

Meet the Recipients of the 2014 CMMS Deshae Lott Ministries Outreach Program Quality of Life Grants



Mark Kendall Recipient of a \$500 CMMS Deshae Lott Ministries Quality of Life Grant

Mark Kendall of Layton, Utah has cervical myelopathy, cervical incomplete tetraplegia, dysphagia, neurogenic bowel and bladder, cerebral palsy, cognitive deficits and seizure disorder. He needs assistance with all of the daily activities listed on our application except for breathing, seeing and hearing, and he requires a home health assistant on a daily basis to help him accomplish these activities. He also requires extensive physical therapy, and his home is in need of essential modifications. He and his wife, Carolyn, applied for the grant to assist with installing a ramp at their house.

Christina Miarecki Recipient of a \$500 CMMS Deshae Lott Ministries Quality of Life Grant Christina is a 48-year-old quadriplegic. She suffered a c5-c6 spinal cord injury in 1994 and was diagnosed with Multiple Sclerosis in 2004. She also suffers from

a number of other medical complications, and needs assistance with all of the

daily activities listed on our application except seeing and hearing. She is seeking to raise money for needed modifications to her wheelchair-accessible van, and the driving evaluations for her to receive the modifications. Total modifications will come to \$15, 958. She has received awards for the purchase of the van from other organizations. Accessible public transportation is not adequate for her needs in Reno, and temperatures at both extremes can be damaging to her health if she has to wait for a bus. She is unable to work, and is on Disability and Food Stamps.



Matt Grillot Recipient of a \$500 CMMS Deshae Lott Ministries Quality-of-Life Grant

Matt Grillot of DeWitt, Iowa is a 37-year-old quadriplegic who sustained a C-5/C-6 spinal cord injury in 1983 while playing "The Incredible Hulk" when he was 6 years old and still in kindergarten. His legs are completely paralyzed and his arms are partially paralyzed. He needs assistance with all the daily activities listed in our application except seeing, hearing, communicating and breathing. He initially used a manual wheelchair, but a perforated stomach ulcer nearly killed him in the 2nd grade and the weaknesss that remained after his five-year recovery process necessitated a power chair.



Various health complications ensued throughout the rest of his elementary and secondary schooling, including numerous hospital stays of up to two weeks at a time, and several periods of home schooling, yet he managed to graduate high school and enter Iowa State University in 1995. He got his driver's license at 20 and passed an evaluation for driving with adaptive controls. In 1997, he took possession of a modified van after a 4-year funding/ design process.

He graduated from Iowa State in 2000 with a BS in Accounting. In 2008 he entered the seminary at Conception Seminary College, but unfortunately, in 2010, he was in an accident with several of his classmates. There were no serious injuries, except to his van, which was totaled, and insurance only paid \$8000 on what amounted to a \$60,000 vehicle. He was able to purchase a used 1997 van with wheelchair lift, but it's too old to retrofit, so he has had to sacrifice some independence and have someone drive him everywhere. In spite of all that, he continued in school and finished his BA in Philosophy. While in school, and between periods of schooling, he has also worked for the National Telecommuting Institute in some capacity since 2004. (The institute provides telephone customer service for various corporations and government agencies, and Matt has worked for several over the years.)

Matt is applying for the grant to add the money to funds he is in the process of raising to purchase a new van that can be modified with adaptive controls. Iowa Vocational Rehab will fund the \$100,000 modification once they know he has the funds set aside to purchase the van: about \$30,000 to \$32,000 for a new van. He would also consider a "gently used" van, but it has to be new enough to have electronics compatible with the modifications. As of now, he has about \$13,500 of his own money (made up of a credit union loan, money from a special needs trust left by his grandfather, and \$2000 in person savings), a \$500 grant from the Iowa Knights of Columbus Foundation, and the resale value of his current van, about \$2000. Besides our grant, he will raise the rest with fundraising, both traditional and online crowdsourcing. Matt's efforts are time-sensitive, as he had to be re-evaluated for driving an adapted van, in order to receive the service from Iowa Rehab, and the re-evaluation is good for a year, which ends in mid-July of this year. The new van will help him live more independently, work outside the home, and become more involved in the local community.

Alexandra McArthur Recipient of a \$500 CMMS Deshae Lott Ministries Outreach Program Quality of Life Grant

Alexandra McArthur of New York City has muscular dystrophy, and needs assistance with mobility, transportation, and position changing, bathing and personal care, dressing and grooming, routine medical procedures and housekeeping.

Alexandra is the sister of Park McArthur, one of our first scholarship recipients. She works for a nonprofit, the Taproot Foundation, as a consultant helping other nonprofits to expand their service capacities. She is also an advocate for people with disabilities. She has



some savings in her name from her parents in addition to her salary from the nonprofit. She pays out of pocket for someone to come in and help her with daily activities, and the grant would go towards that. She does not qualify for Medicaid.

Edward Holland III Recipient of a \$500 CMMS Deshae Lott Ministries Outreach Program Quality of Life Grant

Edward Holland of Hamilton, NJ is a paraplegic who suffers from a number of debilitating conditions, including Autonomic Dysreflexia, a potentially life-threatening condition that develops in spinal cord injury patients and can result in a rapid elevation of blood pressure among other dangerous effects. He needs assistance with all the daily activities listed on our application



except for seeing and hearing. His wife, Jo-Ann Holland, is seeking assistance with paying for skilled nursing care in their home, for which she pays out of pocket, as she is physically unable and medically unqualified to care for her husband on her own. He needs assistance with a daily bowel program as well as catheter changing and maintenance. He is subject to skin breakdown and needs careful, specialized attention to his skin, as well as careful daily monitoring of his respiratory status and vital signs, and assistance with every aspect of daily living.

Melissa Caffey Recipient of a \$500 CMMS Deshae Lott Ministries Outreach Program Quality of Life Grant

Melissa Caffey of Springfield, Missouri, was diagnosed with Limb-Girdle Muscular Dystrophy in 1997 at the age of 21. As a result, she is significantly disabled and requires assistance in all aspects of daily living specified on our



application except for seeing, hearing and written or spoken communication. Still, with the help of an aide, family and friends, she tries to maintain as much of her independence as she can. She is a three-time recipient of our grant, having received the full amount in 2011 and 2012.

One of Melissa's needs is massage therapy, which raises her endorphin levels, helps her relax her muscles, and reduces her need for pain relieving medication. Despite its obvious benefits and the recommendations of her doctor, Medicaid will not cover it, so she has applied for a grant to put toward those sessions. She also wants to purchase a cushioned shower bench, because sitting on a bench with no cushion has become increasingly painful. To assist with either or both of these needs, the Outreach Selection Committee has chosen to award Melissa with the full amount allowable for the grant, \$500.

Kendra Muller Recipient of a \$500 CMMS Deshae Lott Ministries Outreach Program Ouality of Life Grant

Kendra Muller of Riverton, Utah, has a C-6 spinal cord injury as the result of a freak accident in 2011 when she was 14 years old. While at a friend's house for a swim party, she sat with several friends on a hammock suspended from two brick pillars, but one of the pillars collapsed onto Kendra, causing her injury. She is paralyzed from the collarbone down, with no use of her hands. Her survival was in doubt at the time, and she spent 3 months in the hospital. She needs assistance with every aspect of daily life except breathing, seeing and hearing. With an income too high for Medicaid yet not nearly high enough to meet all of Kendra's expenses, the family "falls through the cracks" financially, and



struggles, spending about \$1000 monthly out of pocket for Kendra's medical expenses, as well as another \$250 for another daughter who has been diagnosed with a mental illness. Currently, Kendra needs a specialized desk and also needs help with application fees for college. Her goal is to go to medical school eventually and become a radiologist. The Outreach Selection Committee is happy to award a grant in the full amount of \$500.

Trinity Annalise "Anna" Grice Recipient of a \$500 CMMS Deshae Lott Ministries Outreach Program Quality of Life Grant

Trinity Annalise Grise, called Anna, is a 10-year-old girl who was born with a severe form of spina bifida known as myelomeningocele. She is also hydrocephalic (has a buildup of excessive fluid on the brain), which is a common complication of this disease. She has a surgically implanted shunt to relieve the pressure of the fluid on her brain, and she must have regularly scheduled MRI's to assess the functioning of the shunt. She lives with her grandmother, Vickie Grice, who provides constant care, as both of Anna's parents have struggled with chemical and alcohol dependency. Anna needs assistance with all activities that require movement below the waist, including most aspects of personal hygiene.



Anna's grandmother must lift her for any and all activities that involve getting out of her wheelchair, including getting her in and out of the car, and they must travel often. They live in Seminary, Mississippi, 75 miles outside of Jackson, where she receives most of her medical care and all of her specialized care. Her grandmother is raising funds to purchase a handicapped accessible van with an electric lift. Vickie Grice had done her homework on available vans, new and used, and had also researched available grants to assist in this purchase. She established the Anna Grice Fund through Priority One Bank in Seminary. The Outreach Selection Committee agreed to award the full grant amount of \$500 to Anna, and, per her grandmother's request, we sent the check to the bank to be added to that fund.