

**Defying Limitations**  
*Celebrating Down Syndrome Awareness Month*

**Sheila and Leah Garske, Wausau**

**A True Pioneer**

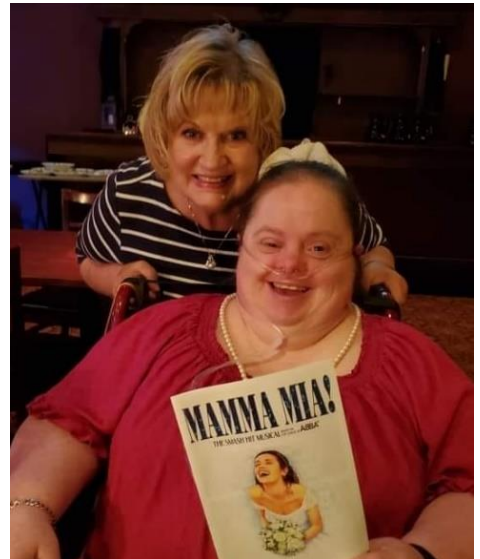
Sheila Garske describes her daughter Leah as a “success story.” Leah, now 49, was born with Down syndrome, but didn’t let that slow her down. She was the first individual with Down syndrome to go to the Wausau School System as a 3-year old and attend and graduate from West High School. “She has been a pioneer and has opened up a lot of things for others with Down syndrome,” said Sheila. “I was hesitant she would get hurt and bullied, but she wanted to do things – and she did!”

Leah was a joiner from a young age and tried everything she could. She was in 4-H and entered projects in the fair and earned ribbons. She was an avid swimmer and enjoyed cross country skiing, snowshoeing and snowmobile and motorcycle riding. She played the snare drum in the Very Special Arts Marching Band and played in the 5<sup>th</sup> quarter at a Wisconsin Badger game and at halftime for a Green Bay Packers vs. Chicago Bears game. She participated in Special Olympics and was also an assistant coach. In 2002, she was named the female athlete of the year in Wisconsin.

**Maintaining Independence**

“She was told of her limitations and she defied them,” Sheila shared. After graduation from high school, Leah joined the job force. For a few years she worked two jobs – McDonalds in the morning, then East Bay (now Foot Locker) in the afternoon. She stayed on working with East Bay for 20 years. She would also go to the YMCA to exercise and took advantage of public bus transportation.

She secured an apartment and made her own meals. Her mother helped her with managing bills and mail, but she was very independent. Her apartment building had many elderly residents, whom Leah loved. After work, she would help neighbors with their laundry and household chores, like changing their sheets (she even learned hospital corners). She became a caregiver for many neighbors and that was just who Leah was!



*Sheila and Leah Garske*

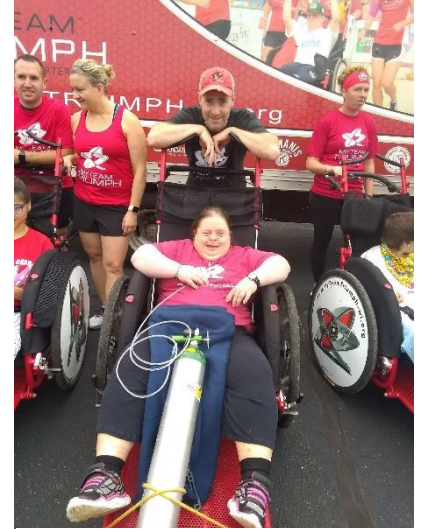


*Leah at a cross country ski meet*

## Alzheimer's Journey

Leah was diagnosed with Alzheimer's at age 39, but likely had already had it for a few years. Research suggests that people with Down syndrome are more likely to experience dementia as they age – with 30-40% having dementia by age 50. "It's been a heart-breaking journey – one I didn't plan on, but I sure do love my tour guide," shared Sheila. Leah had to leave her apartment and was at a group home for a period, but is now at Azura Memory Care facility. "Her care facility is a good place and I'm so glad she's there," said Sheila. "That was a big stress for me because many facilities won't admit individuals under age 55, but they made an exception for Leah."

Since being in a wheelchair, one thing Leah has enjoyed is her participation in My Team Triumph, which is an organization that provides specialized race equipment and lends race day support so people of diverse abilities can come together, as a team, in endurance events. Leah, in a 3-wheel racing chair, is the captain and two people, called "angels," push her. The organization promotes inclusion and helps people with disabilities who face social isolation.



*My Team Triumph race*

## Impact of COVID-19

Prior to COVID-19 Sheila spent time with Leah daily and they would have weekly outings. "She's declined so much since March," Sheila shared. "I was volunteering and I miss going to see her." Sheila continues to talk with her daily and does weekly window visits with Leah (and other residents who pop in behind her). "It's very hard for me to do the window visits because I can't hold my daughter," said Sheila.



*Window visit during COVID-19*

Sheila and Leah have a special connection with the song, *You are my Sunshine*. Years ago, if her mother was ever gone, Leah would leave a message on her answering machine and sing the entire song. Now, Sheila often sings the song at their window visits. "I'm not a good singer," said Sheila. "But just seeing her laugh while I'm singing makes it worth it."

## Seeking Caregiver Support

Sheila is not new to an Alzheimer's journey. In addition to Leah, her mother passed away from Alzheimer's disease 3 years ago. She also had a foster daughter, with Down syndrome, who was with her for 30 years and lost her battle with Alzheimer's disease.

Sheila participates in a support group for loved ones with a family member living in a facility, hosted by the Alzheimer's Association. "I am familiar with all the stages of Alzheimer's, but the support group is an opportunity to hear from other families," Sheila shared.

For National Down Syndrome Awareness Month, we celebrate the successes of Leah and her continued ability to defy all limitations.