ESRD Networks VR
Success Stories

The stories below were shared by four of Network 16’s Patient Advisory Committee (PAC) members.

Nancy: A Little History and a Lot of Hope
Nancy is a registered nurse and has lived with kidney disease since 1959. Before starting dialysis in 1966, Nancy had to undergo a screening by the Admissions and Policy Committee (also called the ‘Life and Death Committee’) in Seattle, WA. All patients were reviewed for dialysis in those days before Medicare paid for treatments. The committee looked for people who could recover and go on to work or be contributing members of society. Returning patients to their prior level of functioning is the reason Medicare began to pay for dialysis.

Dr. Belding Scribner testified to Congress at that time that, unless a patient was rehabilitated, the treatment was inadequate. He emphasized that most patients who received funding would be on home dialysis or transplanted, and would be taxpayers.

“We had a vocational counselor at my kidney center, and I received assistance with my education and career, first as a school teacher, and later as a nurse. Throughout my adulthood, I continued to work and support my children. I retired from my nursing career in 2011, but still substitute teach, and nurse per diem. I never really liked the term ‘Life and Death Committee.’ I always considered it a ‘Life Committee.’ They chose me to live – and with that privilege, there was a responsibility to realize my full potential. All I ever wanted was a normal, decent life with my children and the opportunity to give back to society at least as much as I have been given. I continue to strive toward that end.”

Esther: Nurses do it with Care
I hadn’t figured out how it would happen, but I was thinking about going back to school to study chemistry before I learned I had kidney disease on my 32nd birthday. I was ready to move on to a career, but kidney disease hit acutely and I found myself bedridden with 50 pounds of extra fluid on my body. As soon as I got the fluid off, I began working on a plan to be self-sustaining and have some extra money to help my mother.

About a year later, one of my friends who worked for VR told me about it. I applied and went to an appointment with a VR counselor right away. I had a kidney transplant and took a job as a medical scribe while going to school full-time. I graduated with a nursing degree from OHSU about four years after going back to school.

Medicare continued to pay for my transplant medications beyond the usual three years because I had been active in VR before my transplant. VR paid for most of my education, all of my books, and all other expenses related to getting a job after graduation. Now I work as a home dialysis nurse and train patients and their families to do peritoneal dialysis.
Gary: My Journey with Vocational Rehabilitation

When I consider my journey with VR, I recall a time before I could have fathomed needing such a service. My father was a laborer and instilled in me a desire to work with my hands, become a jack of all trades and most importantly provide for my family. However, having more academic as opposed to physical attributes, I joined the Air Force.

In 1984, I began my career as an inventory management specialist, supply clerk for short. I was stationed at JBER in Anchorage, Alaska. I met my wife Yalanda in Alaska, and we had our first child Icy in 1988. I was reassigned to Japan in 1989, just before the birth of Garyll, my second child.

Due to Garyll’s medical problems, I left Japan and the Air Force in 1990, to start my civilian life in Alaska. I took a job making $7.50/hour as a warehouseman at a rigging shop, and advanced to shop supervisor then foreman – thanks to my father’s example of a good work ethic.

My work involved long hours and hard days. We had our third child Shampayne in 1996, and then became foster parents for four more children – Roland, Damonta, Michael and Jashala. In 2012, just three days after my 46th birthday my life took a new path. Hours after arriving at the hospital with what I suspected was stomach flu, I was told I had a heart attack, three strokes and my kidneys had failed. My life on peritoneal dialysis began a few months later. I joined HealthInsight ESRD Network’s PAC in 2013, to add my voice to the many other voices that have come together to better the lives of kidney patients.

I went back to work in May 2014, but soon discovered that I could not continue as a rigging specialist. In August 2014, I was introduced to VR by my dialysis social worker. My VR counselor made sure I had a laptop and printer and covered any college-related expenses, and I enrolled in a retail management program.

Thanks to VR, my lifelong dream of attending college is fulfilled and I have a new lease on life. VR is making it possible for me to return to the workforce and continue to be the man by father exemplified. I am currently listed for a kidney transplant and have a potential donor. An interesting twist to all of this – my daughter Shampayne attended college with me. She told me if I go to college, she could too.
Michael: Inspired by a Dialysis Social Worker

My name is Michael Mace. I had worked in the restaurant industry for about 20 years and was an assistant manager for Wendy's Restaurants in the Puget Sound area of Washington. I was diagnosed with Stage 5 ESRD in September 1997, after 23 years of being a Type 1 Diabetic. My nephrologist encouraged me to start the kidney transplant workup at that time. I started my kidney transplant application process in October 1997 and then went on dialysis Christmas week of 1997.

I met two social workers at the dialysis unit that encouraged me to finish my transplant workup and advised that I would make a great social worker given my experience working with the public. I made an appointment with Vocational Rehabilitation (VR). The VR counselor explained to me my options, provided me with resources, and sat down with me to set up a step-by-step plan to reach my goals to become a social worker. I finished my transplant workup in March 1998, and was listed for transplant in April 1998. I received my kidney transplant July 20, 1998.

In March 1999, I began my journey to follow through with the VR plan. I started my associate's degree program at Tacoma Community College, and graduated in 2003 with an AA degree and counseling certificate in Human Services. I then went on to obtain my Bachelor of Social Work degree and my Masters of Social Work degree at the University of Washington.

In March 2005, I obtained a social work job working part-time at a kidney dialysis center. In 2006, I went to full-time work as a nephrology social worker. I have been a nephrology social worker for 13 years now. It is with great appreciation for the VR counselors who assisted me to start my journey that I am able to be where I am today. I was able to keep my Medicare and SSDI while completing school and following my aspirations to become a social worker.

As a dialysis provider and a patient, I have been presented with opportunities to learn, grow, and discover my true potential. Following my purpose with focused effort has opened many opportunities to work with and for chronic kidney disease patients and the community to help and educate others on how to better manage CKD and improve their lives. My motto: Find and follow your purpose and thrive on.
300 Pounds Lost, One Kidney Gained, and Financial Independence Recovered
Rob’s Story

Some would call Rob an “old soul.” He seems to have a kind of wisdom that many people don’t pick up before their Golden Years. Rob invests heavily in his relationships. He has cared for family, friends and neighbors in his community for years. Because Rob is a volunteer firefighter and Emergency Medical Technician (EMT), he has become a familiar and beloved figure in his hometown of Mountain, Wisconsin.

Mountain is a rural community located in Northeast Wisconsin. With fewer than 300 families, it’s not surprising that people take care of one another there. “When you think of other people, it makes life rich,” he says. “It feels good to connect with our neighbors and [be part of] our town.” As Rob travelled from prosperity to death’s door and back, he found that a strong connection to his community paid dividends when he most needed them.

Home-Grown Entrepreneur
A blizzard dumped two feet of snow on Mountain in 1987. Cars were stuck all over town, and there weren’t enough tow trucks. Rob was just 16 when he received a call from the sheriff’s department asking for help. He had bought himself a used tow truck, intending to earn some money. This was his chance to try it out for the first time. Soon, Rob was getting calls from four area sheriffs’ departments. It was the season that launched Rob’s towing & trucking business. His enterprise expanded quickly, and was incorporated as Big Rob’s Inc. (BRI) in 1998. “We hired drivers, an office manager, a trucking manager, a dispatcher, two mechanics, two controllers and two attorneys,” he recalls. Rob was glad he could provide employment in his town, and BRI’s growth was a source of satisfaction.

Restless energy and a need to make ends meet fueled Rob’s drive to work several jobs at a time. “In a small community like [Mountain], people sometimes work 3 or 4 jobs to pay the bills,” he explains. Along with BRI and his work as a first responder, Rob became Director of Investigations for the local Gaming Commission. It was a period of prosperity, and he was satisfied with the activity in his 60-hour work week. But Rob’s ambitious spirit was no match for the health challenges he would have to face.

Decline
Rob had struggled with his weight since childhood. By 1999 he weighed 550lbs, and was finding it increasingly difficult to do the things he wanted to do.

“Everything was hard. People stared. Travel was complicated. I had to buy special clothes. But the most difficult part was the effect on my health. It was deteriorating and I couldn’t keep up with work.”

Rob was diagnosed with renal failure, and his company filed bankruptcy in 2000. “Things really started to fall apart,” he recalls. “I went into a depression when I had to tell the employees we were going out of business. All these families depended on [BRI]. I felt terrible.”

With the right support, Rob found his path to a better future. To learn more, call the Ticket to Work Help Line at 1-866-968-7842 (V) or 866-833-2967 (TTY), or visit socialsecurity.gov/work.
Rob began dialysis in 2005. He would need a new kidney and wondered whether his time was up. He was not ready to give up on life, but didn’t know whether his body was. For a kidney transplant to succeed, Rob needed to lower his blood pressure and manage other health conditions that could complicate recovery. Rob and his doctors decided that gastric bypass surgery offered him the best chance. He was approved for Social Security Disability Insurance (SSDI), and prepared for the medical challenges that lay ahead.

Dialysis, With a Side Order of College... To Go

Rob was hospitalized for much of 2006. His surgery was a success, and the results surpassed everyone’s expectations. “The doctors were astonished that the weight came off so quickly,” he recalls. “I lost both kidneys. But I also lost 300lbs, my high blood pressure, and sleep apnea!”

Dialysis treatment continued for 6 hours per day, 3 days a week, and Rob became restless. “I never in my life came to a stop… I had to keep moving forward,” he said. Rob decided to use his time on dialysis to earn a bachelor’s degree. With help from Wisconsin’s Department of Vocational Rehabilitation (VR), he purchased a laptop and enrolled at the University of Wisconsin Green Bay. Classes were online, and he worked on a degree in interdisciplinary studies while waiting for a kidney.

In November of 2008, Rob was thankful for many things. Neighbors held a fundraiser for medical bills, and the support was overwhelming. But nothing touched him like the generosity of his friend Pam Nelson. During the 15 years that they worked together as emergency responders, she watched him struggle with kidney disease. Pam decided to give Rob one of her kidneys. “She’s a special person,” he says. “She saved my life.” The transplant was a success, and Pam was recognized with a medal for her heroic gift.

**Rob’s Ticket to Work**

After Rob’s health improved and he had earned a bachelor’s degree, he felt ready to return to work. His VR counselor told him he was eligible to receive free employment support services through Social Security’s Ticket to Work program. Social Security disability beneficiaries age 18 through 64 qualify. A range of services that help people prepare for and find employment are available through VR agencies and authorized providers known as Employment Networks (ENs). ENs also offer support services that can help people stay employed or advance in their career. (see boxes: “Employment Networks” and “About Work Incentives”)

**Employment Networks**

ENs offer free services through Ticket to Work that can help you:

- Find answers to your questions about employment and benefits
- Prepare for the workforce
- Find a job and stay employed
- Advance in your current job
- Get job accommodations
- Stay in touch with Social Security
- Stay Organized

Visit [socialsecurity.gov/work](http://socialsecurity.gov/work) for tips on choosing the right EN. Use the “Find Help” tool to connect with providers who offer the services you need to start or advance your career.

With the right support, Rob found his path to a better future. To learn more, call the Ticket to Work Help Line at 1-866-968-7842 (V) or 866-833-2967 (TTY), or visit [socialsecurity.gov/work](http://socialsecurity.gov/work).
Rob received help with his résumé and job leads from Wisconsin’s state VR agency. In 2011, he was offered a job as a Field Agent Examiner for the Department of Transportation (DOT). He looked forward to returning to work, but was also apprehensive. “SSDI and Medicare are stable. The workforce is not. I was glad to find work, but didn’t want to lose my disability benefits,” he said.

An EN Joins ‘Team Rob’

When Rob’s VR services came to an end, his counselor referred him to an EN called Employment Resources, Inc. (ERI). ERI would continue where VR left off, providing services to help him succeed in the workforce. Providers (like ERI) that offer benefits counseling can help people understand what employment will mean for their benefits. Rob was grateful to find attentive professionals who answered his questions, explained the rules around Social Security benefits and employment, and made it easier to focus on achieving his employment goals. He came to the meeting with his benefits counselor carrying a heavy load of concern, and he left looking forward to his new job at DOT.

The benefits counselor at ERI told Rob about Social Security rules called Work Incentives. Work Incentives make it easier for adults with disabilities to enhance job skills and gain work experience. As an SSDI beneficiary, some of these rules were of particular interest to him. When Rob learned that SSDI recipients can receive cash benefits while they test their ability to work during a 9-month “Trial Work Period” (TWP), he became less concerned about returning to work. As soon as the TWP ends, a 36-month “Extended Period of Eligibility” (EPE) begins. During the EPE, SSDI cash benefits are suspended only in months when earnings go over the amount that Social Security calls “Substantial Gainful Activity” ($1,700 for adults with blindness, or $1,040 for adults with other disabilities).

Rob was particularly relieved when his benefits counselor informed him about a Work Incentive called “Continuation of Medicare Coverage”. According to this rule, SSDI recipients who work continue to receive Medicare benefits for at least 7 years and 9 months after completing the TWP. The Work Incentive that put Rob most at ease is known as “ Expedited Reinstatement” (EXR). Rob learned that EXR may enable Social Security to re-start his benefits without a new application, if he has to stop work because of his disability within five years. He felt better about returning to work knowing he would have time to acquire new skills and settle into his job without fear of losing his benefits.

About Work Incentives

Many different Work Incentives are available to help people go to work. These rules can help you:

• Keep your Medicaid or Medicare coverage while working
• Prepare for work while receiving cash benefits
• Work while receiving some or all of your cash benefits
• Get back on benefits if you are unable to continue working

To find out how Work Incentives apply to you, consult a benefits counselor. To find one, use the “Find Help” tool at socialsecurity.gov/work. Or, call the Ticket to Work Help Line at the number below. Ask for help finding an EN that has a qualified benefits counselor on staff.

Most people who become employed with help from a state VR agency find that VR services end approximately 90 days after they start working. Many people like Rob need ongoing support to remain employed and increase earnings over time. To provide support services for employed Ticket program participants, VR agencies sometimes collaborate with ENs. This arrangement, known as “ Partnership Plus,” gives participants continued access to individualized employment services if needed. You may decide to work with an EN of your choice to receive support that continues after you are on the job. Partnership Plus sets people up for success by providing support at each step to financial independence.

With the right support, Rob found his path to a better future. To learn more, call the Ticket to Work Help Line at 1-866-968-7842 (V) or 866-833-2967 (TTY), or visit socialsecurity.gov/work.
“Keeping track of my benefits and the rules I needed to follow was overwhelming,” he said. “ERI was there to answer all of my questions and they helped me with the Social Security correspondence that can be so intimidating. I’ve got a lot on my plate, and it helps to have them on my team!”

Another Fulfilling Day
Motorist despair at the DMV is a familiar phenomenon. But those who land in Rob’s line will find a friendly and helpful reception when they reach the front. “I process drivers’ licenses...” he explains with enthusiasm. “My favorite part of the job is taking people out for their road tests. I meet a lot of interesting people this way, and also come across some welcome familiar faces!”

Rob has traded his SSDI cash benefit for a larger paycheck, and he’s not looking back. He says it feels like he has lived several lives and travelled 10,000 miles since the start of his health challenges. He’s content, and appreciates having days that are once again fulfilling.

“I love my job,” he says. “The people I work with are like family and I get to interact with the community again. When I was sick I had to give up a lot. The [Ticket] program helped me transition back to stability, and it feels great to have choices again. Ticket to Work and Work Incentives helped me recover them!”

Sources: In addition to direct interviews with Rob and staff at ERI, information for this article was paraphrased from a fox11online.com article titled “Thankful for a Special Friend,” published 11/27/08. Reference was also made to “Education on a Road to Recovery,” featured in UW-Green Bay’s Inside newsletter, January 2008 issue.

With the right support, Rob found his path to a better future. To learn more, call the Ticket to Work Help Line at 1-866-968-7842 (V) or 866-833-2967 (TTY), or visit socialsecurity.gov/work.
Whatever it Takes
Peter’s Story

Peter knew something was wrong when he saw the worried expression on his coworker’s face. “I think you’d better get that checked out,” she said, as she looked down at his ankle, failing to disguise her alarm. He had been watching the desktop screen in front of them while absently tying his shoe. When he followed her gaze to where the leg of his pants receded, he realized that his ankle was so swollen, it spilled over the top of his shoe.

“The swelling seemed to come out of nowhere. Both legs had swollen to the size of small tree trunks! They felt heavy and foreign. It was bizarre... and really scary.”

It was another late night at the office, where Peter worked as an information technology (IT) specialist for a sales operation. For 3 years, he had been known for remaining level-headed in the middle of chaos. But that night, in the winter of 2003, he says, “I was the one freaking out.”

One Step at a Time
Peter immediately saw his doctor and after many tests, was diagnosed with End Stage Renal Disease (ESRD). His kidneys were no longer functioning well enough to meet the needs of daily life. Peter had a family history of Polycystic Kidney Disease (PKD), which impairs kidney function and eventually causes renal failure. He was placed on a waiting list for a transplant, and began dialysis treatment. It was the start of a decade-long struggle with health issues that sapped his energy and threatened his life.

Determined to continue working, Peter and his employer arranged a reasonable accommodation, changing his schedule around to make time for treatment. His responsibilities at work remained the same, but the accommodation allowed for more flexibility. The grueling schedule often meant working through the night, going to the hospital for dialysis, and then returning to telework from home. Despite the stress, Peter points out that work helped him feel grounded. “I was able to not think too much about what I was going through,” he reflects. “Dialysis is a bummer, but I got to leave the hospital ...and go back to work.” That is exactly what he did for the next 3 years.

In 2006, Peter became a husband and step-father. “So many wonderful and challenging events came together at once,” he recalls. “…and I learned to take one step at a time.” He was determined to stay employed for as long as possible to establish a home for his family. But a year later, Peter needed to have both kidneys removed in an emergency operation that required a lengthy recovery. The requirements of managing kidney disease derailed his ability to work, and Peter had no choice but to focus solely on taking care of his health.
He began receiving Social Security Disability Insurance (SSDI) and living according to doctors’ orders. Even though the road back to improved health was long and littered with set-backs, he expresses gratitude for the time he could devote to healing.

**Recovery and Renewal**

For the next 5 years, Peter cared for his health, his family and his home and by 2013, the event he had been waiting for finally happened. “My turn was up for a kidney transplant. They found a match!”

The transplant was a success, and Peter remembers feeling different almost immediately.

“I was no longer battling fatigue all of the time. I felt like a new person. After the transplant, I was ready to get out and start the next chapter of my life. It was incredible!”

As Peter’s health quickly improved, he began to feel restless. “I wanted to contribute, earn money and connect with people again,” he says. “My wife was working and the kids were out of the house. I began to feel isolated and had an itch to be at work.”

While Peter’s desire to return to work was clear, his belief that he could actually do it was murkier. “I wanted to go back to the field I knew and loved. But I knew my technical skills were out of date,” he says. “I didn’t think anyone would hire me.”

He was also concerned about losing the benefits his family relied on – particularly his Medicare. He worried about what would happen if health complications became a problem and interfered with work again. Peter knew he needed help, but was uncertain about where to turn.

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**American Job Centers**

**American Job Centers** (AJC), formerly known as One-Stop Centers, provide a full range of assistance to job seekers under one roof. Jobseekers can find a variety of job-search services through an AJC, including:

- Training referrals
- Career counseling
- Job listings

Many AJCs participate in the Ticket program as **Workforce ENs** and provide employment services for people with disabilities, including training and special programs for young adults and veterans. You can find AJCs who are a part of the Ticket program using the **Find Help** tool and searching by your ZIP Code.
Increased confidence with Work Incentives

Peter was able to test his ability to work during a 9-month Trial Work Period (TWP), while still receiving benefits payments. After the TWP ends, a 36-month Extended Period of Eligibility (EPE) begins. During the EPE, most people with a disabling impairment receive benefits for months in which they earn less than Substantial Gainful Activity (SGA). For 2017, Social Security defines SGA as $1,170 for a person who is not blind.

Peter was particularly relieved when he learned about a Work Incentive called Continuation of Medicare Coverage. SSDI recipients who work continue to receive Medicare benefits for at least 7 years and 9 months after completing the TWP.

And if Peter needed to stop working within 5 years because of his disability, he learned that Expedited Reinstatement (EXR) may help him re-start his benefits without a new application. He felt more at ease returning to work knowing he would have time to adjust to the job without losing his benefits.

Learn more about different Work Incentives by reading Social Security's Red Book at www.ssa.gov/redbook. You can also register for a free Work Incentives Seminar Event (WISE) at choosework.ssa.gov/wise or talk with a Benefits Counselor to understand how Work Incentives apply to you.

A Ticket to Success

At the end of 2013, Peter’s wife stopped into their local American Job Center (AJC). There she learned about an employment support program that could help Peter transition back into the workforce.

Peter learned that through Social Security’s Ticket to Work (Ticket) program, State Vocational Rehabilitation (VR) agencies and service providers known as Employment Networks (EN) offer a range of free support services to help recipients of Social Security disability benefits (ages 18 through 64) prepare for, find, or maintain employment. Some providers serve people with a specific type of disability; others offer certain types of services. The Ticket program is free, voluntary, and set up to help people become less reliant on their Social Security benefit payments while they gain financial independence through work.

Peter found the assistance he needed when he followed up with A Ticket to Success, a Tulare County-based EN.

With help from his EN, Peter learned about Social Security rules called Work Incentives.

Work Incentives make it easier for adults with disabilities to explore work and still receive Medicaid or Medicare and benefit payments from Social Security. He felt at ease knowing he was not going to suddenly lose his coverage when he returned to work. He would have time to determine how full-time employment would work out for him. Staff at A Ticket to Success put him at ease, and he decided to “get back out there.”

Together Peter and his EN developed an Individual Work Plan (IWP), a roadmap that would help him reach his employment goals. They took a fresh look at the job market in the field of IT and revamped his resume.
Peter’s EN helped him assess the type of job accommodations he would need. They worked together on interview skills, sent him job leads, and supported him throughout the transition back to work. “They helped me restore confidence in my prospects,” he says. “I felt supported and that made all the difference.”

“I’m someone who doesn’t quit. But re-entering the workforce is tough and you need someone there to help you do it. It’s good to know that there are supports [through Ticket to Work] we can rely on when the going gets tough…”

Another Step Forward

By 2014, Peter found work helping a local organization with their systems administration. He describes this tentative return to IT as challenging and exhilarating at once. “It was a struggle at first,” he recalls. “But sooner than I expected, I realized, ‘I can do this’ and… that felt great!”

Peter is a full-time employee, doing what he loves and using his skills again. CSET, his employer, is a non-profit agency that was established to fight America’s war on poverty.

“I turned a hobby into a career. As a kid I liked to tinker, build circuits and figure out how mechanical things work. Now I get paid to help people solve their tech problems. I feel lucky that I was able to get a transplant and move forward. My work gives me [a sense of] purpose. It is a privilege to do well while doing good.”

The Ticket to Work program helped Peter find his path to a better future. Find yours!
To learn more, visit www.ssa.gov/work and contact the Ticket to Work Help Line at 1-866-968-7842 or 1-866-833-2967 (TTY), Monday through Friday, 8 a.m. to 8 p.m. ET. Ask a representative to send you a list of service providers or find providers on your own with the Ticket to Work Find Help tool.