

Savor Every Smile

BY JOE NIAMTU III

For many people, Father's Day is just another Hallmark holiday when obligatory tribute is bestowed on the traditional head of the house.

Father's Day for most of us is a day to celebrate or remember our father and to celebrate the privilege of fatherhood and family. There are many spins on this day, as some people never knew their father for various reasons ranging from abandonment to dying while fighting for our country.

For some people it is a painful day, as their relationship with their father or children was absent, lacking, or dysfunctional. For the average family this holiday will probably include some cards, phone calls, unwanted socks and ties, and a picnic.

For me, Father's Day is a holiday filled with emotions that tap both ends of the spectrum — happy and sad. I am grateful that my father is 86 years old and still going strong. I will certainly call him in Ohio and wish him a happy day while at the same time fight back emotions that this ritual is limited.

I think back to the hard work ethic he instilled in me — and the attribute to never quit, no matter what. I think about how he came home from WWII to become the first child of our immigrant family

Show me parents of special-needs children and I will show you tough people.

to obtain a college degree. I think about how hard he worked to raise four kids and what an example he set for me as a provider, protector, gentleman, and humorist who wanted his children to have a better life than his generation — and to pursue excellence in whatever path we chose.

My dad worked hard, which set an example for me, and when my accomplishments make him proud, I feel I am paying him back for sacrifices made.

Being the father of two profoundly disabled young sons certainly adds other layers of emotion to Father's Day for me. Most men take for granted the lifelong dream of having a normal, healthy son. Every father, before achieving that status, had thoughts of raising a namesake, teaching him how to fish or hunt or throw a ball or do the big and little things in life.

It took me a while to find the girl of my dreams, and my first son and namesake, Joey, was born in April



BOB JONES JR.

Joe Niamtu hugs older son Joey and his wife, April, hugs their younger son, Evan.

2000. The first three months of fatherhood seemed normal, but Joey began having seizures and missing milestones. He was diagnosed with severe cerebral palsy, and we were told that he would never walk or talk or mentally develop.

He had numerous gastrointestinal problems and went through several operations in his first years of life. Obviously, this was a huge emotional setback for all of us. I can't tell you how helpless you feel

as a parent to know that your child will never grow up, never experience a normal life, never progress.

One of my prime concerns was worrying about who would take care of Joey if something were to happen to me or my wife. I wanted to have another child for many reasons. I wanted a family member who would always watch out for Joey so he would never wind up in an institution. I also wanted to experience fatherhood with an able-

bodied child, and do all the things that dads and sons do:

We underwent significant genetic counseling, blood tests, etc., and were told that Joey's condition was a genetic mutation in early pregnancy and that having another child with the same situation would be very rare. I was elated when my wife, April, became pregnant with our second child.

See SMILE, Page E5

SMILE

From Page E1

We underwent intense and high-risk neonatal care with amniocentesis and multiple ultrasounds. All tests appeared normal and we found out that our second child was a boy and named him Evan. Evan was to be my savior. He would be Joey's protector in the future and my son who, unlike Joey, would be able to experience the things that all fathers (and mothers) want to do.

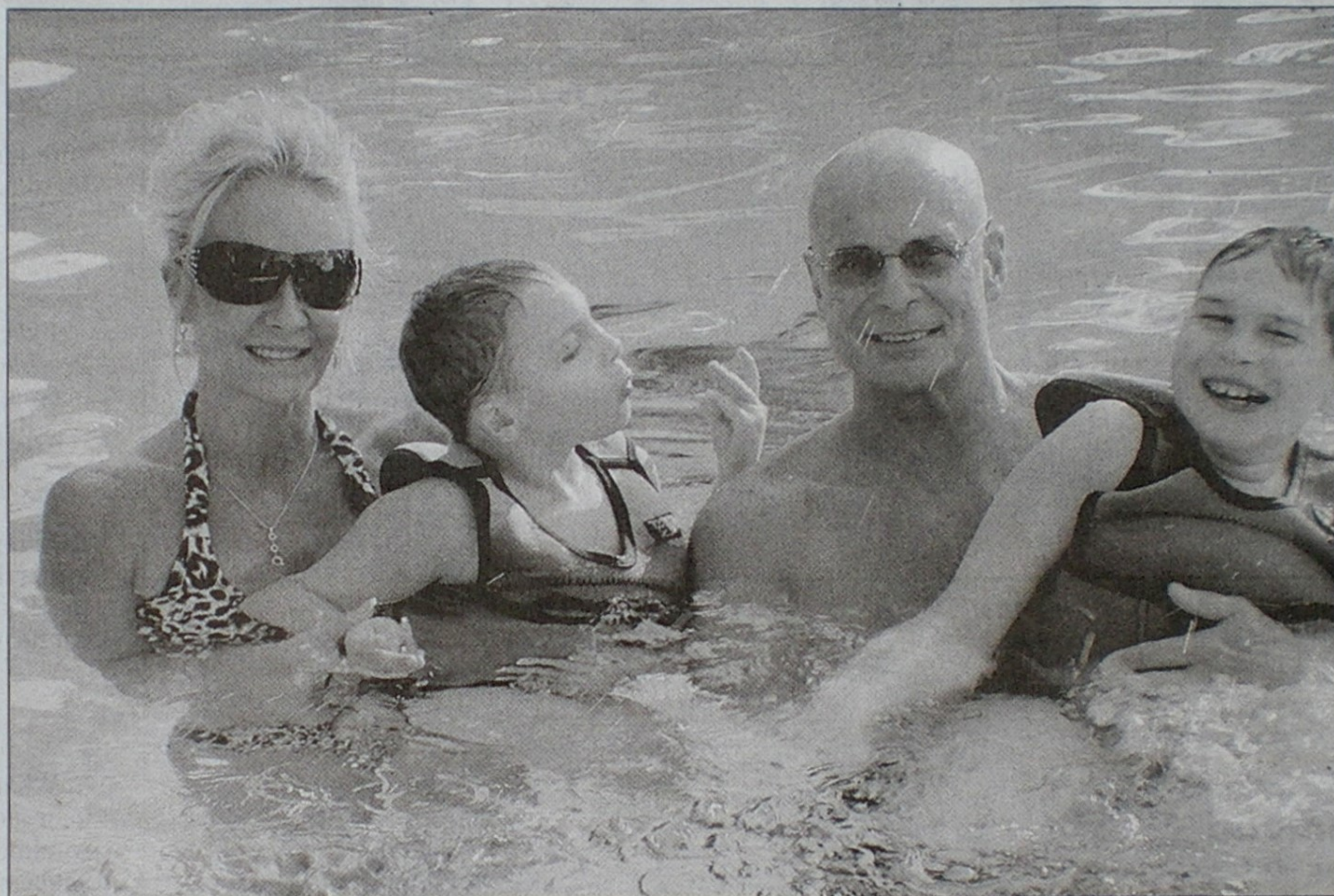
Evan appeared normal and healthy at birth, but he did not roll over or crawl and began missing milestones. The pattern was all too familiar; we had seen it with Joey. Our worst concerns soon came true: Evan had the same syndromes that Joey had. He began having severe G.I. problems and also required numerous operations. April and I spent so many weeks in the hospital or emergency room that it became a way of life.

My wife is the strongest person I know and my sons are my soldiers.

The reality of my life is that I have 8- and 10-year-old sons who are tube-fed, will always be in diapers, will never walk or talk, and will always be 100 percent dependent. It hurts to know this, it hurts to even write this, but it is my life. I will never hear the word "Daddy" and will never get to experience the joys of fatherhood.

I am a dedicated teacher and it hurts me that I cannot teach my sons about all the wonders of life and the human body and how things work. It hurts me that I cannot watch them learn or prosper. I will never see them make friends, go on a date, hit a home run, go to the prom, or get a diploma. All parents with special-needs children have looked at other children learning, running, playing, and laughing — and thought about "how it could have been."

Any parent of a special-needs child can relate — can attest to the



FAMILY PHOTO

April, Evan, Joe, and Joey Niamtu.

difficulty in falling asleep at night due to the fear of the future and the perseverance needed to get through tomorrow. We worry about a lot of little things: Who will carry on my family name? To whom will I leave my cherished possessions? How will I move my sons when they get too heavy to lift?

In reality these concerns are not important — only getting through tomorrow is important.

So what keeps us going? The positives keeps us going — and there are many.

First of all, I am happy that my boys are alive — there have been some very dark days in the ICU at Chippenham hospital when I was not sure if they were going to make it.

And there is the reality that although our situation is bad, others have it much worse. I am lucky that I can afford to keep my children at home and don't have to institutionalize them. That loss would be in-

surmountable. There are many families who cannot do this and there are many single mothers with special-needs children who cannot afford ramps, special vans and equipment, and around-the-clock nursing. I am grateful that I can.

Our situation has also made us advocates for children and families with special needs. We can help others and make the world better by spreading the word and being proactive for those who cannot speak or think for themselves. Unfortunately, when state budgets get tight, the first expenses reduced are social services and the most helpless get the short end of the stick. I have always been a champion for the less fortunate and have done much pro bono surgery and work over the years, but I now have an even bigger reason to do so.

All parents love their children, but the love with a special-needs child transcends description. These

children are entirely reliant on their caregivers and this special bond of love is so hard to put into words — but you can see it and you live it.

My children can only laugh or cry. These are their sole emotions. My job is to make them laugh as much as possible — and if I can get a smile before I leave for work and one when I get home, my day is complete.

Compared to normal families, we live in a world of "different." Our normal is different from your normal. Playing my guitar and making my boys smile and laugh is the same as a normal parent watching his son score a goal or get an A on a test.

Another positive feature of this experience is that it makes you re-evaluate priorities in life. It makes you never take anything for granted, or sweat the small stuff. It has also given me tremendous resolve knowing that if I manage and stay strong with my children's situ-

ations, the rest of life is easy. Society has a lot of definitions for what constitutes a "tough" person; show me parents of special-needs children and I will show you tough people.

It makes me sad when I see parents screaming at or spanking their kids, knowing that if they could just spend one day at my house, they would view their children differently. We take so much for granted, including having healthy children, it seems so easy.

I would urge parents to never take a single second of their child's life for granted, as life is a short and fragile thing. I would urge all parents to savor every second and to kiss their children as much as possible. I also want people to understand that there are many families out there that are barely making ends meet and they need help and advocacy. Groups like Greater Richmond ARC are lifesaving for many local families — and they rely on generous financial support to assist those who so desperately require their services.

My good friend and Hall of Fame quarterback Jim-Kelly had a special-needs son who died when he was 8 years old. His wife, Jill, told me that if she had it to do all over again, she would do it the same way: Her son Hunter changed their lives and the lives of so many in so many ways. He made the world better.

So, Father's Day is different at our house and, for that matter, every day is different at our house. There are enormous challenges but also enormous rewards. Rewards that are deep and pure and cherished; very much the same as a normal family's — yet also very different.

Although my sons have never spoken a single word, they have taught us so much about love and so much about life. If I get a smile from Joey and Evan on Father's Day, it will be a perfect holiday.

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