

Child With Rare Skin Disorder Receives TEMO Sunroom and Spa Gift

Clinton Township, MI – January 21, 2002 —Three-year-old Katie Paratore, born with a rare skin disorder that causes her skin layers to separate and blister spontaneously or at the slightest friction, splashed her way into 2002 in their family’s new five-person therapeutic spa that sits in their new TEMO sunroom. Both were installed at half the retail cost, compliments of Nino Vitale, founder and CEO of TEMO Sunrooms, Inc, in Clinton Township, Michigan.

Katie is one of about 40 kids in Michigan and more than 100,000 Americans nationwide that suffer from the rare and often fatal Epidermolysis Bullosa (EB). Since Katie’s birth just three years ago, four Michigan children have been born with the disease and only half currently survive. The process of simply being born can be life threatening, causing the skin to blister or peel off.

For Katie, born without skin from the shin down, daily life includes endless spontaneous eruptions of skin blisters (10-20 a day). Many are deep wounds that require special bandaging and daily changes to avoid life-threatening infection. The blisters can appear anywhere on Katie’s body – her face, feet, torso, arms, fingers – and can be caused by simply handling a book, walking, being lifted, touched or by nothing at all.

Blisters can even form internally from eating a hard or sharp food, such as potato chips, and can cause serious internal infections such as pneumonia, bleeding and even death.

But worse for an active toddler, blisters can be activated by sunlight, effectively keeping sufferers trapped indoors. This is what sent Katie’s parents, Jim and Sandy Paratore of Chesterfield Township, to Tony V’s Sunroom and Spas, the retail showroom for TEMO Sunrooms, last June.

Robert Randall, a Tony V’s sales representative, met the Paratores and learned that they “Were looking for a way that they could somehow let Katie enjoy the outdoors and provide their daughter the water therapy recommended by Katie’s doctors.”

The soothing jets from the spa would help ease off Katie’s bandages, and would help avoid creating new blisters just from the process of removing the bandages. It would also provide the necessary daily removal of damaged skin, a debriding treatment similar to a burn victim’s.

“Putting the spa in a sunroom would allow Katie to enjoy the outdoors, protected from the heat, and insects that could cause infections and skin damage,” said Randall. Because Katie always has open wounds, she cannot use sunscreen or insect repellent.

The idea seemed perfect until the Paratores learned the cost of the sunroom the size they hoped for, with a spa, would run over \$30,000, beyond the Paratores’ budget. Jim is a nurse at St. John’s hospital and Sandy works part time in the billing department at Troy Beaumont Hospital. They’ve just had their second child, a daughter born three months ago. Among the many medical costs added to the family budget are the expensive Kerlix bandages that Katie requires daily, which their insurance does not cover because they are not reusable.

However, the Paratores hoped their insurance company might assist with the cost of a home therapeutic spa for Katie. OSHA regulations restrict Katie from using public or private therapy medical spas. Her open wounds would leave Katie more vulnerable to infection. Even so, the insurance company denied the Paratores’ request.

That’s when Randall stepped in to see what could be done to help make the Paratores’ dream for Katie come true. He first investigated the local chapter of a foundation that grants the wishes of terminally ill children and learned that Katie would not be eligible for help. Wishes had to come from the children themselves, who are typically older, and the spa and sunroom was a wish Katie’s parents wanted to make on Katie’s behalf.

One more resource remained a possibility. Shortly after Katie was born, friends and neighbors of the Paratores conducted a fundraiser to provide some much-needed financial assistance with medical costs. Over \$80,000 had been raised. Rather than use all of the donations for themselves, the Paratores legally established a foundation – Kisses for Katie – to assist other families with EB. Currently only one organization for EB exists, and is designed primarily to raise research funding. There was as yet no organization designed to help families with practical expenses.

The Paratores have since used the foundation to help numerous families in Michigan as well as families out of state afford medical supplies such as bandages and wheelchairs. The Paratores considered seeking financial assistance from the foundation that they helped create. Checking with the IRS and non-profit foundation regulations, the Paratores learned that they could legally allow the foundation to assist with the cost of the spa, as long as other children with EB could also have access to it.

“That was no problem,” said Sandy Paratore. “We had intended to do that anyway. We stay in close contact with other families who have children with EB.”

When a new child with EB is born in the area, the Paratores are quick to assist the parents – and hospital nursing staff – with advice on how to care for a child with EB. Advice such as how to hold the baby in lambs wool to avoid creating blisters; how to change a diaper, bathe, dress and bandage the child; and how to take a blood pressure without injuring the skin.

“Another family cannot go like we did,” said Sandy. “We felt alone, without support, without people to talk to who had been through it or understood what to do.”

There are only two doctors in Michigan that specialize in EB. The Paratores had to learn to care for their child and her special needs through trial and error – a process that can result in unintentional injury. A simple child’s sticker placed on Katie’s clothes accidentally slipped onto to her skin and caused blisters so serious they took six months to heal.

The Paratores are thankful that an East Pointe mother of a child with EB eventually found them and became “our guardian angel,” providing years worth of invaluable health care tips that they had learned through trial and error themselves. “Kids are suffering needlessly because so few people understand this disease,” Said Sandy.

Sandy and Jim are dedicated to becoming other families’ guardian angels by offering support, financial assistance, and health care tips, including how to properly feed a child with EB.

“Diet is a huge problem,” said Sandy. “People with EB need extra calories because they are constantly using their resources for wound-healing.” Malnourishment among EB patients and other related complications can often lead to death.

“In the end,” said Sandy, “We decided not to use foundation money for our sunroom and spa project because it would take away resources from other families that needed it too.”

That’s when Randall took the project to Nino Vitale, asking how it could be made affordable to the Paratores.

“I heard about Katie and her special needs and wanted to work with her parents to do what I could to help,” said Nino Vitale, who authorized the 50 percent discount on the entire package, working within the Paratores’ personal budget.

“A lot of people that heard about Katie, such as the electricians, installers and cement layers, donated their time to help bring the cost of the project down,” said Randall. “It was a group effort to help Katie.”

This is not the first time TEMO Sunrooms or Tony V’s Sunrooms and Spas have helped others in need. “About once a year we hear of a special case and we do what we can,” said Randall.

The 12 by 17-foot sunroom was installed just off the Paratores' kitchen. "It's great because this provides a huge convenience. I have a room where I can change Katie's bandages. And Katie can use and play in the spa with the whole family near her." Sandy looks forward to the summer when Katie will get to enjoy feeling like she's outdoors, without endangering her health.

Katie, who loves all things Disney, refers to the spa as a miniature pool – her "Minni pool."

Sandy says she is grateful for TEMO's and Tony V's support. "Everyone was always so nice to us. When you ask for help, you don't always expect a yes. To us, this experience is not about the money. It's about people connecting – that's priceless."

The Paratores are determined to keep connecting with other EB families, doing what they can to help and bring awareness to others about the disease. They are planning a fundraising golf event in June. For information on how to participate, or to learn more about EB, visit kissesforkatie.org, or call the Kisses For Katie organization at 586-948-2259.

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