



Sarah Schwegel, 17, will be a TV star on Labor Day weekend.

Sarah, a Kirkwood resident, recently taped a film on her life that will air between 12:10 and 1 p.m. locally on Monday during the national Muscular Dystrophy Association (MDA) Telethon.

Right after the film, Sarah will be interviewed in a live segment.

That's because, a decade ago, she was named national goodwill ambassador for MDA.

"I loved it, the whole experience," said Sarah, as support dog Gracie, a 9-year-old black Labrador retriever, snoozed near her motorized wheelchair. "During 2001, I went all over the country to corporate sponsor events, to talk to people about why it's so important to help MDA. And getting out of school to do all the traveling was awesome."

When she turned 8, Sarah even got a "happy birthday" phone call from telethon host Jerry Lewis.

"He's hilarious, so goofy, even clowning around at our photo shoot for the cover of Parade magazine," Sarah said.

These days, Sarah, a senior at Kirkwood High School, prefers to stay behind the scenes of the telethon, which is based locally at Grant's Farm.

She and her mother Sandy Kline will be soliciting volunteers and working in the "money room" Sunday and Monday, helping to count cash from game booths and from donors dropping by.

Sarah was diagnosed, just after her first birthday, with spinal muscular atrophy (SMA), a motor neuron disease which causes severe weakness of all voluntary muscles.

But she doesn't let the disease slow her down.

"I get tireder and sick more often than other people, but I just live with it," she said.

MDA has provided, from the time Sarah was a tot, assistance with the purchase and repair of her wheelchair, free MDA summer camps for 11 years at Babler State Park in Wildwood, and free visits to the MDA clinic at Children's Hospital.

When Sarah was first interviewed in 2000, she had been serving as MDA Missouri Goodwill Ambassador, because of her commitment and support of local activities.

"The national group asked our local MDA chapter to send them a profile that Mike Bush with Channel 5 had done on me," Sarah said. "From that, I was selected to interview and have a TV profile made of me to air during the national telethon."

She and her family were flown to Los Angeles, then the telethon's headquarters. It's now in Las Vegas.

"After the profile was shown and my family and I were interviewed, we were leaving the stage when Jerry Lewis came up and asked me to stay," she said. "He basically told me he thought I was cute and funny and wanted me to be the national goodwill ambassador for the coming year."

These days, Sarah's got a lot to keep her busy.

She's a member of the National Honor Society. She swims and likes to read. She's active in her Concordia Lutheran Church's youth group and HiLights youth praise band.

And she's goalie for the Firecrackers, a Disabled Athlete Sports Association power wheelchair soccer team. She'll soon travel to tournaments in Minnesota, Tennessee, Indiana and elsewhere.

"We came in fourth place in our division in the national tournament this year. It's a really cool sport," she said.

With a 3.6 GPA, Sarah's applying to Washington University and Maryville University.

"I'm really interested in occupational therapy, through maybe rehab counseling or a public health degree, with maybe a minor in political science," she said.

Sarah looks at what she can do, not at what she can't.

"I don't feel SMA affects my life that much," she said. "If there is something I can't do, I find something better to do."

By Mary Shapiro