

"Please pray our children have an easy passing."

Family Spotlight: The McNeils



"We are grieving, but thanks to you and Jill's House, our children know only unconditional love."

—Shannon McNeil

[Watch their moving story.](#)

"Almost six years ago, my husband Matt and I were told our two beautiful children were going to die," said Shannon McNeil, mother of Waverly, 10, and Oliver, 7. "Since then we have done everything in our power to make sure they know they are loved and celebrated. Matt and I cherish each and every moment, and we are exhausted physically, emotionally, and relationally."

"Sitting in a neurology consultation room at Children's Hospital, we were given the answer to why our four-and-a-half-year-old daughter, Waverly, was no longer progressing developmentally. She had a very rare genetic condition. Within four weeks we were hit again with the news that our 15-month-old son, Oliver, had the same disease. The lifespan of someone with Sanfilippo syndrome is 12 to 18 years. All of the milestones they would achieve would slowly be undone until their bodies succumb to the disease.



Lift up families like the McNeils when you Sponsor a Child for a Night.

"In the past few years we have had an international move back to the U.S., job changes, the purchase of a one-level home for eventual wheelchair-bound children, and trading in an SUV for a handicap-accessible van. However, those were simply logistics. Caring for Waverly and Oliver has become much more difficult. Both children have lost their ability to hear, and Waverly no longer walks unassisted. One of my saddest days was when Waverly said 'mommy' for the last time.

"Our lives changed dramatically. Playdates and sleepovers became physical therapy sessions and doctor appointments. Coffee dates and phone calls with long-distance friends became hospital visits and long holds on the phone with insurance companies. Conversations with Matt revolved around equipment orders, schedule conflicts for appointments, and how to adapt to yet another skill loss as the kids regressed in the disease. Date nights were replaced with falling asleep on the couch from utter exhaustion and stress.

"And then we found Jill's House, a place of rest and renewal, a life-changer.



Waverly was surrounded by her brother, Oliver, Jill's House staff and friends for her tenth birthday. Her mother called it "bittersweet" since each birthday brings Waverly and Oliver one step closer to the end.

"Like so many families who have children with special needs, we don't have immediate family nearby or friends who are capable of handling the unique challenge of caring for our kids. The physical requirements are immense; and the emotional requirements are even greater. Birthday parties, for example, should be times of great joy and celebration. For us, they are bittersweet. Matt and I do our best to put on happy faces, but the reality is that as the children get older, they get one step closer to the end.

"We try to accept that Waverly and Oliver will miss out on so many milestones in life, such as their first dates, driving a car, and getting married. But they have also missed out on so many quintessential childhood activities.

"We would attend birthday parties at bouncy gyms only to feel relegated to a corner because our kids couldn't keep up or jump anymore. We would visit a playground to find the one handicap swing was broken and unsafe. Our world began to shrink.

"Jill's House opened our world back up.

"Waverly and Oliver finally have a place of their own. Jill's House was made for kids just like them. Every room and activity is modified to allow them active participation. Sleepovers and playdates are possibilities once again.

"Date night returned for Matt and me. Having both time and a mental break, conversations can naturally drift from topic to topic. We have an opportunity to connect and feel refreshed, to re-center ourselves to deal with the never-ending stress of parenting two terminally ill children.

"The next few years are going to be extremely difficult. As we try to brace ourselves and prepare for the ultimate passing of our precious children, we know they are loved beyond measure by the Jill's House staff.

"Because of Sponsor-a-Child-for-a-Night partners, not only are they loved, they are safe. Waverly has complicated medical needs, including feeding tubes. The worry-free breaks Matt and I get help us prepare for the very different, inevitable life we face. We are grieving, but thanks to you and Jill's House, our children know only joy and unconditional love.

"Thank you for making these stays possible and giving our family the strength to face this very difficult time. I hope and pray you will help other families like ours by becoming a monthly Sponsor-a-Child-for-a-Night partner."

Editor's note: *At the conclusion of the video interview, we asked Shannon and Matt how we, the Jill's House family, can pray for them. After several moments of silence, Shannon softly answered: "Please pray my children have an easy passing." Join us in lifting up this family and others like theirs, through prayer and support.*

Become a Friend of Special Children when you Sponsor a Child for a Night on a regular monthly basis, or increase your current sponsorship for families like the McNeils who are raising multiple children with special needs.

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