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Dr. Joe Niamtu

Encouraging all Richmonders to "Help Dr. Joe, Help ARC," Dr. Niamtu will appear in a Greater Richmond ARC commercial this coming week.

Stephanie Brummell

Richmond.com

Monday, April 14, 2008

"Spend a day in the home, or in the life, of a person with a disability. It draws the compassion out of your body to the point you didn't know you had it."

For maxillofacial surgeon Dr. Joe Niamtu, a major goal in life was to raise a son, experiencing all the joys of fatherhood while also passing along valuable life lessons. When his wife April gave birth to not one, but two sons with incurable brain damage, those goals change. As the honorary spokesperson and longtime advocate of the Greater Richmond ARC (Association of Retarded Citizens), Dr. Niamtu is asking all Richmonders to "Help Dr. Joe, Help ARC."

Have you always lived in Richmond?

Nope, I'm originally from Canton, Ohio.

What brought you to Richmond?

I did my maxillofacial surgery residency at MCV and I liked it here, well loved it here, and so I stayed here.

Can you give me a little background on Greater Richmond ARC and their mission?

The Greater Richmond ARC is a group that helps people throughout their entire lifespan with mental and physical disabilities. That's their goal. And they provide so many services, all the way from infant intervention to summer camps, to employment for people with disabilities, therapy, which leads into how I became acquainted with them.



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And what is your experience with ARC on a personal level?

Well, unfortunately it's extensive, and no one is ever affiliated with a group like this because they wanted to be. I didn't get married until I was 48 years old; I held out! But I got married and wanted to have a son to take fishing, throw the football with, have follow me around the hospital and what not. So we had a son and named him after me, Joey, in April of 2000. At about 3 months old, he started having seizures and we went to the hospital and they told us our son had brain damage, other severe problems and that he would never be normal. They called it cerebral palsy, but they really didn't know what it was. So there we were saying, "Now what?" You don't know anything that you'll need – speech therapy, occupational therapy, wheelchairs, feeding tubes, oxygen – all these things that you know nothing about. Needless to say, you're worlds on end, just the emotional impact from having an abnormal child. So we found out about ARC, called them, and that one phone call took care of everything. Within probably a day, we had people and support and equipment; it was just unbelievable.

You also have a second son, Evan. Can you tell me about him?

I wanted to have someone who could take care of my son, because I'm not going to be here forever. We went through a lot of genetic testing and high-risk neo-natal care with amniocentesis and extended CT scans, and we were told that having this happen again, would just be a fluke. So we had Evan, in 2002 and, unfortunately he had the same thing.

What was your reaction to a second son born with the same defect?

There's nothing good about any of this, I have two beautiful, normal-looking kids, and it's unfortunate that they're always going to be at an infant level. But if there is anything good to say about it ARC, again, was there for us and has been there for thousands of families throughout the Greater Richmond area. And I'm lucky that I have the means to be able to keep my children at my house and not institutionalize them and there are a lot of people out there who have it equally as bad, or worse, than I do and ARC is just a tremendous organization. If I could sit down and explain to a group of people, my firsthand experiences with them, they would support this charity above many others.

Can you tell me about your position as honorary spokesperson for Greater Richmond ARC?

Well, I'll tell ya, there are some things I can't do well – I'm not a good dancer or singer – but I do a lot of public speaking in my job, I speak all over the world on cosmetic facial surgery. So, I can command an audience and get a point across while keeping people's interest. Coupled with the passion from being involved with this organization on a firsthand basis and wanting to help other people, I think that they saw a use for me within ARC to help spread their word, so they asked me, which was an honor. My wife helps as well, because from a mother's aspect, there's a whole different side to this story.

Can you elaborate on what you meant when you said your children will always be at an infant level?

Their ability to function will always be at a one-year-old level. If my children were sitting on a couch and you walked in



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the room, they look like a normal 6- and 8-year-old. But they can't walk, they can't talk, they can't do any purposeful movement; they are tube fed and will always be in diapers. It's a pretty tough pill to swallow.

What are some of the biggest challenges you've faced raising your two sons?

It's a tremendous disappointment in life, times two. And, you know [having children] is what you're supposed to do and it gives you something to live for and things to do for the rest of your life. So, watching these guys every day not progressing and seeing children their age that are running and jumping and yelling and singing, is extremely tough. It's something that I think about every minute every day; it's a loss and it's a grieving process. Unlike a death, which is a final situation, it's very sad and you grieve, but it's a terminal situation and it's done. This is something that is kind of reversed, because it's always there and you have to continually watch these little babies get older, and the problem is, the future only brings more problems.

What are some of the things you've learned from this experience?

I've learned a lot about love, at the purest level, and a lot of about life. You know, even though my sons can't communicate verbally, I can put them on my lap and make them laugh. So where someone else's child may score a soccer goal or a home run or get an A+, my version of that is just getting a simple smile from one of my sons. And that just lights up my heart. It makes you look at life different and it makes you very sensitive to other people's problems because you realize what hardships they may be going through. And it makes you also proactive in wanting to improve things or change things or make things better for people. Unfortunately there's no miracle cure for something like brain damage, but I know the pain of it and I want to help other people who have that pain because it kind of guts you. You feel pretty empty and pretty hollow. But, they didn't come with receipts, and my job is to provide them the best life possible and to love them and nurture them and make them comfortable.



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It was announced in the beginning of April that you will be premiering in a TV commercial this week. Is this your first TV spot as an advocate for ARC?

This is actually the second series. We made this commercial down in a big, old, empty warehouse down in Shockoe Bottom late one night after work. And things just came together. When I watch this thing, it even makes me cry. It was just one of those candid moments where I had a very good interviewer who asked very potent questions and my answers were commensurate with what I'm going through and they're from the heart. It's a very emotional commercial; there's a short version and a long version. The short version is just your typical charity callout, but the longer version is really a heartfelt rendition of some of the problems that people with children with disabilities face. I'm proud of it because it was the right mood at the right time with the right person and it came across from the heart and from the soul; I can definitely say it's a very front-line representation.

I'm assuming you didn't have stage fright then?

Stage fright is not one of my problems; the bigger problem was probably the reflection off my bald head! If anything, I was maybe a little embarrassed because I was emotional in my responses. My voice was shaking a little bit, my eyes were tearing. I'm usually an upbeat person, talking about upbeat stuff, and this was just a different type of interview.

In summary, what is your message?

One of my personal goals in life is to take the misfortunes that have happened to me, and since my children will never



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be able to say a word, my goal is to speak for them and to speak for ARC. I'm a big supporter of them, both working and financially, but no one person can do it by themselves, and so my goal is to help people, help me, help ARC. And I want to do that through and for my sons.

Going back to the name Greater Richmond ARC, some months ago legislation to remove the term "mentally retarded" from all state code was brought to the General Assembly. What is your position on the use of this term?

I think it's a politically incorrect term and I think it's as off-color as other politically incorrect terms, whether they be religious, racial or what have you, and unfortunately the word "retarded" is pervasive in pop culture. I don't think people use it intentionally to be mean, but I want to tell you this, when you have a "retarded" child, it hits your spine like a lightning bolt. So, yes I have very strong feelings about that and I would love to see ARC change their name to something to do with "adults and children with disabilities" or "special needs citizens." Unfortunately, ARC is a big national organization, and I think the change will happen one day, but it's one of those deals that as much as I don't like the name, that little fact is so overshadowed by how they help people and what they do.

Are there any upcoming events with ARC that you would like the public to know about?

Yes, they have their annual wine tasting event which is the last Saturday in April, the 26th.

[The Greater Richmond ARC Ladybug Fund Wine Tasting and Silent Auction will be held from 5 to 8 p.m. Saturday, April 26 at Plant Zero, located on Zero E. Fourth St. Tickets are \$75 per person. For tickets and more information, call Yvonne Verno at 804-358-1874.]

They also have a golf tournament and a number of different events and benefits. The bottom line is, when I talk to people I tell them that everybody is probably going to support some charity at some time. And all charities are worthy, but this is something that is right here, in their own town, that is a direct benefit to people in our community. This organization really helps people from the cradle to the grave, it really does.

Beyond the events that Greater Richmond ARC hosts, what is the one thing you wish Richmonders would do to raise more awareness and gain more knowledge themselves.

I think it would be such a huge learning experience for every person, especially younger children, to spend a day in the home, or in the life, of a person with a disability. It draws the compassion out of your body to the point you didn't know you had it. When you see how tough some people really have it makes you really thankful for what you have. You know my children will never taste ice cream. They'll never go on a date or kiss a girl. The list of things they can't do is endless, but again, what they can do is they can inspire people to help others, and there are so many people with disabilities who could benefit from local compassion.



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What do you admire most in another person?

The ability to have fun and appreciate life, physical fitness is very high on my list, and motivated people of any kind. I love being around motivated people and I hate being around people that are not pursuing their full potential.

What is your favorite spot in Richmond?

My favorite spot in Richmond is the James River, because that's what kept me in Richmond. When I was a resident at MCV, I fell in love with the James and one of my dreams was to move here and live on the James, so that's what I did. I love being home with my children and out on the river.

What makes your position as honorary spokesperson for Greater Richmond ARC the best job?

Making a difference in the lives of the ARC target people, meaning people with disabilities, and also showing the light to citizens in the city who aren't aware of all that ARC doesn't.

What would be the best compliment someone could give you?

That I did, in fact, make a difference in the lives of people through what I do for a living and for what I do through charitable organizations. That I've stood up for the little guy, for the people who can't stand up for themselves.

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