

Legislative Report
SFY 2018 (7/1/17 to 6/30/18)

The Spinal Cord Injury and Brain Injury (SCI/BI) Rehabilitation Fund was established during the 2012 Utah Legislative Session (Section 26-54) as a restricted special revenue fund that consists of gifts, grants, donations, etc. that may be made to the SCI/BI Rehabilitation Fund from private sources. The SCI/BI Rehabilitation Fund is administered by the executive director of the Utah Department of Health in consultation with an advisory committee. Funds shall be used to assist “qualified IRC 501(c)(3) charitable clinics” to provide physical, occupational, and speech therapy and equipment necessary for daily living activities for people with spinal cord and brain injuries.

State Fiscal Year 2018 marked the end of a five-year cycle of contracts which provided services under the SCI/BI Rehabilitation Fund. A new Request for Proposals (RFP) was submitted and finalized on June 30, 2018. Two agencies were awarded contracts for the next five years from July 1, 2018 through June 30, 2023. These agencies are Neuroworx and the University of Utah Sugarhouse Rehabilitation Center. Contracts are currently in negotiations.

Table 1: SCI/TBI Rehabilitation Fund Potential Cost Savings

Outcome of services	Percent of clients*	Number of clients	Savings per client	Total savings
Return to work and/or school (n = 30)	88%	34	\$17,824	\$606,016
Improvement in transfer skills (n = 26)	100%	26	\$4,051 - \$8,103	\$105,326 - \$210,678
Improvement in wheelchair mobility (n = 6)	83%	5	Power chair: \$5,000 - \$17,000 Manual chair: \$11,000 - \$13,000	\$322,000
Improvement in ambulation (n = 21)	92%	24	Avoiding one fall: \$14,000	\$336,000
Improvement in quality of life (n = 36)	97%	35	Treatment of depression: \$9,240 - \$13,860	\$323,440 - \$485,100
Improvement in overall mobility and wellness participation (n = 46)	74%	34	Avoiding re-hospitalization: \$45,770 - \$60,375	\$1,556,180 - \$2,052,750
Participation in wellness program (n = 50)	68%	34	Disease management/ quality of life savings: \$1,632	\$55,488
Total per year			\$108,517 - \$145,794	\$3,304,450 - \$4,068,032

Source: Utah TBI Rehabilitation Fund

* Percent of clients who participated in indicated service and saw improvement

Luke's Story

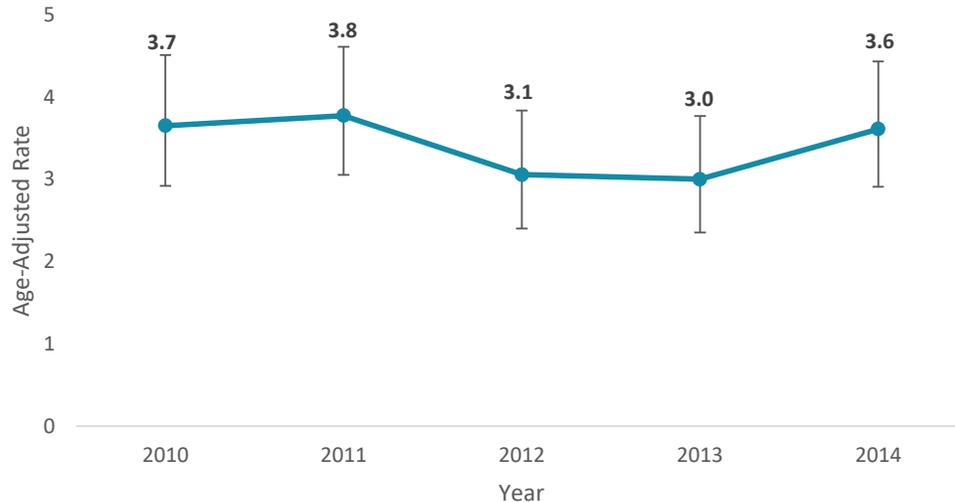


Luke suffered a spinal cord injury resulting in paralysis from the waist down after falling 30 feet from a tree. Prior to his injury, Luke played football and wrestled. By utilizing the SCI/BI Rehabilitation Fund, Luke was provided with physical and occupational therapy. He was discharged from outpatient therapy in September 2018 walking with forearm crutches and is functionally independent. Luke has returned to school at Bear River High School, continues to be a member of the National Honor Society, participates in student government, sings with his school choir, and often travels with the football team to support and cheer them on.

SCIs in Utah (2010-2014)

- In 2014, there were 95 Utah residents who were hospitalized due to a traumatic spinal cord injury (SCI).
- The age-adjusted rate of SCI hospitalizations stayed fairly consistent from 2010-2014; in 2014 the age-adjusted rate was 3.6 per 100,000 population (**Figure 1**).
- Falls were the leading cause of SCI hospitalizations from 2010-2014, followed by motor vehicle traffic crashes (**Figure 2**).
- SCI cost of hospitalization from 2010-2014 totaled more than \$54 million (**Figure 3**). This does not include the cost of care after hospitalization.
- The average length of stay in the hospital for a SCI was 8.5 days.
- Males accounted for three-fourths (72%) of all SCI hospitalizations.
- Utahns 85 and older had the highest rates of SCI.

Figure 1: Age-Adjusted Rate of SCI Hospitalizations per 100,000 Population, Utah, 2010-2014



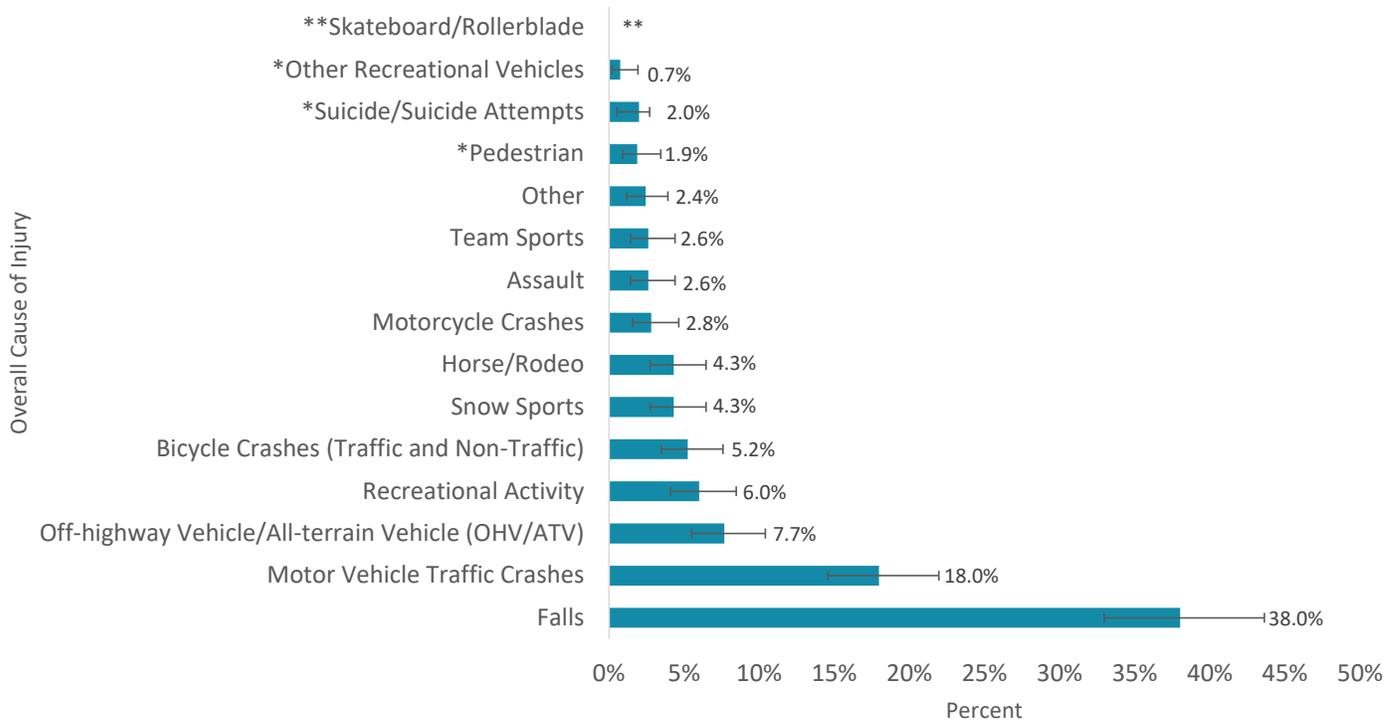
Source: Utah Department of Health, Violence and Injury Prevention Program, Traumatic Brain Injury Surveillance Program.

Steven's Story



Steven received a brain injury in May 2015 from respiratory failure during a heart attack. After his injury, Steven was unable to maintain his balance and walked with a very robotic pattern. He was unable to initiate self-care activities or participate in any leisure or recreational activities. Steven also suffered from some speech and language barriers. He was intelligible less than 40% of the time and spoke using one-word responses. Because of the therapies he received through the SCI/BI Rehabilitation Fund, Steven is now able to walk with a quicker speed and perform multiple tasks while walking. His balance is much improved and he is now jogging and playing golf. He is able to complete all his activities of daily living independently and returned to driving. He is exploring new job opportunities. Steven is also able to converse with others at the conversation level, with 85% intelligibility. He loves to talk about his favorite sports teams with others and is participating in a communication group.

Figure 2: Percentage of SCI by Overall Cause of Injury, Utah, 2010-2014 (N=534)



Source: Utah Department of Health, Violence and Injury Prevention Program, Traumatic Brain Injury Surveillance Program.
 *Use caution in interpreting, the estimate has a relative standard error greater than 30% and does not meet UDOH standards for reliability.
 **Data have been suppressed and do not meet UDOH standards for reliability.

Figure 3: Total Cost of SCI Hospitalization, Utah, 2010-2014 (N=784)

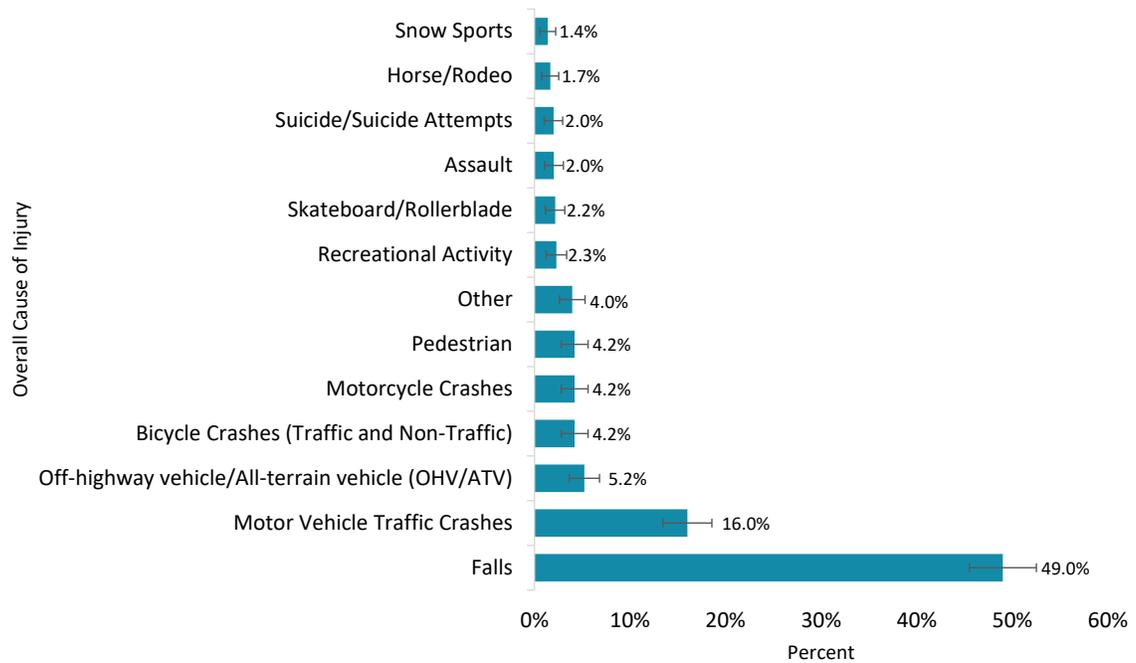


Information provided by Utah Department of Health, Violence and Injury Prevention Program, Traumatic Brain Injury Surveillance Program.

TBI's in Utah

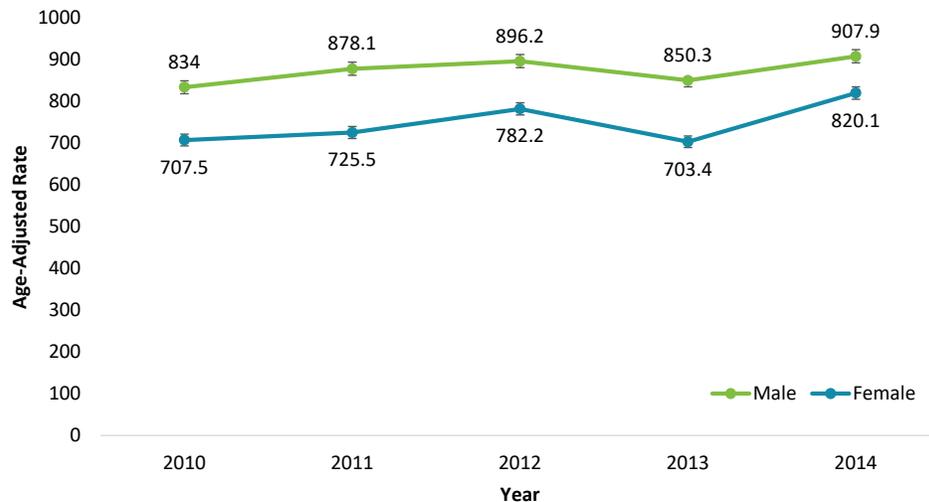
- Traumatic brain injuries (TBI) is a leading cause of death and disability in Utah. Every day, 60 Utahns are admitted to the ER, seven are admitted to the hospital, and at least one person dies due to a TBI.
- TBI's resulted in nearly \$118 million in hospitalization charges in 2014, a 24.2% increase from \$95 million in 2013. This does not include costs for disability and long-term care, nor lost wages.
- Falls are the leading cause of TBI, followed by motor vehicle crashes (**Figure 4**).
- Utahns aged 85 and older have the highest rate of TBI.

Figure 4: Percentage of TBI Hospitalizations by Overall Cause of Injury, Utah, 2015 (N=784)



Source: Utah Department of Health, Violence and Injury Prevention Program, Traumatic Brain Injury Surveillance Program.

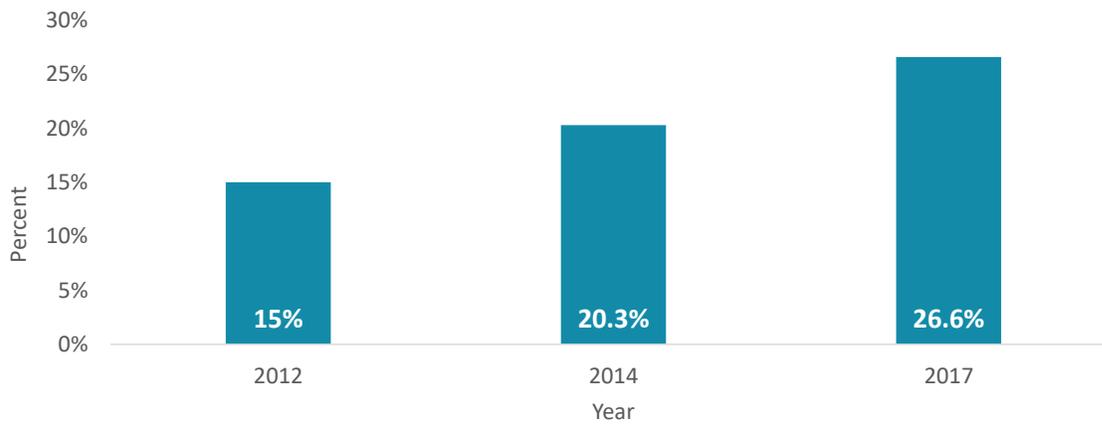
Figure 5: Age-Adjusted Rate of TBI Incidents per 100,000 Population, Utah, 2010-2014



Data includes TBI hospitalization, death, and ED visit cases. Information provided by the Utah Department of Health, Office of Health Care Statistics and the Office of Vital Records and Statistics.

In December 2017, the Utah Department of Health Violence and Injury Prevention Program conducted a random digit dial survey among Utahns aged 18+ to better understand the level of awareness and knowledge of TBI's and to collect information regarding households which had one or more individuals who have suffered a TBI. This survey was first conducted in 2012, and TBI knowledge has increased since then (**Figure 6**). Approximately one out of every 14 Utah households has an individual who has ever sustained a TBI. Additionally, 70% of respondents were not aware of any services or treatment for a TBI. Of those who were aware of services or treatment for a TBI, medical services were the most frequently reported. The majority of households with a member who had a TBI reported that there is a need for assistance in areas of: behavioral issues (17.7%), transportation (17.2%), social situations (9.8%), occupation (7.9%), personal care (7.0%), and safety (6.3%).

Figure 6: Percentage of TBI Survey Respondents with a High TBI Knowledge*, 2012-2017



Source: Utah Department of Health Violence and Injury Prevention Program, Traumatic Brain Injury Surveillance Program.
*Knowledge is self-reported on a five-point scale ranging from "not very knowledgeable" to "extremely knowledgeable".

The SCI/BI Rehabilitation Fund has made a positive impact on people living with Traumatic Spinal Cord Injuries and Traumatic Brain Injuries. A high percentage of clients achieved their goal resulting in the following outcomes (**Figure 7**):

- 100% of clients showed improvement in transfer skills
- 97% clients reported improved quality of life
- 92% of clients demonstrated improvement in ambulation with or without assistive devices
- 88% clients returned to work and/or school
- 83% of clients showed improvement in wheelchair mobility skills
- 68% clients participated in Extended Sustainable Rehab Services

During State Fiscal Year 2018, a total of **48 TBI and SCI clients received 2,581 sessions of physical, 449 sessions of occupational, and 165 sessions of speech therapy (Figure 8)**. There was a higher number of speech, physical, and occupational therapy visits from SFY 2017 to SFY 2018 (3,007; 3,294 respectively) (**Figure 9**).

Sarah's Story



Sarah, an active Brigham Young University (BYU) student, noticed some weakness and muscle atrophy on her right side while participating in a weightlifting class. A neurological evaluation revealed a tumor involving her cervical spine. The tumor was surgically removed in December of 2017, unfortunately with an associated paralysis of her right side. Sarah's insurance only allowed 20 therapy visits a year and those were exhausted quickly. Because of SCI/BI Rehabilitation fund, Sarah was able to get more therapy. She is now able to walk without assistance and is independent with all activities of daily living. Sarah graduated from BYU and has returned to running and skiing.

Figure 7: Percentage of Clients Achieving Goal, Utah, SFY 2016-2017

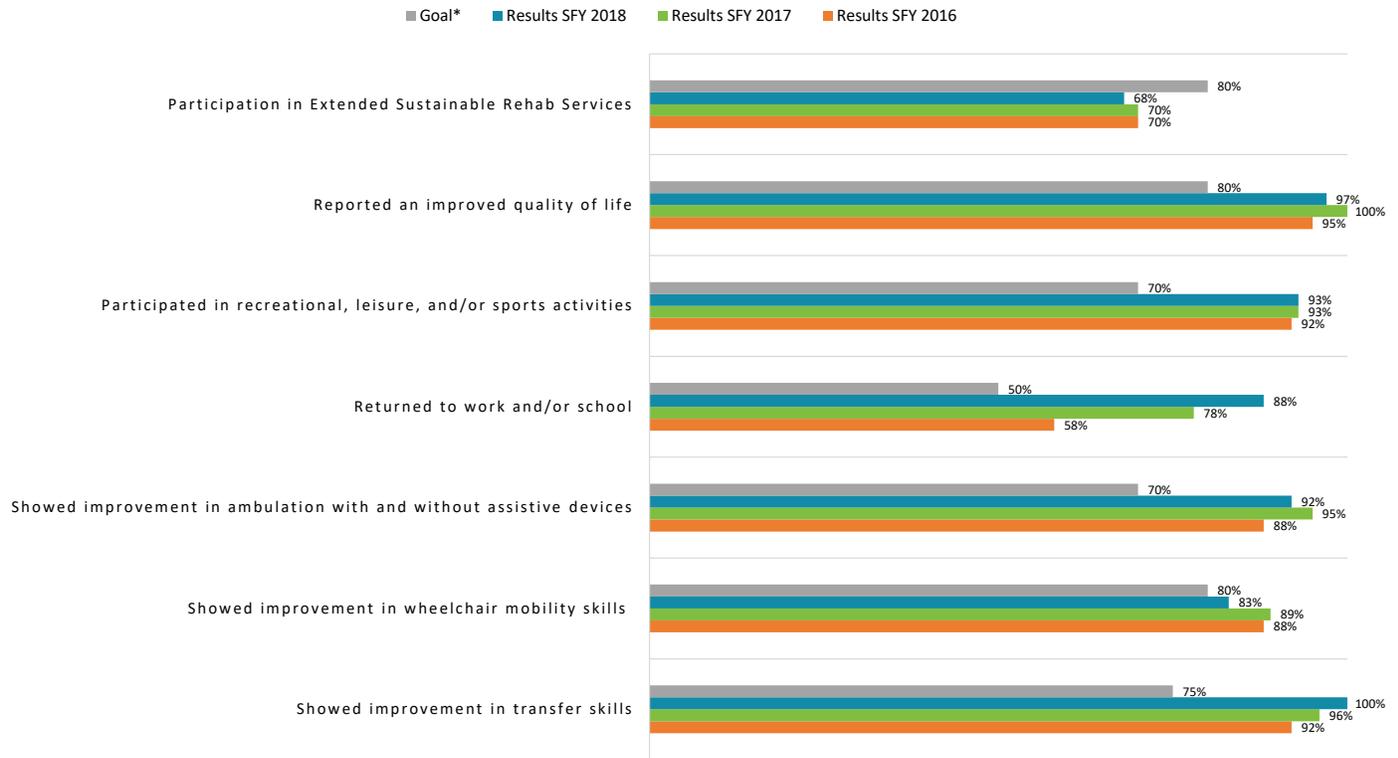


Figure 8: Occupational, Physical, and Speech Therapy Visits per CPT code, Utah, SFY 2018

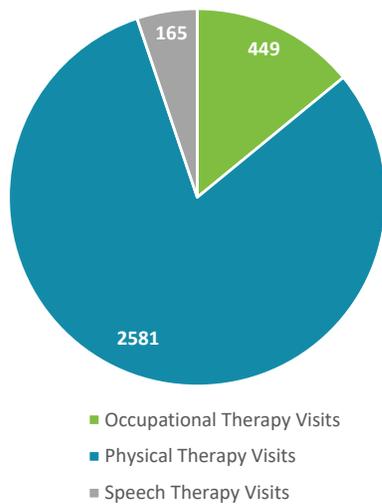
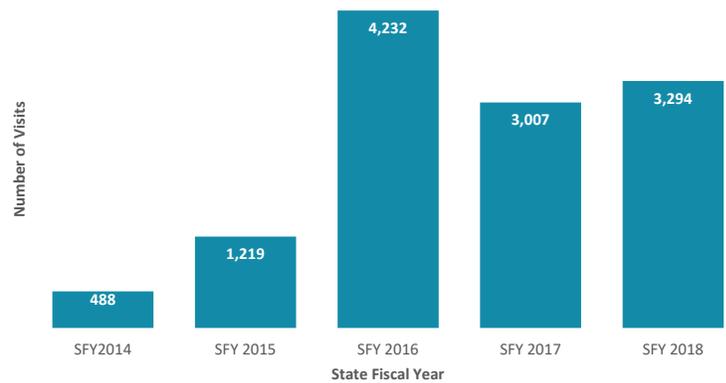


Figure 9: Number of Speech, Physical, and Occupational Therapy Visits, Utah, SFY 2014-2018



Source: Utah SCI/TBI Rehabilitation Fund
*SFY 2016-2017 goals were set by the Utah SCI/TBI Rehabilitation Fund stakeholders.

Accomplishments of Contractors

Contracting agencies from the SCI/BI Rehabilitation Fund formed a partnership with the TBI Fund to help promote both funds and to raise awareness of TBI and SCI in Utah.

University of Utah

- The University of Utah Sugarhouse Rehabilitation Center was awarded another five year contract through the RFP process.
- Staff held 11 presentations throughout the year including one for the Salt Lake Criminal Justice System reaching 40 professionals such as parole and probation officers, administrators, and case managers.
- Staff participated in the TBI Grand Rounds, a two-day Mild TBI/Concussion Grand Rounds for internal and external providers.
- Staff promoted the SCI/BI Rehabilitation Fund including the Brain Injury Alliance of Utah annual conference, TRAILS Expo and USHA.
- Staff educated an estimated 560 professionals.
- 15 of 28 clients required loaner equipment and 15 pieces were loaned out and currently 100% of equipment is currently on loan.
- 40 new patients were referred to the SCI/BI Rehabilitation Fund in SFY 2018 while 16 of them were denied funding, 39% of those were denied were able to find funding.

Neuroworx

- Neuroworx was awarded another five year contract through the RFP process.
- Staff continued their partnership with DPT programs to educate students about the SCI/BI Fund. They reached approximately 100 new students in SFY 2018.
- Presented at the Utah Physical Therapy Association Fall Conference which reached many occupational and physical therapists from around the state.
- Presented at the American Spinal Cord Injury Association in Minnesota.
- Staff held a total of eight presentations, reaching 326 professionals.
- Able to locate medical equipment in the community for individuals to complete Activities of Daily Living.
- 28 individuals were provided an assessment to see if they qualified for the SCI/BI Fund. Eight were denied, but found other ways to pay for the same services.

Zack's Story



Zack sustained a spinal cord injury in June 2016 from a motor vehicle rollover. Zack was discharged to his parents with paralysis from his waist down and not able to bear weight on his left arm. At the time of discharge, he was dependent for all of his transfers, dressing, bladder and bowel care and cooking. Through participation in the SCI/BI Rehabilitation Fund, Zack was able to obtain physical and occupational therapy and wellness. He has made great improvement and is now modified independent (using some assistive devices only) for bladder care, transportation, self-feeding, basic food prep/cooking, and grooming. He is able to perform transfers and dressing with very minimal assistance. Zack is an integral member of the community and helps organize activities for a young adult sport group and volunteers at an elementary school.

Needs and Concerns Documented by Contractors

- More education and awareness about the SCI/BI Rehabilitation Fund services is needed among providers outside the Wasatch Front.
- Barriers to services continue to be transportation from rural areas of the State.
- Limited use of the fund to participants along the Wasatch Front. Providers are continuing their efforts with extending services in rural areas outside the Salt Lake City area.
- Limited money for marketing or outreach of the Fund.

Advisory Committee

Members of the advisory committee met four times during SFY 18 and conducted business according to the Open and Public Meetings Act. Minutes are posted at pmn.utah.gov. Reports from the contractors were received and reviewed with the Committee.

Members of the Advisory Committee are as follows:

- Andy Curry, SFY 2018 Chair and spinal cord injury representative
- Kris Sanford, spinal cord injury representative
- Nita Smith, current Chair and TBI representative
- Trisha Keller, TBI representative
- Dr David Ryser, TBI/SCI professional
- Representative Eric Hutchins
- Senator J. Stewart Adams
- Dr Joseph Miner, Executive Director of the Utah Department of Health.

McKenna's Story



McKenna was involved in an auto pedestrian accident in December 2016 while crossing the crosswalk at school. She was treated at a local clinic where she received sutures to her chin. Several days later, she recognized more of a headache, light sensitivity and difficulty focusing. She continued on with her life and had to return to high school on a part time basis. She was having difficulty learning new information and retaining information. She also had difficulty processing what people were saying to her and unable to sit still. She lost her job due to being unable to recall and process details. It was when she started at Southern Utah University that she knew she needed help. McKenna was able to receive telespeech services through the SCI/BI Rehabilitation Fund. Since discharge from therapy, McKenna completed two semesters of full time college course work. She reported having energy to be involved in social activities like a normal college student, rather than being fatigued from class. She is currently on a mission for her church and her mom reports that she is doing "very well." McKenna's mother reported. "We are so thankful for the telespeech program and also are so appreciative for the SCI/BI Rehabilitation Fund. After our daughter was hit by a car, it took a year to convince her of her brain injuries. We finally found the help we needed, but she needed ongoing help and was moving to Cedar City for college. Unfortunately, there was no one in southern Utah that could help her to continue to heal and she couldn't be driving to SLC. Telespeech is such a special program. It allows people to get the specialized help they need when none is available. It was successful and McKenna is now living a normal life and was able to receive help to help her to progress and become well again."