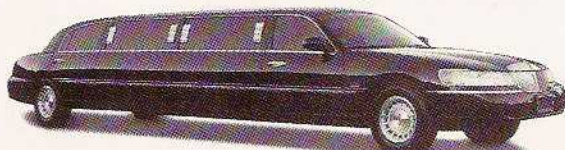
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ding," Arnold says. "Given the situation, Tom called and told me not to worry about it. But Martha was the one who said the baby's stable, go do what you have to do." At the wedding, Arnold was struck by what Goddard had to say about marriage.

"He talked about it being a rope made out of three strands: the husband, the wife and Jesus, and when you twist them around it won't break apart as long as you keep Jesus around it," Arnold says. "This was great! This guy knows God!"

After the service, Arnold felt compelled to introduce himself and remembers breaking down and asking Goddard to pray for Andrew. Goddard said to Arnold, "Let's pray right now," and they did. "I'll never forget the difference. It wasn't a Hail Mary."

What Goddard did next surprised Arnold.

"Dale asked where my son was, and said he was going to visit him the next day—and he did!" To Goddard though, making the trip to visit Andrew was all in a day's good work.

"That family needed extra help," Goddard says. "At that

point they weren't spiritually strong. When I got there that first time, Andrew was so small. They were so limited in what they could do and they were on the brink of losing another child."

That first trip was but one of many to come for Goddard. But as he watched Andrew deteriorate, bounce back and then continue to deteriorate over the years, he also witnessed the strength of the Onteses' faith continue to grow to the point that Arnold and Martha will remain strong even after Analisa dies.

"Should she pass, I am confident that Arnold and Martha would continue to grow because they have a hope

"This was a good kid," Kaplan says. "Even when he was sick he was always bubbly and we had some special inside jokes between us. It was a very personal thing."

and expectation that one day they will all be together again," he says.

MAMAS BEAR

Shortly after Andrew's second birthday, they almost lost him. Two weeks after being admitted into the hospital, he had to be temporarily paralyzed and placed on a breathing machine.

"They wanted his lungs to rest," Martha says. "And that was the first time for us he was close to death."

Then came a new but familiar shocker: Martha found out she was pregnant with Analisa, nicknamed Mamas Bear.

"We're not stupid," Arnold said. "During the time leading up to Martha being pregnant with Analisa, we were going through genetic counseling—and even the genetic counselors told us that what happened to little Arnold and Andrew couldn't possibly happen a third time. There was one thing we still wanted and that was a family—and at that time leading up to this hospital stay, we still thought Andrew was going to be OK."

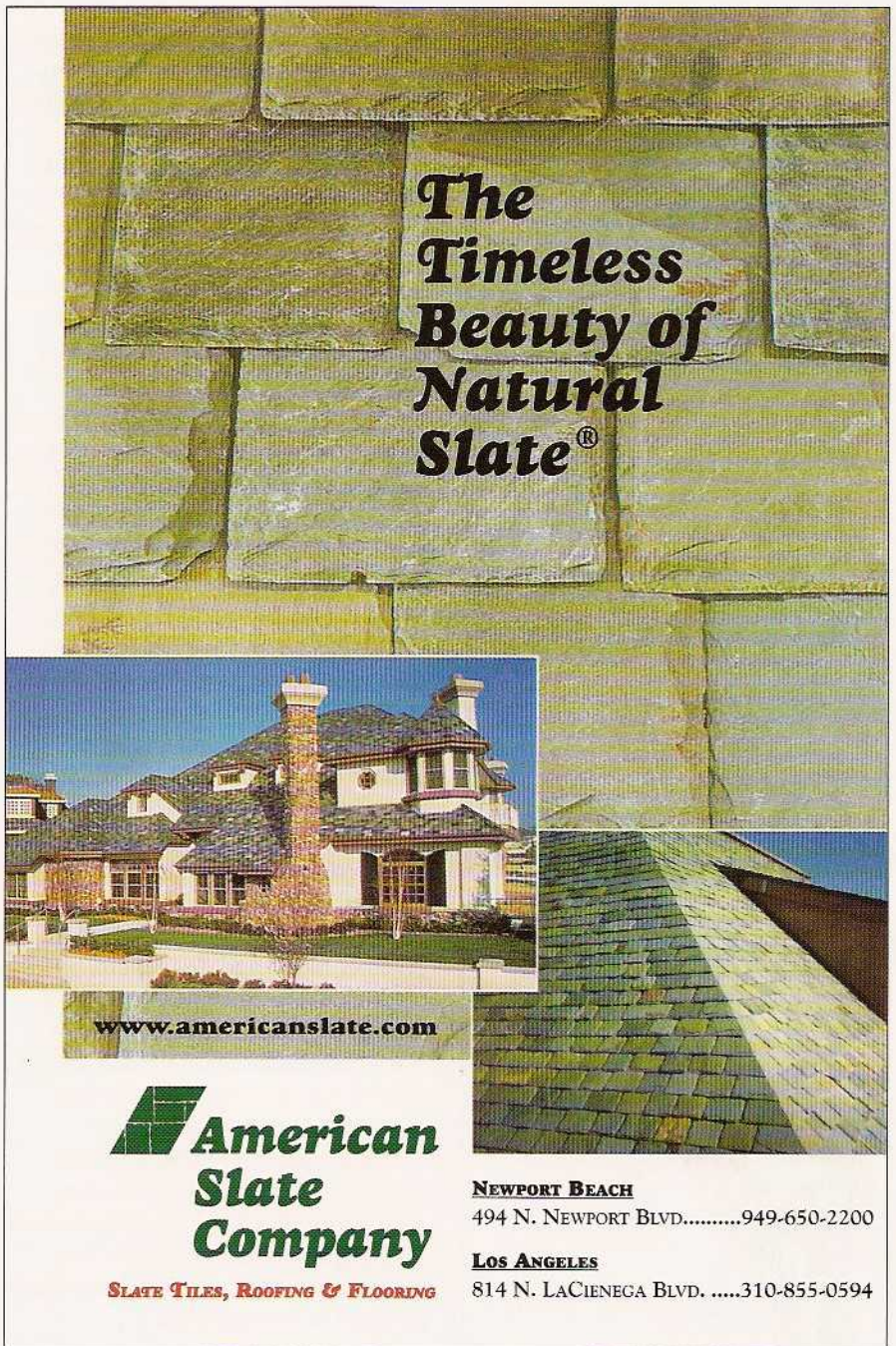
Dr. Thomas Coates at Children's Hospital helped bring that perception closer.

Coates became involved in Andrew's treatment when a nurses' strike at Kaiser Permanente at the time led to staffing complications that delayed a critical transfusion Andrew needed. In desperation, Arnold and Martha practically carried Andrew and his blood over to Children's Hospital, where the transfusion was administered.

"Dr. Coates told us that transfusions were only going so far and that Andrew was going to burn out and die," Arnold said. "From there he got on the phone with Kaiser and joined the team so that he could take care of him."

Seeing that Andrew's spleen was huge and over-filtering his blood, the decision was made to do a relatively new surgery known as a splenic embolization, in which a part of the spleen is injected with a foam to kill it off so it won't be as active. It worked. And it was as if a new world had opened up to them.

Andrew was 2 1/2 when Analisa was



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born April 23, 1992. The doctors decided to induce labor so that she was born a month early, like her brother.

"When she was born, she was pink and everything was great," Arnold says. "And I remember going to the bathroom and getting on my knees literally to thank Jesus for letting her be healthy."

But she wasn't. When Arnold next saw his daughter in the neonatal intensive care unit, she had started to turn yellow.

"It was the same as before," Martha says. "But the difference was after so many years of going through this, we knew what to tell the doctor to look for." Analisa had her spleen removed in June 1992, and Martha removed her ability to have any more children.

"After Analisa I had a tubal ligation," she says. "That was an obvious choice."

Andrew got sick soon after. "He got some of that e.coli bacteria," Arnold says, "and with his situation, that's bad."

The Onteses fell back into the familiar routine of transfusions for Analisa. They'd take her home and bring her back every three days to give her blood and do it again.

"We did that for three months," Arnold says, "up until July 4, 1992, when they both were released and able to see each other for the first time outside of a hospital."

From that point on, Arnold and Martha's life consisted of dealing with two sick kids going in and out of the hospital. And in the time that passed, they did their best to let their children be normal kids.

"We never treated Andrew and Analisa any different because of their health," Arnold says. "If they were bad, they were punished. If they were good, they were rewarded."

'I HOPE I DON'T DIE BEFORE CHRISTMAS'

"One of our plans was to move and raise our family somewhere different," Martha says. They searched from Santa Barbara to San Diego trying to find the perfect place, and South Orange County was the first area that Arnold and Martha agreed

would be a great place to move to. In 1996, they did. In that same year, Analisa began to see Dr. Rukmani Raghunathan, a pediatric hematologist and immunologist at the Kaiser Permanente Anaheim Medical Center. Raghunathan, or Dr. Ruki, as the family refers to her, was first successful in treating Analisa's lupus-like symptoms.

In September 1997, they celebrated what would turn out to be Andrew's final birthday. During a summer that was highlighted with a trip to Disney World, underwritten by the Make-A-Wish Foundation, Andrew got an infection that ravaged his lungs.

Raghunathan suggested a medicine called gamma interferon. The body produces interferon to fight viral infections. "The interferon did seem to help," Raghunathan says. "But the problem was that his lungs were so totally shot by that time." But death was not an option for Arnold.

"Even though he was on oxygen full time, if someone had told me he'd be dead in three months, I'd say 'No way,'" Arnold says. "It was the furthest thing from my mind."

"But if you looked at him," Martha counters, "he was just skin and bone."

"I remember him saying to me 'I hope I don't die before Christmas,' because he thought he was going to get a puppy," Arnold says.

The Thursday before Andrew died, Arnold and Martha took him to the hospital, where for the first time, his doctors were saying they didn't think he was going to make it. He woke up one last time, Dec. 8. Two days later, he was gone. Arnold, scrambling to get a job finished in Orange County, was on his way back to Martha, who was at Andrew's bedside in the hospital in Hollywood when he died.

"When she was born, she was pink and everything was great," Arnold says. "And I remember going to the bathroom and getting on my knees literally to thank Jesus for letting her be healthy."

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"At that point, it was enough," she says. "When I saw the numbers going down on the monitor, it was like 80 pounds went off my shoulders. He's gone now, but I know where he went. He's with God now and I know he's better where he's gone."

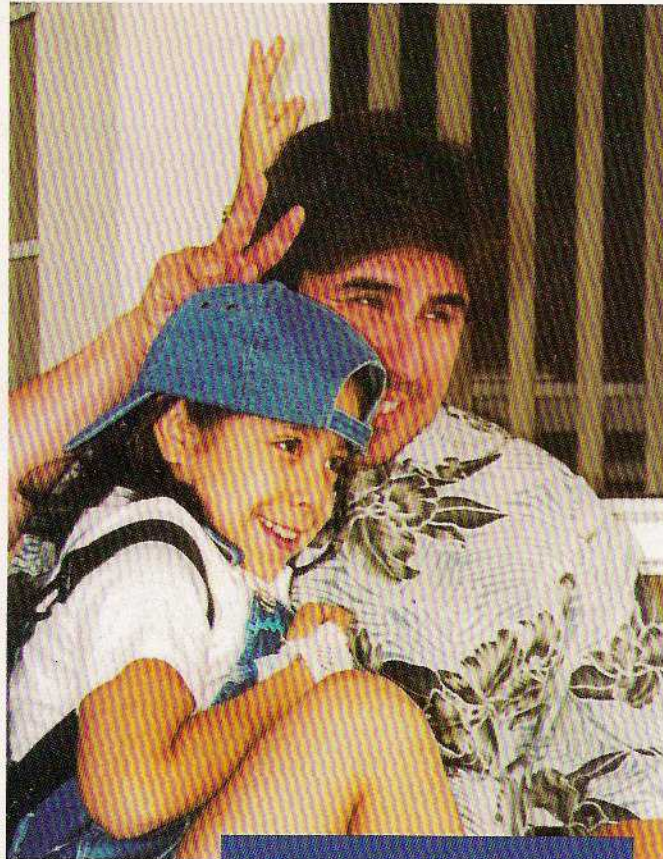
But after Andrew's death some cracks emerged in the strength of Arnold's faith. Doubts and questions manifested themselves after he was not able to be there during his son's last moments.

knows otherwise.

Analisa wanted her dad to take her to a nearby Christian bookstore, but he wasn't interested until Martha stepped in and told him to take her. He reluctantly agreed.

"We get there and Analisa heads to the kids' section while I go down an aisle, look down and see this book. So I picked it up and started reading it."

Immediately overcome, he put the book down, brought Analisa home and



Arnold and Analisa pose for Martha as she captures a moment on the family's patio in Trabuco Canyon.

The Thursday before Andrew died, Arnold and Martha took him to the hospital, where for the first time, his doctors were saying they didn't think he was going to make it. He woke up one last time, Dec. 8. Two days later, he was gone.

"I finally broke down and said to the Lord, 'If you're real,

you've got to help me. If you're real, tell me why wasn't I there? What was it like when you took him? Does he think about me? Is he waiting for me? Answer those questions if you're real and you really care.'"

The answer came in the form of a book titled *Mommy Please Don't Cry*, by Linda DeYmaz. In it a child who has died talks to his parents from heaven. How he came upon the book is an end result that plenty of people would dismiss as coincidence, but Arnold

told Martha—who started crying as well. He realized he had to get that book, but when

he returned to the store the next day, it was nowhere to be found.

"I went to the salesperson and told her I was looking for a book called *Mommy Please Don't Cry*. I pointed to where I'd seen it and she looked at me like I was from Mars."

She led him to a different section of the store than where he found the book, and there it was, on the bottom shelf. The employee told him that there was no way it would be where he said it was, unless somebody had misplaced it there.

"I was just so thankful. God didn't answer me in a way that was obvious, he did it in a way that was spectacular." And it allowed Arnold to recapture the peace that had been missing after Andrew's death.

AT THE PRESENT

In the quiet of the Onteses' living room after videos of Andrew have stopped and the television has been turned off, Analisa's labored breathing is the only sound. Arnold asks his daughter if she is OK. Analisa nods and climbs up into his lap. After Andrew's death, Raghunathan had Analisa tested extensively through the National Institute of Health.

"We needed to see if she had problems with interferon production, or problems with the interferon attaching to the appropriate cells," she says.

It took more than a year, but the results of the tests showed Analisa was not producing the cellular protein that inhibits viral growth.

"She was getting a lot of infections and on antibiotics all the time," Raghunathan says. The good news is that the interferon has helped Analisa significantly. But her doctor is cautiously optimistic about her patient's prognosis. "She has preexisting lung damage and that's going to be the problem," Raghunathan says. "She may not live to a ripe old age of 85, but I think her chances are better than her brother's were."

So the Ontes family takes it one illness at a time. In late October, a high fever put Analisa in the hospital, but medication knocked it down and brought her home early.

If doctors do ever isolate and identify the exact causes of Analisa's disease and from there develop a cure, certainly the Ontes family would consider it another one of its many answered prayers. But the cure for the Ontes family at the present is the inner peace that comes from knowing one day will come when Arnold, Martha, Boo Boo Bear, Panda Bear, and Mamas Bear will be reunited in heaven. **OC**

William Campbell is a freelance writer based in Los Angeles.

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