

# Show of support lifts spirits as fight continues against incurable disease

## Mother continues search for kidney

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Joy LoSchiavo's bright blue eyes shine as she watches her daughters Jianne, 9, and Julia, 5, sing, dance and play.

Then, sadly, she talks about her greatest fear: not living long enough to see her children grow up.

She may not.

At 31, LoSchiavo is battling a rare, often fatal autoimmune disease, called scleroderma, that progressively attacks skin/connective tissues and even internal organs. There is no known cause — or cure — for the disease.

More than a year ago, LoSchiavo, an Orange resident, lost kidney function because of scleroderma. She was diagnosed with the disease 5 1/2 years ago and could die without a transplant.

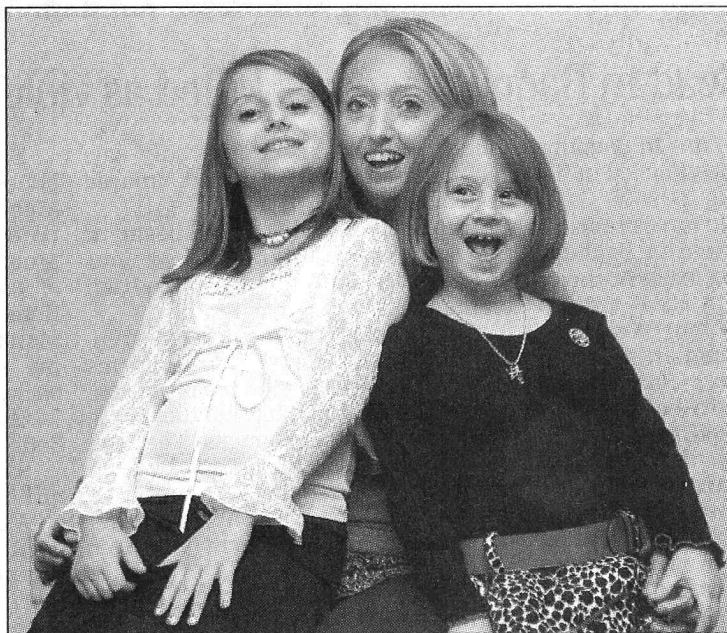
During a recent fund-raiser in Stratford to benefit the American Society for Scleroderma Research, a foundation established and run by her father, Stratford Deputy Police Chief Joseph LoSchiavo, Joy was extremely weak after undergoing one of three weekly dialysis treatments that keeps her alive.

Nearly 300 people, including Stratford Mayor James R. Miron, showed up for the Nov. 11 event at Liedle's Catering in Stratford.

Joy and her daughters were there, along with about a half-dozen others who suffer from the disease.

"I'm in pain all the time and my joints are so stiff it's hard to even get dressed," said LoSchiavo, who still seems full of life despite a gaunt appearance and fingers clenched in a fist.

"I've got to keep going be-



Autumn Pinette/Connecticut Post

**Joy LoSchiavo poses with her daughters Gianna, 9, and Julia, 5, during a fund-raiser for the American Society for Scleroderma Research recently at Liedle's Caterers in Stratford. LoSchiavo suffers from scleroderma, a rare autoimmune disease, and is in desperate need for a kidney.**

cause my daughters need me and I want to be there for them," she said. "But with this disease you have to be realistic, you never know when ..."

She didn't have to finish her thought.

There are many forms of scleroderma, which itself means "hard skin." The disease causes skin discoloration and thickness, resulting in pain and difficulty moving limbs. The same thickening process may also occur in blood vessels, lungs, kidneys, the intestinal tract and other key organs.

Donn Kovac, 18, of West Haven, knows all about that.

A former school athlete, Kovac described how the disease changed his life.

"I used to be involved in all kinds of sports; now it's hard to even walk," said Kovac, who struggles to breathe because of lung damage caused by the illness.

Tall and very thin, Kovac

walks slowly and often stops to take a breath.

He recalls being diagnosed with scleroderma when he was about 13.

"At first, my hands were turning blue and my parents didn't know what was wrong," he said. "It's not an easy disease to diagnose. Eventually, they figured it out and it's been a struggle ever since."

But both LoSchiavo and Kovac said they are encouraged so many people turned out for the benefit, which helped raise about \$25,000 for research.

Joe LoSchiavo said he established the foundation, which recently gained non-profit status and has raised nearly \$100,000 in three years, to raise awareness and money to find a cure — even though that may come too late for his own daughter.

"We're making progress. Doctors are finding new and better treatment methods all

the time," LoSchiavo said. "But our long-term goal is to find a cure so that someday people don't have to go through the agony of this disease."

Joy LoSchiavo nearly died from complications related to the disease five years ago, her father said, but she pulled through and regained use of her kidneys, which had temporarily failed. More than a year ago, however, she lost use of her kidneys for good and could die if a donor match is not found soon.

Her relatives have been ruled out for various reasons. Those with B or O blood types are being sought to donate a live kidney to her.

After a recent story about Joy's plight appeared in the *Connecticut Post*, some people called to offer a kidney, although no match has been made, LoSchiavo said. Others responded by making financial donations to the foundation.

About 300,000 people nationwide have the disease.

But some forms are not fatal.

Jocelyn Schur, 17, who was diagnosed with the disease five years ago, has improved so much that she appears healthy, with long dark hair and a bright smile.

Scars caused by the disease on her arms and legs are covered by dark stockings and long-sleeves.

"I'm lucky because the disease has not affected any of my internal organs and the doctors say whatever damage has been done could be the worst," said Jocelyn. "But I know the disease can become active again at any time."

To inquire about making a kidney donation to Joy LoSchiavo, contact Audrey White, the transplant coordinator at Hartford Hospital, at (860) 545-4368.

The Web site for the American Society for Scleroderma Research is [asfsr.org](http://asfsr.org).