

Jay Napier-Ganley



Jillian Napier and Jim Ganley have three children: eight-year-old Jack, four-year-old Jensa and baby Jay, who is two-and-a-half years old. The Napier-Ganleys are a family that redefines “active.” Jack plays soccer, hockey and basketball. Jensa also plays soccer and she does ballet, gymnastics and figure skates. Mom Jill is a volunteer coach and runs her own business, Varsity Kids, a sports program for elementary school kids. Dad Jim works six days a week: as a high school English teacher, the yearbook editor and manager of the school’s blog and website.

Since the family does not live near any municipal or school bus routes, in a typical day, Jillian is driving back-and-forth to drop kids off and pick them up from school and sports activities six to eight times. That schedule alone would be enough to exhaust most marathon runners.

But that’s not the complete picture of Jillian’s day. Jay, her youngest, was born with Miller-Dieker Syndrome, a genetic mutation of his brain. Jay will function at the level of a two-to-six-month old for his entire life. He cannot talk, walk, sit up, roll, move his hands purposefully, feed, dress or bathe himself. As an infant, including him in the bustle of the Napier-Ganley family was little effort, but now at 35 pounds and the size of a typical four-year-old, Jillian was feeling the real, physical stress of lifting Jay in and out of their station wagon so many times a day. And so was Jay.

Since he can’t swallow, Jay is fed through a tube into his stomach — a process that takes up to 90 minutes each meal. Car seats don’t accommodate the tubes and machinery Jay needs, so each time he had to go for a ride, his tubes had to be disconnected and re-attached ... In and out, and in and out

of the car; shirt up, shirt down; cold air on his tummy in winter; awakened from sleep ... It was uncomfortable for both Jay and Jillian. The family's need for a wheelchair-accessible van was obvious.

"Aside from the fact that Jay has to come with me, since we have very limited outside help, it's really important to me that he's included in all of our outings. He's part of our family. Jensa is so proud of him; when she introduces Jay she says, 'This is Jay. He's my brother. He has special needs.' Years ago, society was uncomfortable with people who had special needs because they just weren't included in the same way we now include children like Jay in our communities and schools," Jillian adds.

Giving in Action has provided much more than just a vehicle to drive the Napier-Ganley children around their community. Giving in Action has provided a vehicle for the community to meet and learn about Jay, a child with a severe disability.

Jillian says, "It's obviously good for Jay to be out and about, but it's also giving an

advantage to everyone in the community who meets him. At school, for instance, when I take him out of the van, kids have swarmed us, asking questions about him. They're so inquisitive."

Jillian believes that as a society, it's important to include as many people with disabilities as possible in everyday life. Introducing young people to children like Jay will go a long way in breaking down the fear that people in older generations used to experience meeting children with disabilities. This will help to make the journey toward greater understanding and acceptance of people with disabilities a much easier road to travel.

Jillian apologizes for getting emotional when talking about Jay and her gratitude to Giving in Action, "It's nice to celebrate Jay's abilities rather than commiserate about what he can't do. Our kids do that naturally. We don't like to look at this as a struggle. Jay is a wonderful boy. He's not challenging. We're blessed." 🌸