Brave 5 year old battles rare disorder

De KAREN MARTIN

Five-year-old Amie Darnell is a brave little girl. She's a living example of what can be accomplished when a child has a rare illness.

Amie was diagnosed with hypotonia at birth, a condition that affects her muscles and results in a lack of muscle tone.

Her mother, Tammara Darnell, said she was devastated when she received the diagnosis.

"It's been a long road," Tammara said. "But we've been blessed with an amazing support system, including Amie's doctors, therapists, and family.

Amie's condition has led to a series of surgeries and medical procedures, but she remains determined to live her best life.

"Amie's a fighter," Tammara said. "She doesn't let anything hold her back.

"Every day is a challenge, but she's always smiling and never giving up.

Amie's story is one of hope and resilience, a reminder that even in the face of adversity, there is always a reason to keep going.

"Amie's a true inspiration," Tammara said. "She's taught me so much about courage and determination.

"I'm grateful for every day we have together and I know that Amie will continue to amaze us with her strength.

"I'm proud of my little girl."
to Dr. Michael Zasloff, chief geneticist at Children's Hospital in Philadelphia. Mrs. Darnell said Zasloff is the only physician in the world who has done research on FOP.

Zasloff has seen 50 of the 52 cases known to exist, Mrs. Darnell said.

"We were lucky Amie was diagnosed so fast. Sometimes it takes years," Mrs. Darnell said.

After a four-hour examination, Zasloff pronounced Amie's case unusual in that FOP usually begins in the neck and shoulders and proceeds to other joints from there.

But, the outlook is not good. Surgery has been found to accelerate the disease, causing more bone to grow and the resulting paralysis.

One drug, Accutane, provides some relief to FOP patients. "But they're afraid to give it to Amie because she is so young and the side effects are so bad," Mrs. Darnell said.

For now, the Darnells are playing a wait-and-see game. Usually following an active period, the disease will subside somewhat. But no one knows how long the active period will last.

Tammara and Chuck Darnell want people to know about Amie's condition. They feel that unless others know and care about what happens to victims of FOP, the research will never be done that could lead to a cure.

"Dr. Zasloff needs $75,000 to set up to do the proper research," Mrs. Darnell said. "So far, the organization has raised $5,000. There's so few people with this that there's no money."

The biggest job, they said, is educating physicians about the disease.

The Darnells feel other victims of the disease are out there and need the support that an organization like Peepers can provide.

"The biggest thing," said Chuck Darnell, "is to get the information out so other people can see if they have the symptoms. The second thing is support. Without the proper support, we don't even have the hope that people will be working on finding a cure."