



The magazine for active
wheelchair users



Nurses on Wheels

By [Tim Gilmer](#) | April 1st, 2019

Battling Bias, Finding Their Niche

This is the second part of Tim Gilmer's two-part series investigating how people with disabilities are affecting change from within the medical world. Make sure to read "[Disabled Docs: Healing the Medical Model?](#)" in our March issue.



Photo by Mark Woolcott

The premiere issue of *American Nurse Today* in 2006 described the changing landscape of nursing by emphasizing the need for mobility and

portability due to “growth in freestanding clinics, ambulatory care centers, and other nonhospital settings,” adding that nurses being educated in a hospital-based model “doesn’t mesh with today’s trends.” More recently, a 2013 *Huffington Post* article described nurses’ expanding roles this way: “Nurses are giving TED talks, publishing scientific research, developing mobile medical applications, and actively addressing health care policy. ... The field is growing, and so are opportunities for nurse practitioners, DNP and Ph.D. nurses, nurse educators, nurse-anesthetists, and nurse researchers.”

In 2019, a greater percentage of the U.S. population than ever before is covered by health insurance, thanks mainly to the Affordable Care Act. The popularity of the concept of Medicare for All, currently favored by two-thirds of Americans, is likely to grow as the 2020 election nears. Set against this backdrop, opportunities for nurses who use wheelchairs are also likely to grow — except for one major obstacle.

Despite the expanding need for nurses in dozens of different settings, an antiquated, stereotypical view of nursing still persists: the hospital bedside nurse, hustling from room to room with little or no time for breaks, all the while carrying armfuls of supplies while answering call lights and pagers in the midst of caring for and lifting patients. This stereotype, while based in fact, ignores the growing necessity of teamwork in nursing, and it also excludes most nurses who use wheelchairs and wheelchair users who want to become nurses.

Thankfully, a modest but formidable number of dedicated nurses on wheels is committed to breaking down this barrier of bias that too often leads to outright discrimination.



To become a nurse, Andrea Dalzell knocked down every obstacle that her professors put in her way.

The Pioneering Nurse

In the late 1980s, Karen McCulloh was working in neurosurgery intensive care nursing when she began experiencing symptoms of multiple sclerosis. With its attending vision and mobility losses, as well as an unexpected significant loss of hearing, eventually she had to confront an unimaginable question: Can I still be a nurse if I'm blind, deaf and use a wheelchair?

Even though multiple disabilities significantly reduced her physical function, McCulloh still had years of training, valuable job experiences and a passion for nursing. She wanted to continue doing what she loved. "At this time, I was blind in one eye with low vision in the other, deaf in one ear, a hearing aid in the other, and used a cane or wheelchair in some situations. So I went to a rehab counselor, and he says, 'So, you were a nurse.' I said, 'No, I AM a nurse.' I walked out of his office and never returned." Another rehab counselor told McCulloh they were evaluating her for a sheltered workshop. "I told her, 'I am a licensed RN with extensive work history!' I cannot tell you how this impacted me. All of a sudden your life experience and employment history counts for nothing."

McCulloh decided to return to college but was denied entrance to several Bachelor of Science in nursing programs. She was finally admitted to Loyola University of Chicago, but not to its BSN program. With two kids in college, she graduated from Loyola with a Bachelor of Science, but couldn't find a job in health care. The year was 1994.

"I decided I had to write my own script," she says.



Devon and Michelle Kephart found a home in Denver.

“Nondisabled nurses rejected me because I was disabled, but I knew I needed to confront bias and not give up, so I moved more into education and set up my own business, focusing on community health disability education. I created that field — you won’t find it in any workbook — maintained my license and moved into executive leadership.”

In 2003, she co-founded the [National Organization of Nurses with Disabilities](#). She was also the founding executive director of Disabilityworks from 2005 until 2010. She was appointed by the Secretary of Labor as the only person with disabilities to sit on the National Job Corps Advisory Committee from 2006 until 2008, while serving as chairperson of the Subcommittee on Disability. McCulloh also served as the chairwoman of the board of directors for Access Living of Metropolitan Chicago, and in 2008 was a member of the Obama-Biden transition team. In 2011, President Obama appointed her to the AbilityOne Program, where she served until 2016.

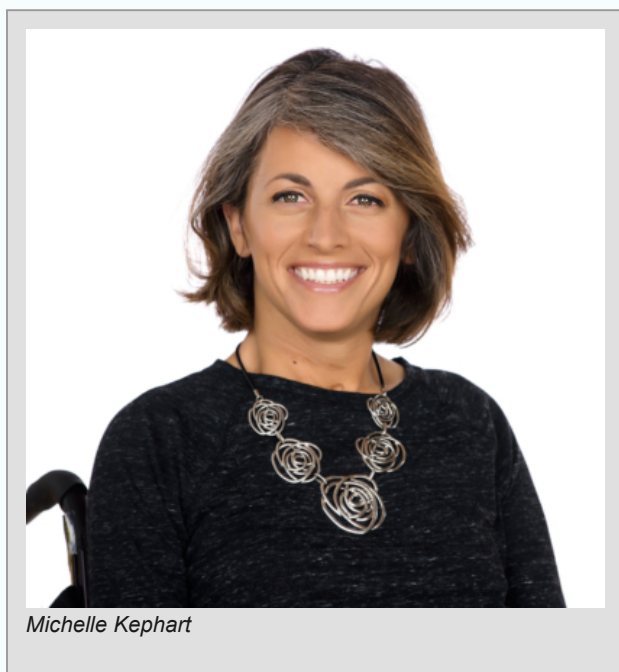
Summing up her struggle to re-enter nursing, she says, “The irony for me is, I was not considered qualified to enter school for a BSN, but the president of the United States saw me as qualified to work for him.”

Today, she has her own consulting business where she focuses on diversity and inclusion working with

businesses and nonprofits. “I’m interested in the workplace development side. We will lose 500,000 nurses to retirement by 2022. Bureau of Labor statistics predict we’ll need 1.5 million nurses in the coming years. We are seeing an increase in nursing students with disabilities, but the challenge is still at the workplace, especially for nurses who use wheelchairs.”

Nevertheless, she has reason to be optimistic. The nursing field is changing with more and more non-hospital nursing opportunities. But one thing, thankfully, never changes — the most important factor of all: “What drives us,” says McCulloh. “Our passion.”

‘The Hardest Thing I’ve Ever Done’



Michelle Kephart

Passion is a prerequisite for becoming a successful nurse, especially if you must convince others that a physical limitation — such as quadriplegia — will not affect your overall proficiency.

In the summer of 2008, Michelle Kephart, a University of Iowa nursing student, broke her neck in a fall. Now paralyzed, after six weeks in intensive care she was transferred to Craig Hospital in Denver. She was halfway through her nursing program, and a friend’s suggestion that she would be out of rehab in time for next semester caught her off guard. “It was the first time I ever thought of going back,” she says. “I was so busy dealing with everything. But thinking about returning to the path I had chosen made me happy.”

Her friends and staff at Craig were supportive, and her boyfriend, Devon, was especially helpful. “Even though we had no idea what nursing would look like, we decided there was no reason not to go on,” she says.

She soon found that returning to nursing school as a C5 quad was going to be tough. “I had to fight hard to get them to continue the program for me. We finally agreed I would take only two courses, one day per week, to see if I could do all I needed.” Determined, she did well in both classes but was told she would have to redo a patient assessment even though she had completed one before her injury. “The first time I did it with another classmate and one professor evaluating. This time I had to do a full head-to-toe videotaped assessment that would be evaluated by three different professors, pass or no pass.”

Kephart fought the altered assessment with help from the local Independent Living Center, met with faculty and sent a complaint to the Equal Employment Opportunity Commission. She was allowed to have an LPN student assist by holding a stethoscope, but the assessment was done entirely by Kephart. She passed, got her RN degree and the EEOC ruled, essentially, “no harm, no foul,” even though the nursing school had clearly violated the ADA. “I would not be hired in any position that I couldn’t do something physically, so it [the altered assessment] was unnecessary,” she says. “Their job is to teach, not screen out.”

In 2010, not yet ready to live on her own, she moved to Houston, lived briefly with her dad, then moved to Georgia. There she lived with her mom and volunteered at a community hospital in Savannah. Kephart took a part-time position as a disease management coordinator and diabetes educator. “I had an office, and a lot of what I did was counseling and guidance and making adjustments.” The program grew to include cardio, women’s health and nutrition over the next three years, and she was promoted to full time. “It worked out well, but there was never any certainty to it,” she says.

In 2015, Devon, who had joined the Peace Corp and, later, the Air Force, returned from serving overseas and was stationed in Colorado. They married, and Michelle got a job teaching in an online nursing school program at

[Western Governors University](#) in Salt Lake City. Twice a year she travels to attend academic meetings at WGU, but the rest of the year she telecommutes from her home office in Aurora, Colorado. Her main daytime helper is Rumba, a golden lab who picks up dropped items for her, opens the fridge and gets her lunch.

Ten years after her injury, she is now three years into her teaching job. "Other than adjusting to paralysis, returning to nursing school and finding a career path is the hardest thing I have ever done," she says. As far as I know, I'm the first quad to graduate from nursing school and begin a nursing career. You have to be willing to get out of your comfort zone."

And she is grateful that she did. "I am so happy with my job now. It is ideal, it is perfect. I love it."

The Path of Education



When accident or disease forces a nurse to become a wheelchair user, they must be courageous, creative and willing to make career moves to continue working. Dawn Dubsy was a pediatric nurse when she contracted malaria in Ghana, in 2008, and had to have all four limbs partially amputated. As a power chair user, she thought her days as a bedside nurse were over, so she decided to become a nurse case manager and further her education. In 2010, after rehab, surgeries and

complications, she went back to work as a case manager and enrolled in a doctoral program. She also created AmericaAgainstMalaria.org, a nonprofit, to help educate children in Ghana about malaria. In 2017, she graduated from the University of Illinois at Chicago with a Ph.D.

In 2018, she moved to Seattle and is now working at Seattle Children's Hospital as an inpatient pediatric case manager. She helps manage length of stay, transition to home, and advocates for services and equipment. "Now I get the big picture better," she says, "how all this affects patient care. From childhood to adult, there is a gap in health care for people with disabilities. Pediatrics has much more support and resources, but that changes when you go from youth to adult."

She says the inequities are more related to policy than money. "In Western medicine we engage in a lot of highly technical services for maintaining life, but we don't think about outcome later when people need additional services." She should know. The hospital she works for provides employee transportation, but not for her. "Every day I have to sit and wait for a public bus, and the employee vans drive past me, none of them accessible," she says. "The hospital is out of compliance with the ADA. I have to sit out in the rain in my wheelchair and watch buses go by. I am an employee but I can't utilize the same services as others use, so it makes me feel unimportant."

As a case manager with a Ph.D., she is overqualified for her job. "You have to fight one battle at a time and advocate for yourself," she says. But her dissertation, which will be published soon, speaks for all nurses with disabilities. "I interviewed 21 nurses with disabilities, four of them wheelchair users, about accommodations in the workplace."

She found that the same lack of accessibility that creates healthcare inequities for wheelchair-using patients also discriminates against nurses with disabilities: too little room to maneuver, inaccessible bathrooms, exam tables that are too high, steep ramps, too-narrow doorways, hard-to-reach items, unclear process for asking for accommodations, and on and on. "In hospitals, we need to make accessibility improvements for not only clients

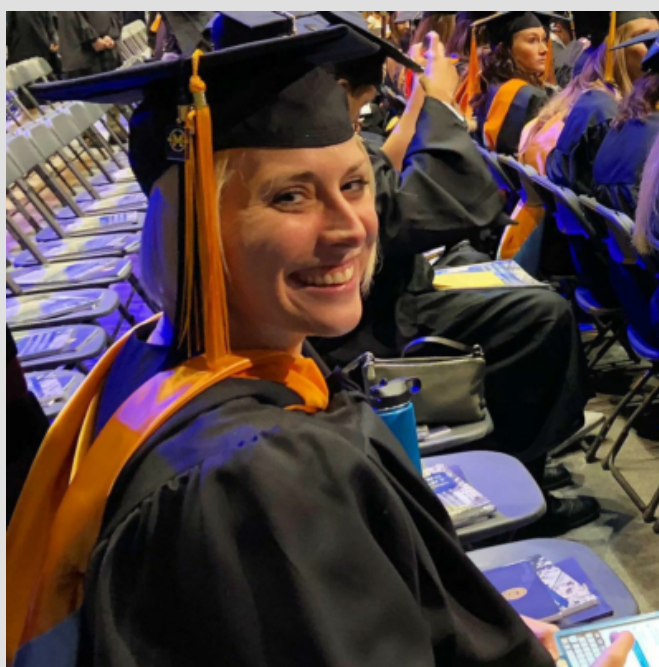
but employees. It's just not disability-friendly. Of all places, hospital design is not aimed toward wheelchair use. Universal design should include pediatrics, wheelchair users, strollers and more.”

Now, despite her everyday challenges as a pediatric case manager, as Dr. Dawn Dubsky she is equipped for the next step in her life. “If I want to go into research or managerial or administrative roles, I have a lot of opportunities that I didn't have in the past.”

Still, she keeps coming back to what happens to her pediatric patients when they become adults. “We need more facilities and providers that can help people in their homes. In the community. What if you don't live in a major city? It's difficult to get to work. What if you need public transport but you are in a rural area and there isn't any?”

The Need for Community Nursing in Rural America

Lindsey Freysinger, 32, lives with her husband on the flanks of Mount Hood in the small town of Parkdale, Oregon, population 311 — about as rural as it gets.



Lindsey Freysinger earned her master's degree in 2017.

Six years ago she was in McAllen, Texas, doing her residency to become a certified registered nurse anesthetist, a program offered by Midwestern University

in Glendale, Arizona. On a trip with a friend, an auto accident changed everything. After spending 11 days in the ICU with a C5-6 incomplete burst fracture, she was medevaced to Providence Portland Medical Center in Oregon.

She began regaining sensation and function during her three-month stay in the PPMC rehab unit. She started walking with braces and crutches but lacked stability and had to use a wheelchair at times. "From hour one, I knew I wanted to return and finish my anesthesia residency because it was my passion," she says. Her school agreed to let her resume her residency after an 18-month leave of absence.

Having returned from her leave of absence, after a week of working in a lab, she had to complete a test that involved working with five practice dummies doing five different procedures. She wanted to use her wheelchair but was told the chair wasn't allowed because it presented an "infection control issue." She got up on her crutches, completed multiple procedures, ran into a few issues but recovered. Then she had to look through a camera while standing, lost her balance, and was told her inability to maintain equilibrium was a violation of technical standards.

"Because I lacked proprioception and sensation, when walking I had to depend on my sight rather than my sense of feeling," she says. "Standing without support, with one eye closed, I lost balance. They closed the door in my face at that point."

Rather than fight an unfair process, Freysinger decided to take time off. "I realized I had gone back to school too soon. I needed to learn all the practical and adaptive ways of getting along."

In 2016, she married and made plans to return to school and obtain her master's in nursing administration and leadership. She enrolled in a web-blended University of Michigan program, her parents moved to Alaska, and she and her husband stayed in the Parkdale home. "I would fly to Ann Arbor once a month, take classes and return to Oregon. With financial help from scholarships, I got my master's in December 2017, did a streamlined

application for the doctoral program and transitioned immediately with help from another scholarship.”

Now she is in the second semester of her Ph.D. program and should finish by mid-2020. “I can’t say enough about the University of Michigan. I have been astounded by their willingness to accommodate. They are excited about it! They continually try to get my input on things. And their services for students with disabilities are absolutely top notch.”

Freysinger foresees a role for herself in community nursing in her rural county in Oregon. “More people are going back to their homes earlier, spending less time in hospitals,” she says. “They are expected to navigate their own health care, but they need help.”

People with disabilities in rural communities are isolated. “Getting nurses back out in the community to address the social determinants of health — your ability to socialize, exercise, get good food, all of that — that is where I think we nurses with disabilities can make an impact, because we get it,” says Freysinger. “I’m not talking about home health nursing, which is still task oriented. I’m talking about a team of nurses focusing on people with disabilities in rural communities. It is important to get them resources and connections that can change their quality of life. Number one for a nurse is to be a patient advocate.”

The Needle in the Haystack

Wheelchair users who must gain admittance to nursing programs, complete their training and then land a job face even more formidable bias and discrimination. Andrea Dalzell, 31, was born and raised in Brooklyn. At the age of 5 she was diagnosed with transverse myelitis and started using a wheelchair at 12. Complications with hip dysplasia diminished her functional ability but did not dampen her ambition. “In high school, nursing wasn’t in the picture. I wanted to be a lawyer so I could come back and sue,” she jokes.

Later, at City University of New York’s College of Staten Island, she wanted to be a doctor, but changed her mind. “I had sat through a med class, and it wasn’t what I wanted to do — wasn’t the way I wanted to care for

patients. Doctors are taught how to treat disease and the process, and nurses are taught to treat the person and how they are handling it. Nurses pick up the phone and tell doctors what's going on.”

Dalzell applied to the CUNY College of Staten Island nursing program in 2016. During orientation, one of the professors, assuming she could not do bedside care from her wheelchair, told her she was



Andrea Dalzell finished her bachelor's with high marks.

dismissed for the day. “I just looked at her and said, ‘I’m not going anywhere,’” says Dalzell. “She had no clue as to my ability level. After orientation I went straight to the access and accommodations office and the diversity office and told them I was being denied entrance due to my disability and would go to the highest court that I could.”

During the meetings that followed, she made it clear that the only accommodation she needed was that she would tell them what she needed when she needed it. “It came down to letting them know that I am vocal about my needs, and communication is all important, and that nurses embody this.”

When it came time to demonstrate her ability to perform CPR — one of the most difficult technical standards for a wheelchair user — rather than ask for an accommodation, Dalzell took up boxing to build up

stamina to be able to do chest compressions. “Nurse managers sometimes thought it was more of a hindrance to have someone in a wheelchair on the floor,” she says. “I had to tell them, it’s not just bedside care, it’s teamwork. Don’t judge me before you know what I can do.”

Dalzell passed the CPR test and became an RN in February 2018 and finished her bachelor of science in December with high marks. Now she is working as a case manager for a long-term managed care company.

“I’m not there yet,” she says. “I’d love to be a pediatric rehab nurse in a facility like Kessler, or where disabled children are being treated. It’s important for kids to see people who have disabilities doing the things you are interested in, extremely important to break the barrier — especially at a young age, especially when doctors don’t give much hope.”

Now, at the beginning of her career, she knows that entering and completing nursing school as a wheelchair user is a rarity. “New York State’s nursing board told me I was the first in the state to graduate with a credential,” she says. “I guess that means I’m one of the few needles in the haystack.”

Nurse Practitioner: An Alternate Path?



Gillian Aitken hopes that becoming a nurse practitioner will improve her career opportunities.

Gillian Aitken, 31, graduated from Grand Canyon University with a Bachelor of Science in nursing in 2014. A wheelchair user since the age of 12, she hoped to be an emergency room trauma nurse, but she found nothing but rejection.

“I’ve applied for thousands of jobs all over, talked with every major hospital in Phoenix,” she says. When she applies on Skype, she gets offers, 20 so far, but when she shows up for an in-person interview, the offers are withdrawn.

ER nurses in wheelchairs may be nonexistent, but trauma nursing is Aitken’s passion. “I even volunteered and went to the Woolsey Fire in California,” she says, referring to the fire that devastated Southern California in 2018. After four years with no paid work, she sought a different path. “I applied to Duke University’s nurse practitioner program and was accepted. It’s both online and in-person. I’m in my first year of a two-and-a-half-year program, and I continue to volunteer as a Red Cross disaster relief nurse.”

A nurse practitioner performs many of the same tasks as a nurse, but is more autonomous. “A nurse assesses patients and implements treatments ordered by provider while advocating for the patient. Nurse practitioners assess patients, order diagnostic testing, and treat patients while advocating as well,” says Aitken. “Nurses have a much more physical job while NP’s jobs are far less physical and more autonomous.” NPs can prescribe medicine, but not narcotics.

No doubt her career chances will improve as a nurse practitioner, but she will still have to hustle to find a job. If she can’t, she can always open her own office.

Rosemary Ciotti was a nurse practitioner in 1992 when she got waylaid by an autoimmune disease and ended up a wheelchair user. She moved to Arlington, Virginia, in 1994 because her husband was hired in the Washington, D.C., area.

“I landed in the land of the ADA,” says Ciotti. “I was the



Rosemary Ciotti checks New Mobility contributor Sheri Denkensohn-Trott's vitals.

new wheelchair user in the hood with a baby on my lap. Disability activists in the area saw I would get stuck in doors, had problems with Metro trans, and the rest was history. They did a kind of 'intervention.' All these politically engaged advocates saw I was an NP and realized they needed me. So a whole new career was born. I started advocating for their medical care, taking on docs who discriminated, organized peoples' care, made house calls, went to hospitals. I was a patient advocate, would see them at bedside and could make things happen so they could get immediate care."

All this happened quickly after Ciotti moved to Arlington. "I was 40. They reached out to me with my baby and helped me build my life back. We traded what we knew." Later, at a Harvard conference she met Karen McCulloh of NOND, who invited her to be on her board of directors. "I'm NOND's person at the capital, lobbying right here, active in Capitol Hill actions."

At 61, Ciotti is now a seasoned advocate: "You are either at the table or on the menu," she says.

National Organization of Nurses with Disabilities

Karen McCulloh co-founded NOND in 2003 and served as the first president of the nonprofit. Currently she serves as director. Besides McCulloh, three nurses in

this article serve on NOND's board of directors with specific roles: Rosemary Ciotti, Dawn Dubsky and Michelle Kephart. A fourth, Gordon Ninde, a co-founder, is no longer active in NOND but has made a successful career in nursing in Colorado.

Calling itself "the voice of disability in nursing," the nonprofit "promotes equity for people with disabilities and chronic health conditions in nursing through education and advocacy." Their website is proof of this statement, with extensive listings of articles, helpful resources, a job board and one of the most comprehensive, information-packed FAQ sections available anywhere. Go to nond.org.

Can a Wheelchair User be a Floor Nurse in a Hospital?

In 1992, Gordon Ninde, a climbing and mountaineering enthusiast from Durango, Colorado, fell 40 feet while rock climbing and sustained a T9 complete spinal cord injury. Instead of being taken to Craig Hospital, one of the best SCI centers in the nation, he was flown to St. Anthony's in Denver — where he stayed for a month. "I had just graduated from college and didn't have any health insurance. I had to stay at St. Anthony's until I could qualify for Medicaid before they would move me to Craig," he says.

At the time of his injury, nursing was not on his radar. He had a bachelor's degree in environmental biology from Fort Lewis College in Durango. "I had wanted to do field biology so I could do climbing and outdoor things I love," he says.



Shown here with his family, Gordon Ninde is a nurse case manager.

Following his discharge from Craig, he moved in with his parents for a year and a half, then rented a subsidized housing accessible apartment. “The rehab people got me a forest service job doing computer mapping of watersheds, but I didn’t enjoy sitting in a cubicle,” he says. “I wasn’t sure what I wanted to do, but I had an interest in medicine, so I went back to college and took more biology courses, genetics and physiology to round out my degree.”

He picked up his licensed practical nurse certification from a local vocational school, then applied for nursing school at Pueblo Community College. The ADA was in its infancy. “The instructors wanted to make it work but were very uncertain since they hadn’t dealt with anyone in a wheelchair. I just wanted to do the best I could,” he says. “At the time I didn’t know much about ‘reasonable accommodations,’ so we just worked it out.”

When it came time to demonstrate his ability to do CPR, he climbed down out of his chair, did the compressions on the practice dummy, and activated the proper code to get help.

While in his second year of nursing school he got a part-time job as a unit secretary at Durango’s Mercy Regional Medical Center. Since he had already made connections at the hospital by the time he graduated, he applied for a part-time nursing position and was accepted.

And so began a career in nursing that many thought would never be possible. Now 50 and a registered nurse for more than 20 years, Ninde currently works as a nurse case manager at Mercy Regional Medical Center, having started on the medical surgical floor, eventually becoming charge nurse of that unit, managing the night shift as well as performing other duties. “I worked a total of seven years at night before transitioning to days. Nights were easier for me as a chair user, since days involve a lot more moving patients around.”

He is unique in more ways than one. As far as anyone knows, he is the only wheelchair user to be accepted into and graduate from a nursing school in Colorado, and as a full-time floor nurse who uses a wheelchair, he is a rarity. More importantly, his dedication and competence have been recognized by his peers. In 2013 he was honored for his “innovation and adaptation” by the Colorado Nurses Foundation, one of 38 nurse “luminaries” in the entire state who were recognized for “excellence in nursing” that year at the annual Nightingale Awards ceremony.

Near the beginning of his career, Ninde met and married Claire, who is communications director of the San Juan Basin Public Health Department. They still live in Durango and have a 13-year-old daughter. Besides nursing, Ninde remains active in adaptive skiing and other outdoor activities — such as rafting, adaptive dog sledding, and traveling — but that is another story.