

Meet Liam and Gavin

They are your average grade-school kids. According to their parents Liz and Greg Fitzgerald, they're both "hams" who want to entertain everyone around them. Gavin (right) is eight years old and collects comic books. His favorite superhero is Hawkeye and when he's older he wants to run a comic book store. Liam, 12, wants to be an actor or a lego designer — he can't decide — and he loves creating and designing. Both boys take karate lessons, they both love summer camp, and they both have severe hemophilia.



Close Call

Hemophilia is a bleeding disorder that prevents blood from clotting effectively. The Fitzgeralds discovered Liam had hemophilia within two days of his birth, after doctors raced to diagnose him in a frenzy of hospital transfers. Gavin was diagnosed the same day he was born. When he was just a toddler, Gavin developed a spinal bleed so dangerous that he required a Flight for Life from Green Bay to Milwaukee. The harrowing experience gave the Fitzgeralds an increased awareness of what having hemophilia would mean for their family.

Even with clotting factor medicine, both boys still develop internal bleeds. Greg and Liz try their best to keep their kids safe. They traded in their traditional crib for a softer play version, and when their kids were older decided to invest in a car with high-quality safety features. "We make sure they wear helmets," Liz said, "and we always have our factor bag with us. But they're just regular kids. We know they'll get bruises sooner or later."

GLHF helps the Fitzgeralds live with hemophilia

Both Liam and Gavin have to infuse with a clotting factor every other day. The medicine is vital to their health, but costs quickly add up and not every insurance company is willing to cover the bill. When both boys developed an inhibitor (their bodies resisted the clotting factor), they had to take yet another drug to make sure the factor would work. Gavin had to fight the inhibitor for almost five years, and needed very high doses of the drug for it to work. Twice, Gavin's medical bills ran dangerously close to their annual insurance cap of \$2 million.

Fortunately, the Fitzgeralds have a good insurance policy and were prepared thanks to advice from GLHF and the Hemophilia Treatment Centers. Though their family budget was strained, they didn't request financial aid through GLHF's Patient Financial Assistance program. "We knew there were other families who needed it more," Greg says. "But it takes an edge off, knowing that GLHF is there. It gives us peace of mind."

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GLHF brings families together for support

The Fitzgeralds also find support in the network of families they meet through GLHF, and they're glad to provide advice and encouragement to others. Liam and Gavin enjoy GLHF events like summer camp because they hang out with friends who understand what it's like to live with the disorder, as well as learn more about living with hemophilia.

"When we were first learning about the disorder and pretty uncertain ... we met a mom at the treatment center," Greg says. "She told us her 17 year old son had it. Just that one simple sentence was so relieving, it took such a burden off us. If there's a teen with this ... if they can make it to 17, we can do this. It was as simple as that."