



**MJ Purk is framed by blankets specially made for children diagnosed with spinal muscular atrophy. Purk, along with her caretaker and Pocahontas native, Brenda Hanson, have delivered over 1,000 of the blankets to children across the globe. Submitted photo.**

## Purk and Hanson bring comfort and understanding to 'SMA angels'

**By Chris Vrba**

In a realm where longevity is measured by months rather than years, and success is determined not by dollars or career accolades, but by simply taking a deep breath and making it to the next day, an angel has arrived. Except, instead of arriving on golden wings, this cherub has descended on a four-wheel scooter and wields a quiver full of brightly colored blankets as arrows.

Meet Margaret Purk. At 24 years of age, Purk just may be the world's oldest person living with Type I spinal muscular atrophy (SMA), a genetic defect where proteins necessary for the development of motor neurons cannot be produced. As a result, muscles never form, and the patient, more often than not, passes away within two years of birth.

SMA is the leading genetic cause of death for infants. There is no known cure or treatment, though researchers at Ohio State University are preparing for clinical trials of a chemical treatment that holds promise for SMA patients and their families.

Purk, better known as "Queen MJ" in SMA circles, has defied

the odds. The New York and Ohio resident is mere paperwork away from obtaining a degree from Wright State University in the Buckeye State, and has founded B4SMA, a philanthropic care organization that makes colorful, homemade blankets for newly diagnosed children.

In the short time the organization, which is an acronym for Blankets For SMA Kids, has been on the scene, MJ, along with dedicated caretaker and Pocahontas native Brenda Hanson, have sent over 1,000 blankets to kids all across the globe. In late June, MJ and Brenda were traveling through town on their way back to Ohio after attending a national SMA convention in the Twin Cities.

**HANSON WAS WORKING** WITH the Muscular Dystrophy Association in Des Moines when she first learned of a widower in Rye Brook, N.Y., who was seeking a live-in care assistant for his two toddler daughters who both had SMA. In 1992, Hanson visited the hamlet of 10,000 situated just northeast of the Big Apple along the Connecticut border.

"Two weeks later, I flew out

and that was that," Brenda recalled.

Once there, Hanson helped take care of MJ and her sister, Emma. The Purks' mother had passed away in a car accident. Emma, too, soon passed away due to complications from SMA.

But MJ was an entirely different story. Knowing a bit about the basic demographics of SMA patients, Hanson never imagined that 21 years later, she'd still be at her charge's side.

"When I moved out to take care of them, I didn't think it'd be that long," Hanson reflected and said, "But she's stubborn. I've enjoyed the ride."

Quite a ride indeed. The pair travel in a custom conversion van, equipped to carry MJ's customized, and quite sophisticated, motorized scooter, as well as her bed. The scooter is a necessity, because without it, Purk's body would, more or less, lie limp, not entirely a formless mass, but a human frame unable to move independently.

Hanson described Purk's ambulatory impediments as "Anything that involves gravity," with MJ quickly chiming in, "It's

**See BLANKETS, Page 7A**

**BLANKETS:** Purk defies longest odds to become champion for children with horrendous genetic condition



my worst enemy."

Statements such as that highlight an almost eerie cognitive synergy between the pair who have largely been by each others' sides every day for over two decades.

"After 21 years, we know what each other's thinking," Brenda offered. "Sometimes," MJ added with a wry smile.

**PURK'S MOVEMENTS ARE LIMITED** to choppy, deliberate finger strokes and she breathes with the assistance of a ventilator, something she has had to do since she was nine. Around that time, MJ received spinal fusion surgery, a requisite procedure for "long-lived" SMA patients, which reduces the pressure on the lungs from a deformed spine.

Respiratory problems are part in parcel for children who have SMA. With underdeveloped pulmonary muscles, it is difficult for people with the condition to breathe. As the kids get older, the shallow breaths are increasingly incapable of supplying the body with sufficient oxygen. As a result, many children die.

Fortunately, Purk said, physicians are better at spotting the disease in its earliest moments, and kids are now living longer. She added that many infant deaths that were chalked up to Sudden Infant Death Syndrome (SIDS) were likely undiagnosed SMA patients.

"It used to be that if a little kid dies, it might be called SIDS and be done with it," Purk remarked. "People are living longer, but I wasn't expected to live past three."

The oldest person living with Type I SMA that MJ is aware of is a boy who recently turned 18.

"I'm not the oldest person having it, but I'm one of the most active," MJ remarked.

**PURK'S FIRST BRUSH WITH** philanthropy came when she was young. While in the hospital recuperating from spinal fusion surgery, she met a young girl down the hall. Purk had a plethora of well-wishes in her room - flowers, cards, and stuffed animals - while the other little girl had none. Purk felt hurt, and wished there was a way to cheer the gal up. She

gave a Beanie Baby to the young patient.

"I just liked how she smiled when I gave it to her," MJ reflected.

The simple gesture and simple response stuck with Purk. It would play a prominent role in her later life.

Though MJ's movements may be limited, her mind is razor sharp.

"I would have conversations and forget that they're three and four," Brenda recalled of her early days spent with MJ and Emma.

From an young age, her father took pains to cultivate the fertile fields of MJ's mind. At six, MJ was given a computer. At 10, she had her first Internet connection. For someone bound to a chair and limited by where and when she could travel - in winter she's essentially housebound - the connection opened a window to a world she once could only see through thick double panes.

It was revolutionary.

"I found out there were other people who have the same thing. I knew there were other people out there, but I didn't know to what extent. I became more active," she said.

**THAT'S WHEN PURK'S ACTIVISM** and philanthropy came together. Shortly after, MJ and Brenda piled into the van and visited their first SMA conference. While there, MJ handed out 300 Beanie Babies.

"It's good to be able to share experiences and reach out to other families," Purk said. "For a lot of SMA kids, their only sort of connection to the world is the

Internet."

As MJ grew older and continued to defy all medical odds, her philanthropic efforts burgeoned. She's produced short movies dedicated to honoring the memories of the "angels" whose lives have been cut too short by SMA. She's also a computer sophisticate, and has used her ex"Purk"tise to design hundreds of web pages.

However, her charitable works have really come to fore in recent years. When Brenda returned to Pocahontas for a vacation eight years ago, her mother, Janis Hanson, taught her how to quilt. Brenda quickly took to it and made 20 blankets while home. Brenda and MJ decided they would make the perfect addition to the care packages they had been sending to fellow SMA families.

"It was just something we thought we'd include in care packages," MJ said. "We decided to send them blankets, because everyone likes blankets."

"It's like a hug from someone who knows what they're (the child with SMA) going through," Brenda added.

In those eight years, MJ and Brenda have sent blankets to over 1,000 "SMA angels" across the globe.

The pair's organization, B4SMA, operates on a shoe string budget.

"We're funded by no one except ourselves," MJ asserted.

To accomplish the task, the duo receive donations of fabric, needles, and thread. They have even enlisted Brenda's relatives, including Janis and the Applegates of rural Rolfe, as well as Brenda's maternal grandmother, Inez Loss of Rolfe, and Brenda's aunt, Joann Grove of Minneapolis, Minn., in helping make blankets for the cause.

**BECAUSE OF HER EFFORTS** and her longevity, MJ has gained notoriety in the SMA community. While at the late-June conference in Minneapolis,

MJ was sought-after by the many families and researchers in attendance.

But it was an experience with a five-year-old boy named Roman that will stick with Purk the most. Roman was sporting a mohawk for the occasion, and MJ could tell he was in a bit of distress. He couldn't talk, but he could make rudimentary grunts to communicate. MJ asked if he wanted to touch his spiky hair and he acknowledge yes. So, Brenda put Roman's hand on his head so he could touch his new do.

"We put his hand up and he kept feeling it," Hanson recounted.

"He'd never felt it before," MJ added.

More importantly though, MJ serves as a shining beacon of hope and inspiration for the young SMA angels. She's a testament to tenacity and the embodiment of triumph over the longest of odds.

"I'm no different than anybody else," she proclaimed.

"Just because she can't walk, doesn't mean she can't do anything," Brenda added. "You can do anything you want to. We don't say 'you can't', we just figure how you can."

And it is because of the relentlessness of both Purk and Hanson trying to figure out a way to say 'can,' that Margaret has become Metratron, with Brenda as Seraphiel - the head and protector - of the choir of SMA angels.



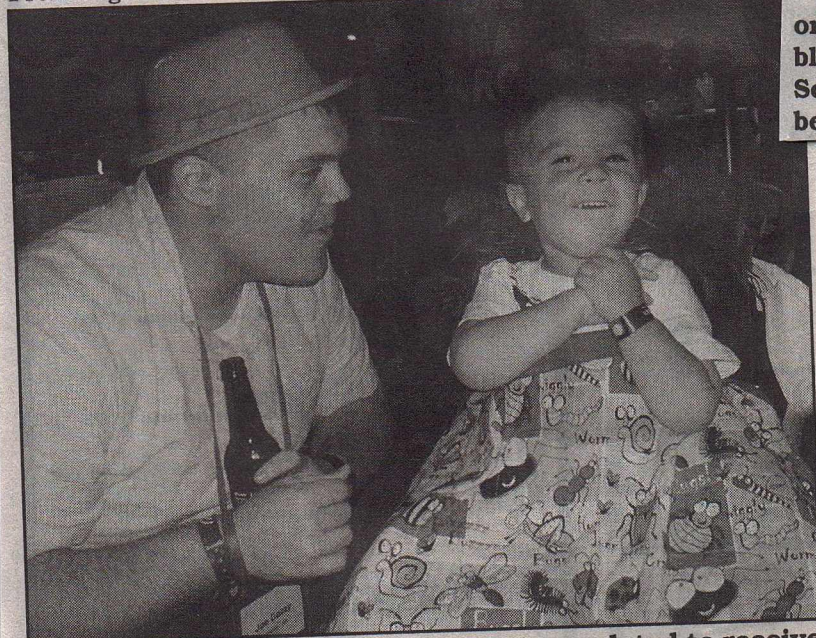


**MJ Purk puts herself in position to take a photograph in front of the old capitol in Iowa City. Despite having very limited movement of her fingers, Purk takes advantage of a specially modified camera to satisfy her shutterbug love. All photos courtesy of MJ Purk.**



**MJ Purk and Brenda Hanson have formed a philanthropic organization called B4SMA, which delivers homemade blankets to children diagnosed with spinal muscular atrophy. So far, the pair has sent out over 1,000 blankets. Many have been made by local volunteers.**

From page 1A



**Roman, one of MJ's "SMA Angels," was elated to receive his blanket at a recent convention.**