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A Message

Steven Oliva, CEO



The spinal cord is the longest nerve in our bodies and allows us to perform countless functions. Tragically, damage to the spinal cord can quickly change one's life. In 2009, there were approximately 760 new cases of Spinal Cord Injury (SCI) in Florida alone, and that number is projected to continue to grow.

WellFlorida Council partnered with the Florida Department of Health, Brain and Spinal Cord Injury Program, the Florida Alliance for Assistive Services and Technology (FAAST), and the FAAST Spinal Cord Injury Resource Center to create Florida's first comprehensive needs and resources assessment of individuals with SCI.

The goal of this partnership and assessment is to identify and understand the most critical needs of individuals with SCI. *Spinal Cord Injury in Florida: A Needs and Resources Assessment* will be used in the development of Florida's first five-year strategic plan for SCI. Visit the Resources page on www.wellflorida.org to download the full report, or, for a snapshot of the leading issues of SCI in Florida, simply download the SCI Fact Sheet.

Spinal Cord Injury in Florida

Identifying and Responding to the Needs of the Community



Spinal Cord Injury (SCI) is damage to the spinal cord that results in a loss of function, such as mobility or feeling. SCIs are caused by bruising, crushing or tearing of the delicate cord tissue. Swelling of the cord after the injury can cause even more damage. Though every SCI is unique in regards to the level of impairment, its impact on Florida's residents, families and the healthcare system cannot be ignored.

WellFlorida Council, in partnership with the Florida Department of Health, Brain and Spinal Cord Injury Program (BSCIP), the Florida Alliance

for Assistive Services and Technology (FAAST), and the FAAST Spinal Cord Injury Resource Center (FSCIRC) have come together to conduct Florida's first comprehensive needs and resources assessment of individuals with SCI. The goal of this assessment, conducted under the guidance of the FSCIRC Advisory Group, is to identify and understand the most critical needs of individuals living with SCI.

Spinal Cord Injury in Florida: A Needs and Resources Assessment includes an analysis of demographic and socioeconomic indicators, analysis of

Continued

Spinal Cord Injury—What Does it Mean to Survivors?

“Everything has changed since the accident...

I can't do what I want or go where I want. I have to depend on others, where before the accident I was completely independent.”

“I think of my family. I think it hurts them more than it hurts me. I just keep on going.”

“Disability never even occurred to me until I got injured.”

“Spinal cord injury depends on what you make of it. It all depends on your attitude and how you decide to move on from your injury.”

“It redefines your life.”

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www.wellflorida.org

Spinal Cord Injury in Florida, cont.

SCI-related data indicators, and input from the SCI community (i.e., focus groups, one-on-one interviews, and an online survey). Please visit www.wellflorida.org for a copy of the full report, fact sheet and technical appendix.

Summary of Findings

The national incidence of SCI is 40 cases per million of the population. Based on Florida's population, approximately 760 SCIs occurred in Florida during 2009.

Over 800 SCI-related hospitalizations occur in Florida per year. Floridians between the ages of 45-64 years and 15-34 years accounted for over half of all hospitalizations. Males were nearly three times more likely to be hospitalized than females. Falls and motor vehicle accidents were the leading cause of SCI-related hospitalizations.

Florida's Central Registry, which collects information on individuals who experience moderate to severe brain and spinal cord injuries, reported 2,730 new injury referrals during calendar years 2005-2008. Florida's Trauma Registry, which collects data from the state's verified trauma centers, reported more than 1,800 discharges for patients with SCI identified as their primary diagnosis from 2006-2008.

The SCI community identified the following as the biggest issues for SCI in the state of Florida (order does not indicate ranking):

- Access to services that promote independence (e.g., personal care and transportation)
- Financial burden
- Lack of qualified, knowledgeable SCI providers
- Decreased access to appropriate rehabilitation services
- Access to information and education



- Lack of opportunities to promote healthy living
- Lack of transition support services (e.g., transitional living facilities)

The SCI community identified the following as the most needed services or supports for SCI in Florida (order does not indicate ranking):

- Rehabilitation
- Personal care assistance
- Accessible, affordable housing
- Transportation
- Employment or vocational services
- Family/caregiver support services
- Peer support

In response to *Spinal Cord Injury in Florida: A Needs and Resources Assessment*, over 30 members of the SCI community met in Tampa at the end of January 2010 to begin the development of Florida's first five-year strategic plan for SCI. Participants worked to identify key priority issues, strategies and action steps for six issue areas including: public and professional awareness; resources and educational capacity; services that promote or maintain independence; survivor, family and caregiver support; acute and transition SCI support services; and accessibility. The FSCIRC Advisory Group will be working over the next few months to finalize the plan. The plan is scheduled for release in June 2010.

SCI Resources: Helpful Local and Statewide Programs

One of the biggest issues for people living with Spinal Cord Injury (SCI) is having access to services that promote independence, according to the 2010 *Spinal Cord Injury in Florida: A Needs and Resources Assessment*. Florida organizations, both regional and statewide, that help promote independence and offer resources to SCI consumers and professionals include the following:

The Florida Alliance for Assistive Services and Technology (FAAST) is a statewide nonprofit program that provides hands-on assistive technology (AT) demonstrations and trainings, community outreach to rural and underserved groups, accessible and affordable housing, and advocacy and education on consumer choice.

FAAST's Statewide Device Loan Program allows consumers to borrow assistive devices, giving consumers an opportunity to try out AT and find the device that best fits their needs prior to making a purchase. The loan program also allows professionals access to a wide variety of AT to increase their knowledge.

FAAST's New Horizons Fund offers loans for the purchase of AT and to purchase of equipment for starting or maintaining a home-based business.

FAAST Spinal Cord Injury Resource Center (FSCIRC), located in Tampa, serves as the statewide clearing house of SCI resource information for persons who have survived an SCI, their families and friends, healthcare professionals, support groups, the media and the general public. FSCIRC provides a database of contractors, Centers for Independent Living, equipment companies, home modification companies, hospitals, rehabilitation centers, case managers, driver evaluations, recreational organizations, transitional living facilities and physicians with SCI experience throughout the state. *Continued*



Resources for SCI

Florida Alliance for Assistive Services and Technology (FAAST)

www.faastrg.org

Phone: (850) 487-3278

Toll-Free: 1-888-788-9216

FAAST Spinal Cord Injury Resource Center (FSCIRC)

www.flspinalcord.us

Phone: (813) 844-4286

Toll-Free: 1-800-995-8544

Florida Department of Education, Division of Vocational Rehabilitation (VR)

www.rehabworks.org

Phone: (850) 245-3399

Toll-Free: 1-800-451-4327

Florida Department of Health, Brain and Spinal Cord Injury Program (BSCIP)

www.myflorida.com

keyword: brain, spinal cord

Phone: (850) 245-4045

Toll-Free: 1-866-875-5660

Center for Independent Living—North Central Florida (CILNCF)

www.cilncf.org

Phone: (352) 378-7474

Toll-Free: 1-800-265-5724

Working Together to Build Healthy Communities

Want to learn more about WellFlorida and/or our Community Partners?

Would your organization like to submit an article for publication in the WellFlorida newsletter?

Interested in becoming a board member at WellFlorida or with one of our Community Partners?

If you answered yes to any of those questions, please contact us. Fill out the form below and mail it to us OR email Monica Sesco at msesco@wellflorida.org OR call 352-313-6500 ext. 105.

Area(s) of interest: _____

Please send me additional information on:

- North Central Florida Ryan White CARE Program
- Healthy Start of North Central Florida
- Central Healthy Start
- Rural Health Partnership of North Central Florida
- WellFlorida Council

Name _____

Address _____

Phone _____ Email _____

Local and Statewide SCI Programs, cont.

Florida Department of Education, Division of Vocational Rehabilitation (VR) is a federal-state program that works with people who have physical or mental disabilities to help them prepare for, gain or retain employment. VR provides numerous services and programs for job seekers and employers.

Florida Department of Health, Brain and Spinal Cord Injury Program (BSCIP) provides services including: case management, acute care, inpatient and outpatient rehabilitation, transitional living, assistive technology, home and vehicle modifications, nursing home transition facilitation, and long-term supports for survivors and families through contractual agreements with community-based agencies. BSCIP funds programs such as FFAST and FSCIRC, and provides additional services through VR, Centers for Independent Living and other programs. The BSCIP web site has links to brain and spinal cord community partners, news and more.

Centers for Independent Living provide services through a statewide network of private nonprofit, nonresidential, locally based and consumer controlled organizations. The Center for Independent Living of North Central Florida (CILNCF) is headquartered in Gainesville and serves 16 counties. CILNCF offers an equipment loan closet, employment services and solutions, the High School High Tech program, travel training, disability awareness training and accessibility studies. The organization also builds wheelchair ramps for those without the means to modify their homes. Weekly workshops and activities aimed at fostering independence are posted on the CILNCF web site.

More information on these organizations and their programs can be found by using the contact information located in the sidebar.