

## 5 A better life for Liam



Photo courtesy of the Thom Family

“We’d just like to give Liam some dignity,” says Chrissy Thom.

Liam, Chrissy’s son, has his mother’s pink cheeks and cheerful demeanor. He’s also one of only about 100 children in the world with macrocephaly capillary malformation syndrome. The disorder is a genetic condition that causes an enlarged head, developmental delays, low motor skills and poor muscle tone—and a precarious future.

“They don’t know a lot about this disorder, so we’re really uncertain how long Liam will live. Liam has what is known as hydrocephalus, or ‘water on the brain’, so he has a shunt that drains the spinal fluid from

his brain and recirculates it,” says Chrissy, a vibrant woman with short dark hair, a direct gaze and radiant smile who speaks straightforwardly about her son’s serious challenges.

“Liam is four and a half, but he’s about one and a half years old cognitively. He has no speech... we understand what he wants from his facial expressions and the sounds he makes. He’s a pretty happy kid, but our main issue is with bathing him. I have to lift him in and out of the tub. He’s 65 pounds, and he’s not exactly a dead weight, but he can’t really help me get him in and out and he slips easily – he’s kind of like a noodle sometimes. It’s really hard on my back, and it’s only going

to get worse as he gets bigger ... so that's why getting the help with our bathroom is so appreciated."

Funding from Giving in Action is enabling the Thom family to renovate their bathroom so it can accommodate Liam's wheelchair. The new bathroom will have a roll-in shower to make bathing Liam much easier. The shower will also have a seat, so that eventually, Chrissy hopes, Liam will be able to bathe himself.

"When he's seven or eight and is more aware of his body, we'd like him to be able to have the same autonomy and privacy anyone would want. Liam loves the water, so getting

his bath is like his big reward at the end of the day, and we'd like it to continue being a really positive experience for him," she says.

"When you have a child with special needs you always feel like you should be doing more," Chrissy explains. "We don't know for sure, but we are planning on Liam being with us for a long time, and we want him to have everything he can. The grant from Giving in Action has been extremely helpful. It'll make it a lot easier for me and my back issues. But it also gives me as a parent that sense that I can do something for my child to make his life better, and that makes a huge, huge difference. 🌸"