

Community Focus

## The Spirit of Service

### Two Richmond moms dedicate themselves to spreading the vision and mission of FightSMA.

Katherine Houstoun

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Behind every successful non-profit organization lies an effective fundraising machine. And behind every effective fundraising machine lie the people who devote their time and energy toward raising those necessary dollars.

For **FightSMA/Andrew's Buddies**, a Richmond-based nonprofit organization that raises awareness and funding for Spinal Muscular Atrophy (SMA), two of those individuals are **Denise Barns** and **Leslie Griles**, the co-chairs of this weekend's **SMAsquerade** event.

SMAsquerade benefits research for SMA, a progressive muscular degeneration disease that is passed from parents to children through a recessive gene. One in 35 people carry the life-threatening gene – unknowingly – and there no cure or treatment. SMA kills more babies under the age of 2 than other genetic disease.

As young mothers, both Barns, who has two children under the age of 5, and Griles, whose son just turned 1, can empathize with those who unknowingly pass on the gene to their children and wake up to find one of them debilitated by the incurable illness.

"I think the statistics are staggering," said Barns, 34, a stay-at-home mom. "You're at a small cocktail party and one out of 35 of you is carrying a gene, unbeknownst to you, and if you marry a person with that same gene, you have a chance to have a child with a severely debilitating disease that is life-threatening, and you don't know it."

FightSMA/Andrew's Buddies was started 15 years ago by **Joe and Martha Slay**, whose son **Andrew**, now a student at the University of Virginia, is afflicted with SMA. The organization, which has spun off 17 chapters throughout North America, has been integral to raising funds for SMA research. Last December, FightSMA launched a **SMart Board**, composed of 30 young Richmond women, including Griles and Barns, who currently serves as the board's president.

"We wanted to form a nucleus of young women who could really carry the responsibility for our chief fundraiser here in Richmond, which really serves as a model for all of our other 17 communities," Martha Slay said. "Many of these young women will be moms, if they're not mothers already, and it's a sensitive and vulnerable area in their lives, so they will be naturally very empathetic to the plight of SMA moms and children."

"Our mission has two focuses," said Barns of the SMart Board. "One is to spread awareness, obviously. If all of us can get more people involved in just knowing about it and spreading the word, that's huge. The other aspect is the fundraising."



Pat Kane / Richmond.com

Denise Barns and Leslie Griles are co-chairs of the 2006 SMAsquerade FlightSMA event.

This Saturday's SMAsquerade event, which will be held at the **Virginia Aviation Museum**, will be a combination of those two focuses.

"One of the things Denise and I agreed on was that we want to bring in tomorrow's fundraisers and supporters of FightSMA: people who can't afford to bid \$10,000 on a live auction package but who want to get involved with the organization," said Griles, 33, who works at Slay Public Relations. "We've created some really fun ways for the under-40 crowd to get involved in the organization."

The two co-chairs have worked tirelessly to put together the event, which will feature a pretty hefty live auction, including a private jet trip to New York City and a VIP trip to Los Angeles, and flight-themed details, including stewardesses, traffic directors and an appearance by the Red Baron. Though the responsibility has taken them away from their families, both agree that the effort has been worth it.

"My four-and-a-half year old is old enough to know what I'm doing," said Barns, who once worked in development for the Muscular Dystrophy Association and the Make-a-Wish Foundation. "I watch her and her little friend play and she'll say, 'I'm going to a meeting for FightSMA. I'm going to go help the sick kids.' She knows this is a normal thing; moms and dads do this. It's becoming part of her vocabulary. To me, that's the biggest lesson I can give her."

For Griles, who has been volunteering with FightSMA for eight years, it's all about the results.

"At the end of the night, everybody will go away with this incredible sense of the organization and the cause," she said, "but beyond that, it truly comes down to the dollars and what those dollars will do. This organization really is about research. We spoke with a mom and daughter yesterday, and she said, 'FightSMA was there for me since hour three of the diagnosis. And they've been there for me every step of the way...' And that's what those dollars go for. That money really does go to changing people's lives."

- SMAsquerade FlightSMA takes place Saturday at 7:30 p.m. at the **Virginia Aviation Museum**. The black-tie event will feature live and silent auctions, first-class fare and music by Trademark. \$125 per person. Tickets are available in advance and at the door. Call (804) 515-0800 for more information and to volunteer with FightSMA/Andrew's Buddies.