

## Wheelchair gives kid, family new freedom

By RACHEL TUELLER

For the DiGiovanna family, life and all its daily routines changed dramatically one month ago when 11-year-old Anthony was placed aboard a wheelchair customized just for him. But it's more than the soothing gel seat that alleviates soreness and the specialized color - his favorite, "toxic green" - that's changed things for the family. It's the new life, a newfound freedom and independence the chair has brought Anthony and Joseph DiGiovanna, his father.

It's a freedom both have longed for and waited for many years.

Born with muscular dystrophy and unable to walk, Anthony was often immobile and reliant upon others for assistance without the use of his new wheelchair.

### **A life of freedom**

"It's so much freedom. Now he just drives right into the van and we just go places," said DiGiovanna. The chair has given Anthony a freedom to function like many children his age. DiGiovanna now calls his son to dinner rather than carrying him to the table. "He doesn't have to be picked up and carried everywhere," said DiGiovanna. When the two go shopping, Anthony simply embarks on his own journey, talking with his father with walkie-talkies as he explores the aisles. Occasionally, he'll radio his father about his discovery - a new toy or game.

"Before, I would have to lift him up and put blankets in the shopping cart," said DiGiovanna.

The chair has brought a greater sense of ease into daily routines, too.

"Both my boys love to cook," said DiGiovanna of Anthony and his 8-year-old brother, Joshua. But Anthony's cooking slowed when he grew worried about being near the stove. "Now he just rolls his chair up and cooks," said DiGiovanna.

These days, joining the children in his church group during the Calvary Kids Class is more accessible and next year, as he enters intermediate school, the transitions that come between classrooms every 45 minutes will be easier as well. Anthony enjoys the chair and displays all its technological advances with a certain pride and flair. He reclines his chair and smiles as the feature allows him to easily shift his weight. In the old chair, his back was frequently sore. He shows the "Fox brand shocks" that ensure a smooth ride on the long walks across bumpy terrain, an important feature for a boy who now enjoys running the track with his schoolmates and going for walks with friend Brad - also confined to a wheelchair.

"I just drive really fast - it cools me off," said Anthony with a wide, shy grin.

On Thursday afternoon, Anthony quickly and easily slips off to his friend's house four doors down without incident. The neighbors know when their expected guest arrives with a simple toot of the horn.

"He has fun now that he feels independent," said DiGiovanna, watching with pride as his son maneuvered his chair quickly, quietly and smoothly down the street toward his friend's home.

### **A hard battle**

But it's a freedom that was hard-won after a year of petitioning Medicaid for the resources to meet Anthony's needs. After months of working through appropriate channels to obtain resources like the wheelchair to assist Anthony, DiGiovanna's requests were denied despite letters from Anthony's doctor and physical therapist who agreed the chair met his unique needs.

"They basically said it was too expensive," said Matt Knotts, an advocate with the Disability Law Center.

During DiGiovanna's process with Medicaid, he learned about the Disability Law Center, a protection and advocacy organization for people with disabilities, and requested assistance.

DiGiovanna also discovered that garnering the support and assistance of the DLC didn't require travel to its Salt Lake City offices.

"Through conference calls, faxes and mailings we were able to share all of that information and settle that without extended travel. We'd absolutely come down if need be but the documentation was so good and in place it was just a matter of getting people the right information," said Knotts.

The DLC next filed for a hearing on the DiGiovannas' behalf.

"We were able to settle the case before a hearing was required," said Knotts.

While the DLC does not purchase equipment, the center does provide the kind of representation that became vital for the DiGiovannas to obtain necessary equipment.

"Mr. DiGiovanna had tried for quite some time to get this thing settled. Our ability to come in and represent can sometimes settle a problem very quickly. While some people would say three, four or five months isn't quick, if it would have gone to a full hearing it would taken even longer," said Knotts, who has worked under the supervision of an attorney as an advocate for the Disability Law Center since 1994. "We want to make sure people with disabilities have the access to the equipment that they need and access to our services to protect their rights."

### **Never give up**

While the battle's been a long one, it's not one DiGiovanna is willing to relinquish.

"It's been a constant fight for the last five years," said DiGiovanna, who hopes next to apply for a cough assist machine for Anthony whose lungs don't have full capacity. "If he gets sick, it could be bad. That's the next fight - Josh is next."

What DiGiovanna learned from this fight left him with concerns for his 8-year-old Joshua, also afflicted with muscular dystrophy.

"They don't know me - but they will - because I'm going to give my boys the best life I can. As long as they're ambulatory I'm going to make sure that they feel just like any other normal kid," said DiGiovanna.

DiGiovanna believes Medicaid officials who denied his initial claim should be monitored more closely. Officials, DiGiovanna said, should be working for the people.

"I've paid 40 years into Medicaid, now they're going to start paying back," he said.

Though the road has been long, DiGiovanna hopes others will take courage in the lessons he's learned from his experiences.

"They can fight when they need to for things. They don't have to just sit down and accept it," he said.