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The Living Well With Limb Loss Magazine

Adaptive Living & Technology



Cover Photo:
Upper limb prosthetist Pat Prigge, Advanced Arm Dynamics,
works with transhumeral amputee Kate Jorgenson, age 13.

Health
Insurance 101

**Hiring Workers With
Disabilities Is Good for Business**

30th
Anniversary
30 YEARS SERVING THE LIMB LOSS COMMUNITY

Kate demonstrates her dexterity with her new prosthesis by going through the range of tasks involved with potting a plant.



Kate's Fate:

One Family's Fight for Fairness

by Pat Prigge, CP, FAAOP(D), Jennifer Peterson, MS, PT, and Sherri Edge

M For Kate Jorgenson, a 14-year-old from the farming community of Westbrook, Minnesota, giving up has never been an option. Whether it's on the basketball court, playing in a piano recital or learning how to use her new prosthetic hand, Kate is hardwired to succeed. Three years ago she was doing chores on the family farm when her ATV hit some loose gravel, causing it to roll over. Kate's left arm was severed in the accident. Initially, doctors were able to reattach the limb, but as the days passed, blood clots and infection set in, and her arm had to be amputated above the elbow. Her parents, Nikki and Jim, say that day is etched starkly into their memory.

"She was coming back out of sedation, and we were all very upset and crying," Nikki recalls. "And Kate looked up and said, 'Just stop crying, I'll be fine.' She made us all calm. And it's been that way ever since. She has just moved forward."

With her parents at her side, Kate endured nine surgeries in the 16 days following her accident. After surviving this intense situation, the Jorgensons were not expecting to face yet another tremendous challenge: a protracted battle to gain insurance authorization for the advanced prosthesis their daughter would need.

"It was quite a journey, trying to navigate the waters and getting the proper approvals through insurance," says Jim. "Obviously, we'd never been down that road. I think that probably the biggest obstacle through this process is just the lack of knowledge of the insurance people who reviewed the situation."

Understanding the Options

We met the Jorgensons in June 2013 when a trauma center requested that we come talk with the family. Kate was 11 years old and her amputation had occurred just a few days earlier. Her parents had many questions about current prosthetic options and surgical techniques, and this initial visit gave them the opportunity to start visualizing Kate's future. About six weeks later, the Jorgensons came to the prosthetic center for a full consultation and therapy screening. We discussed a range of surgical options, including cadaver bone lengthening and targeted muscle reinnervation (TMR). We explained that TMR surgery is an option for people with amputations above the elbow, taking severed nerve endings in the residual limb and reassigning them to muscles. Later, when these muscles are flexed, they send a signal to electromyography (EMG) sensors in the prosthesis, telling the hand to open or close, the wrist to rotate or the elbow to move. Without TMR, a prosthesis has just two sensor sites that receive muscle signals; after TMR, there's the potential for four to six sensor sites. This increased information could significantly improve Kate's ability to intuitively move her prosthetic arm and hand. Transferring the nerves into muscles has the additional benefit of preventing painful neuromas from forming in the residual limb.

The Jorgensons invested a lot of time and energy in understanding these complex surgical options and making medical decisions for Kate. We connected them with Dr. Brian Carlsen, a reconstructive microsurgeon and hand surgeon with the Mayo Clinic, to provide additional information and insights.

"We met with our prosthetic team multiple times before Kate was even fitted," Nikki says. "They would show us different devices and what the possibilities were, and help guide us down the path of all these new unknowns."



Kate works on prosthetic controls training with Jennifer Peterson, upper-limb prosthetic therapy specialist.

In January 2014, Kate began regular pre-prosthetic upper-limb therapy, focusing on posture, body mechanics, and improving the strength and stability of her left shoulder and upper back. In the spring, Blue Cross and Blue Shield of Minnesota authorized Kate for TMR surgery with Dr. Carlsen, and in June, one year after her accident, she became the youngest person in the world to undergo TMR.

Don't Give Up

Kate came through the surgery well, and by mid-August she had five palpable muscle signals from the TMR nerve reassignment – an exceptional outcome since full reinnervation sometimes takes up to two years. Her pre-prosthetic therapy was expanded to include at-home TMR exercises and clinical visits for neuromuscular training. In September, we submitted a request to the insurance company for preauthorization for a prosthesis with six EMG sensor sites to receive muscle signals. The preauthorization request was denied, stating that the requested services were not medically necessary. We issued an appeal and received a denial stating that a functional evaluation needed to be completed to validate the use of a myoelectric prosthesis. After fabricating a trial prosthesis for Kate, she was fitted with a loaner Dynamic Arm Plus and VariPlus Hand. The trial prosthesis included four sensors, and with extensive therapeutic training,

Kate learned to use the prosthesis to meet the functional needs of her daily life. We issued a second appeal with evidence from the evaluation and received a denial stating that, “The proposed prosthesis is not eligible for coverage because it is not medically necessary.”

We began 2015 by initiating an external appeals process through the Minnesota Department of Commerce. Jim Jorgenson reached out to the Office of the Minnesota Attorney General and asked them to contact Blue Cross and Blue Shield of Minnesota and request that Kate’s appeal be reconsidered. At this time, the Jorgensons also retained legal counsel. In March, Kate was evaluated by a physical medicine and rehabilitation (PM&R) physician. Upon receipt of this physician’s recommendation, the insurance company overturned their denial and authorized a prosthesis with the ability to utilize six myoelectric sites. Countless hours were invested in collecting information, communicating back and forth with the insurance company, and moving forward with our detailed rehabilitation plan. Fueled by the Jorgenson’s persistent advocacy for their daughter’s rights, Blue Cross and Blue Shield of Minnesota came to understand that Kate’s advanced prosthesis was important and necessary for her independence.

“It’s just been an incredible opportunity for Kate and for us,” says Nikki.

Better Outcomes Are a Reality

Insurance denials for upper-limb prostheses are commonplace, especially for myoelectric devices that offer more advanced functional capabilities. The obvious reason is the higher initial costs associated with these types of prostheses. Insurance policies often state that they cover prosthetic devices for basic activities of daily living (ADLs). According to Medicare, basic ADLs include “bathing, dressing, using toilet facilities, eating and moving from place to place” (medicarerresources.org). If we were to boil life down to these very basic tasks, then it could be assumed that most people have completed their ADLs by 8am and don’t need a prosthesis anymore. But when we look at the actual daily life of an individual like Kate, we see an entirely different list of activities: going to school, engaging in social interactions with peers, playing sports, or doing chores on the family’s farm. In another year or two she will be learning to drive a car, going out on dates and getting her first part-time job. Then there will be college, a career and all that follows. This is the fullness of life, and if health insurance companies developed a better understanding of specialized upper-limb prosthetic rehabilitation, it could become a reality for more people with limb differences.

The Jorgensons are pleased with Kate’s outcome and they’re not going to stay quiet about it.

“My advice would be: Don’t give up; be persistent,” Jim says. “It’s well worth the effort and persistence to continue to pursue myoelectric prosthetics. It wasn’t easy – many hours of conversations, phone calls and letters. And it’s like no other battle that you will probably face, but the reward is unbelievable.”

Kate’s accident and limb loss are traumatic medical events that will impact the rest of her life. And yet, our years of experience in requesting insurance authorizations have shown that many upper-limb prosthetic devices are somehow viewed as luxury items, deemed “not medically necessary,” and therefore denied. Prosthetic devices are no more of a luxury for a person with limb loss than a heart valve is for someone with a congenital heart defect.

As upper-limb prosthetic specialists, our goal is to continuously improve the prostheses and rehabilitation we offer our patients. It is critical to educate insurers about advances in upper-limb prosthetic technology and the enhanced quality of life these advances can help restore. After surviving traumatic accidents, limb loss, surgeries and rehabilitation, people should not have to settle for outdated and limited options in upper-limb prosthetic rehabilitation. 🌀



Kate with her parents, Nikki and Jim Jorgenson.

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