BISMARCK -- Kevin Peterson got off the phone with an NDAD client services representative earlier this year and felt, well, different. Hopeful, to be specific.

Peterson, a 50-year-old Bismarck resident with muscular dystrophy, said hope almost disappeared after all-too-many calls elsewhere for assistance to obtain a scooter lift for his Chevy Venture van.

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KEVIN PETERSON: ‘Something was wrong,’ but unsure what

Peterson could not afford to purchase the scooter lift on his own, and Medicare wouldn’t cover the cost. He knew the lift’s value to his life could not be measured in dollars.

He sought help from lots of sources, and the responses, he said, always had been discouraging: “I tried every avenue that I could. I didn’t know where to turn anymore.” When he tried to obtain financing, he recalled, “the bank wouldn’t even look at me.”

Then came his conversation with NDAD’s Stephanie Tornatore. “Very, very, very nice,” he said to describe Tornatore, who works out of NDAD’s Minot office. “Unbelievable. Cool, calm, collected. And concerned. I’ve never met her, but over the phone, she’s amazing. She’s just ‘on’ it... And she was so, so nice about everything.”

“After I talked with her,” he recalled, “I got off the phone and I just sat here and I thought, ‘You know, there might be some hope here.’”

Tornatore sent Peterson an application for assistance, which he completed and returned. Several weeks later, he received a call from Tornatore with good news: NDAD, working with Great Plains Rehabilitation Services, would get him the scooter lift for his van.

That decision put him a mere lift installation away from vastly improving his access to the world outside his south Bismarck mobile home. He again would live less like a shut-in.

“I cried when she said that it was approved,” Peterson said softly. “I cried.”

He prefers tears of joy over the emotional pain he’s battled over decades, as the progressive skeletal muscle weakness associated with his type of MD gradually reduced, then stole his ability to move freely. MD’s advance over the past five years in particular has hastened his physical decline, he says.

Peterson’s MD, much less its variation (fascioscapulohumeral), wasn’t even diagnosed until about six years ago by a physician specialist in Fargo who told him “he couldn’t believe I had not been diagnosed with this years and years and years ago,” Kevin recalled.

“I don’t think it would have changed my outcome, really,” to know it was MD sooner, Peterson said. “But it would have eased my mind.”

All these years – since way back in the eighth grade – Peterson said he had known “something was wrong.”

“I couldn’t keep up with everybody in gym,” said Peterson, recalling a gym teacher who questioned his inability to do some activities. “What’s wrong with you?” the teacher asked, Peterson didn’t know, even as he developed a limp. “But I could feel something, and I kept on telling Mom, ‘There’s something wrong. I’m just... weak.’

“So I’d go to the doctor. Every one of the doctors said, ‘There’s nothing wrong with you.’”

Eventually, physicians acknowledged his physical symptoms but without identifying a cause.

In adulthood, Peterson became a USDA government biological technician. His work with the USDA ended after almost 13 years when budget cuts led to his furlough. He was married at the time, and a father.

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Kevin Peterson, in his home during an early stage of remodeling. His home now has a new floor, cabinets and kitchen appliances.
KEVIN PETERSON

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“I could have transferred to Ames, Iowa,” he re-called, “but we just had our first child,” a son named Michael. A daughter, Brittany, came a few years later.

Peterson took a job delivering various types of grocery, vending and café supplies to area communities. Later, he sold cars for a living, but his body couldn’t keep up with the auto dealership’s longer hours and physical demands, he said. So, he purchased a lawn care business that, for about 17 years, allowed him to manage his own time and rest when he needed it. Ultimately, his health forced him to give it up.

Peterson already had been making medical trips to Mayo Clinic in Rochester, Minn. After a battery of tests and examinations, he was diagnosed with polymyositis, a type of muscle inflammation, and he was prescribed high doses of prednisone, a steroid, to try and treat it. After about two years, when the pills “did nothing for me,” he successfully asked to stop taking that medicine.

He continued trying to remain as active as possible, including hunting North Dakota wild game large and small. He feared that if he didn’t try to stay active, his mystery ailment would, in his words, “grab me from behind.”

Meanwhile, he made donations to the Muscular Dystrophy Association (MDA) after seeing a boy and a girl with MD during a Mayo Clinic visit. Neither was able to feed him or herself, he recalls. That memory stays with him still.

So, when the MD diagnosis finally came about five years ago, Peterson felt both relief and heartbreak. “It took me a long time to accept it – that I’m not going to change, that I’m not going to get any better... They don’t know what course it’s going to take. It’s progressive, there’s no doubt.”

Fall and rise

Around the start of this year, Peterson fell and shattered the bones in his lower left leg, and then he learned osteoporosis was part of the cause. That leg is “all metal right now. It’s metal and screws,” he said. After about two weeks in the hospital, his incapacitation challenged his ability to stay in his mobile home.

“Ohh, you talk about depression,” he said, wide-eyed. “I didn’t know if I was coming out of that one. It really scared me.”

It also left Peterson thinking about his ability to remain a resident of the mobile home where he has resided for three years.

His mobility had improved with a ramp built by his brother and son, with donated materials from Lowe’s in an arrangement with the Muscular Dystrophy Association. MDA also helped him obtain a scooter. Still, without regular assistance, his inability to get that scooter in and out of his van severely limited his destinations.

When Peterson suggested that he should move into assisted living, his son and daughter would have none of it.

Instead, Peterson’s family renovated a large section of his mobile home, including replacing the subfloor and providing new hardwood flooring, plus new appliances and cabinets that better suit his limited reach.

With help from more intense rehabilitation, he can move around his house again with a walker. “I can cook my food. I can do my laundry. I can do what has to get done without having to rely on somebody, because that’s what I don’t want,” he said. “I want to stay independent as long as I can – if not forever.”

“I know what I can do,” Peterson told NDAD. “So just do what you can do and don’t worry about what you can’t do... How else are you going to be? I keep it in the back of my head: I could be a lot worse. And if I just give up – it don’t get you nowhere.”

Peterson gives credit to family and friends who provide help when he needs it – and to timely support from MDA and, now, NDAD. The latter’s help in obtaining his van scooter lift changed his life, he said.

Without having to rely on help from others, Peterson goes to church, medical appointments, physical therapy and even the mall to “just drive around... and be with people,” he said.

“I wake up every morning and say my daily prayer. I thank God for letting me be on this earth yet. That’s all I can do.”

“I never dreamed that anything like that would happen to me, but it just kind of fell apart. But it’s not all the way apart.”

He smiled resolutely. “I’m still here.”
The 2013 Escape to the Lake adaptive water recreation event June 15 at Nelson Lake near Center, N.D., attracted several dozen participants with disabilities, plus family members, friends and caregivers. NDAD, Texas Adaptive Aquatics, Sporting Chance and the Aberdeen (S.D.) Aqua Addicts provided on-site support and activities, including lunch and an acrobatic ski show. The day offered lots of sun and equally bright smiles. Planning begins soon for the big 20th-anniversary Escape to the Lake, set for June 2014.

More Escape to the Lake photos at [NDAD’s Facebook page](#).
More Escape to the Lake photos at NDAD’s Facebook page.
Assist gives him more independence, control — and a whole lot less stress

GRAND FORKS -- You don’t see James Knecht on crutches any more.
He knows more than anyone what an accomplishment that is. A victory, in part, over himself.
“I didn’t want to give them up,” Knecht said.
James, 65, was a farm kid in rural Harvey, N.D., when – at age 5 – he was diagnosed with polio.
He has never walked without assistance since. But as recently as about two years ago, he still used crutches as his “main mode of transportation.”

Knecht paused, then chuckled at the thought of it. “I mean, it was pretty dangerous. Pretty slow,” he said. “But that’s what I did.

“And then I got smart and got the scooter.”
That decision to acquire a used scooter about five years ago “just changed my life” and set in motion a series of circumstances that helped him even more, Knecht said. “I started doing things that I hadn’t done all my life. Why I hadn’t done that earlier? I don’t know.”
The scooter doesn’t even come into Knecht’s southwest Grand Forks residence now. He has a battery-powered wheelchair that gets him around more easily from room to room.
Still, his scooter and power chair get lots of use outside the home.

With the help of a motorized ramp, installed in his 2006 Chevy Uplander van and provided by charitable nonprofit NDAD, James has achieved the mobility he relishes.
He couldn’t easily get in and out of his former vehicle, an SUV with a camper-style foot step.

“And when I did get in,” he recalled, “I was always stressed out because I was worried about falling down and stuff like that.”

With the scooter and van ramp, “I can control the situation. . . .

“There’s nothing like driving – to be able to get in a vehicle and drive, go someplace. It’s a big part of life. If you know that you’re stuck right here unless someone comes over and helps you? . . . That’s a big deal.”

Those changes, he said, “took a lot of stress out of my life” by giving him “complete independence.”
And without NDAD’s assist, he added, “I don’t know how I would have done it, because I’m on (Social Security) disability, and that’s all I’ve got.”

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It’s been about 60 years since polio gripped a young Knecht, who came down with it “like it was the flu,” then didn’t get any better, he recalls.

“I just started getting weaker. Finally Mom took me to Minot, and right away it was diagnosed as polio.”

The poliomyelitis threat lingers today in several foreign countries, even though a landmark polio vaccine, then a second, virtually eradicated it. But at its peak in the 1940s and 1950s, polio seemed to be everywhere, and it paralyzed or killed hundreds of thousands of people worldwide annually.

At the Minot hospital, Knecht recalls, “they put the icepacks on me to slow it down. But it was too late.”

Young James spent at least a month in an iron lung, when “the only thing I could move is my eyelids,” he recalled. “It was a matter of knocking me down to nothin’ and then working my way back up.”

Working steadily with a therapist, he gradually gained back some movement, particularly in his upper body. “Some things came back,” he said. “Some things didn’t.” His left leg did not; his right leg “has got a little bit of strength.” Knecht has used a full-length brace on his left leg in the years since.

James’ spine began curving as he aged during his youth. At 12, James underwent a total spinal fusion performed at the University of Minnesota hospital. The procedure was invaluable, he says. “That was an amazing operation at the time... After the first couple of years, I haven’t had one problem with it, to this day. Not one pain.” Not even after a Grand Forks car accident and after falling down “lots of times” since, he said.

“But then, as gravity works on your body the rest of your life, and you put on 30 more pounds, one side of me started going like this,” he said, leaning sideways, “and started squeezing my rib cage.

“There’s nothing like driving – to be able to get in a vehicle and drive, go someplace” when you want or need to do so, James Knecht of Grand Forks said. “It’s a big part of life.”

“Now I’ve got to have oxygen, because that one lung can’t work. I can do without this oxygen, but it just makes my heart work harder,” a threat to cause his heart to become perilously enlarged.

He’s used the added oxygen for about eight years.

After his polio first appeared, his family moved closer to Minot, near Foxholm, before settling in Grand Forks years later during his senior year of high school. Knecht still has two surviving brothers and a sister living in Grand Forks.

A former University of North Dakota accounting student, James returned to Grand Forks after a career spanning more than 30 years working as an office manager and accountant for a large family farming operation near Jamestown, N.D.

Knecht’s one regret, he said, “is not getting that scooter sooner, or using a wheelchair sooner in my life. I just kind stuck with those crutches way too long, and it held me back in a lot of things.”

He needs occasional cortisone shots in his wrists, both injured from decades of using crutches.

“I’m terribly independent. My mother used to tell me that – ‘too independent,’” he recalled, smiling at the memory of Hertha Knecht. “And she realized I’d have to get over that.”

James’ advice to people who need help: contact NDAD and find out whether they qualify. “Just don’t wait. Do it,” he said.

“Get your application in. For me, I just waited too long – but I am a procrastinator.” He smiled again. “Once I got going on it, it went pretty good.”

Grand Forks client services representative Jeri Hietala “was really good. She got back to me. . . . She didn’t put any pressure on me.”

Knecht said the application process to obtain help from NDAD isn’t that hard -- “not if you need it.”
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NDAD is a nonprofit, charitable organization founded by concerned citizens to assist mentally and physically disadvantaged people in North Dakota, many of whom are not eligible for services from other agencies.

Disabling conditions often are very costly. NDAD was founded on the belief that people with disabilities, when given the opportunity, can live more satisfying, productive lives — and NDAD has helped thousands do just that since its start in 1975. This often requires the purchase of specialized equipment, medical treatment, or other services.

NDAD provides financial assistance through funds generated by both the organization and community projects. NDAD also provides information and referral services to help people receive assistance through other agencies, when possible.

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