

Parents issue urgent plea to politicians

By Sharon Tubbs City Times Editor

Published October 19, 2007

Thank God for the box of tissues. Trevor Smith couldn't control her tears.

It could have been nerves. She was in Washington, D.C., without her husband or daughter for the first time.

Or maybe it was the gravity of what she had to tell C.W. Bill Young, the Bill Young, senior legislator known for getting the job done on Capitol Hill, face to face.

There was Trevor - 39-year-old wife of T.A. Smith, part-time sales rep for Kelly Services staffing agency and the mother of 6-year-old Joie - in a big, "stately looking" office.

She told Young about her daughter and about the disease that Trevor had never heard of until doctors diagnosed Joie. Spinal muscular atrophy, SMA for short, is the leading genetic killer of babies, according to the international nonprofit organization called Fight SMA.

On the Hill that day in April, dozens of regular people active in Fight SMA met with legislators or their aides. Laurie Elliott, whose 11-year-old daughter has the disease, had traveled from Hyde Park to sit across from Tampa's own Rep. Kathy Castor.

They wanted to tell the people with political strength about an incurable disease that can lead to muscle weakness in children. They wanted to tell them that researchers think they can make a difference if they get more money for clinical trials and such.

Right now, the federal government authorizes about \$15-million a year for SMA research, which is low compared to more well-known diseases, like cystic fibrosis, which can get tens of millions more.

Both Trevor and her husband are SMA carriers, as are about 7-million unknowing potential parents, according to Fight SMA's stats. Now supporters are pushing the SMA Treatment Acceleration Act, hoping to boost federal support and public awareness.

Trevor told Young this spring that the bill would be ready soon and she hoped he would co-sponsor it.

A few months later, she got a call from Young's aide, Harry Glenn. Young would co-sponsor the bill.

Early this week, 19 representatives had signed as co-sponsors of the bill, introduced by Rep. Patrick Kennedy of Rhode Island. Castor hadn't, but her press secretary confirmed Tuesday that she planned to. Castor has supported SMA research for some time, Agustina Guerrero said.

"It's certainly important for her to hear directly from people in the district," Guerrero said about Castor's meeting with Laurie Elliott.

To his knowledge, Glenn said, Trevor was the first person Young had met with regarding SMA. "She made a good case."

But the bill has a long way to go. It could take a few months or more than a year to muscle through the system of committee hearings and budget talks.

The Senate is considering a version as well, and Trevor and Laurie managed to get meetings with aides for Sens. Mel Martinez and Bill Nelson while in D.C.

Back home in the Tampa Bay area, the two moms busy themselves raising what they can for research and encouraging people to urge their representatives to support the bill. They organized an annual golf tournament with dinner and a silent auction at the House of Blues in Orlando this year. And the SMAsquerade costume ball is Saturday in the Lafayette Room at Mise en Place.

In the past nine years, Laurie said, the local chapter has raised more than \$1-million for SMA research. That's still not much when it comes to medical research.

"I think the legislation gives SMA credibility beyond local moms," she said.

Trevor believes her stop in Young's office made a difference that day. She'd worn a sweater with an SMA pin on her lapel, and between 30 and 45 minutes passed before he escorted her to the door.

Before she left, Trevor said, he gave her a hug.

.if you go

SMA'squerade ball

FightSMA Tampa Bay will host the SMA'squerade costume ball with live music from Bobby Lee Rodgers and the Codetalkers from 8 p.m. to midnight Saturday in the Lafayette Room at Mise en Place, 442 W Kennedy Blvd. in Tampa. The fundraiser benefits SMA research. Tickets are \$125 in advance, \$150 at the door. For more information, call Laurie at (813)251-1611.

© 2007 • All Rights Reserved • St. Petersburg Times

490 First Avenue South • St. Petersburg, FL 33701 • 727-893-8111

[Contact the Times](#) | [Privacy Policy](#) | [Standard of Accuracy](#) | [Terms, Conditions & Copyright](#)