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Masquerading to raise money to fight disease

Charity ball's proceeds will go toward helping children with spinal muscular atrophy

BY BOB RAYNER

TIMES-DISPATCH STAFF WRITER

Andrew's Buddies has raised millions of dollars to help children around the world.

But tomorrow night, the Richmond group's legendary flair for mixing good times and good works will be devoted to a decidedly local cause.

Proceeds from a Venetian-themed masquerade ball and live auction at Tredegar Iron Works will help finance clinical trials at two Richmond hospitals.

The trials will test drugs that could combat spinal muscular atrophy, a disease affecting 20,000 American children.

SMA weakens children's muscles, robbing many of the ability to walk. For some, it steals their lives, often before their first birthday.

Andrew's Buddies has raised \$4.3 million since it was founded a dozen years ago by Richmonders Joe and Martha Slay. That money has helped spur and pay for scientific advances that have unlocked many of the mysteries surrounding the causes of SMA.

Last year, the group — named for the Slay's son, Andrew, a high school senior who has SMA — donated \$1.3 million for research on the disease.

Now, doctors and scientists are testing drugs and formulas that could for the first time restore some muscle strength to children weakened by SMA.

Clinical trials, some already started, are planned for 15 medical centers in the United States and Canada. Virginia Commonwealth University Health System and Children's Hospital of Richmond will be conducting trials here, which should begin in the next six months.

"Many of the mysteries of spinal muscular atrophy have yielded to the relentless efforts of the world's most talented and devoted molecular genetic scientists," said Dr. Robert T. Leshner, a VCU professor of neurology, pediatrics, physical medicine and rehabilitation.

"Those of us committed to the care of children afflicted with life-threatening genetic neuromuscular disorders believe that SMA will be the first of these diseases conquered by the joint efforts of basic scientists and clinical investigators."

Saturday night, Andrew's Buddies will be doing what it does best: getting the word out, bringing people together and raising money to battle the disease.

SMA'squerade, billed as a Venetian carnival, will feature flame-throwers, jugglers, music, food, drinks and masks.

The live auction offers a chance to bid on jewelry; trips to Cancun, Mexico, Palm Beach and a fly fishing resort in Idaho; even an elaborate Venetian mask designed by local artist Susan Cologne.

Masks and costumes, by the way, are not required.

"It's a chance to help defeat a childhood killer and attend a great party," Martha Slay said.

The clinical trials, which will test drugs already approved for other diseases, are an important advance in drawing that killer's defeat a bit closer.

"We're hoping to find a sensible treatment program for SMA kids that will result in an improved life for them," said Dr. Susan Iannacone, a Dallas pediatric neurologist who is coordinating the national clinical trials.

"If we can make the kids stronger, they'll be able to do more than they can now. In the most severe cases, it could mean that infants will be able to survive with some quality of life."

Right now, they don't survive.

The trial isn't expected to bring any miracle cures, Iannacone said, but there's hope that it will find effective treatments for SMA.

Researchers here helped get the trials going by developing a system for testing the muscle strength of patients, providing a means to evaluate whether the drugs are working.

"The people in Richmond have been real important to us," Iannacone said, and they have "continued to help us with our funding. We never have enough money."

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If you go

The details: Andrew's buddies SMA'squerade starts at 8 p.m. tomorrow at Tredegar Iron Works and Gun Foundry

The cost: \$100 per person. Visa, MasterCard and checks accepted

Reservations: Call (804) 698-8839 or go to www.fightsma.com