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South Carolina Spinal Cord Injury Association News



A SNEAK PREVIEW AT THE 2005 SCSCIA CONFERENCE



Back by popular demand, the South Carolina Spinal Cord Injury Association is planning its second statewide educational conference for people with spinal cord injury, their families/caregivers and people who work with them. Mark your calendar now for the conference to be held on May 12, 2005. This day will be jam packed with practical information to help improve the quality of life for both people with spinal cord injury and their caregivers. Here's a preview of the topics that will be covered: current research progress towards treatment of spinal cord injury; wheelchair and seating surface selection and reimbursement; how to advocate effectively to get what you need; updates on common medical conditions; and summaries of research studies being carried out in South Carolina. In addition to these sessions, there will be time both to ask the expert speakers questions and to visit the exhibits that will bring the latest in product and service information. You'll also have a chance to visit with old friends and make new ones.

Just as in 2003, the conference will be held at the Columbia Conference Center and Hotel (formerly the Sheraton) in Columbia. Registration is free for attendees who have spinal cord injury and their families. Look for conference and registration brochures in your mailbox in February.

SCSCIA EDUCATIONAL CONFERENCE SCHEDULE OF EVENTS May 12, 2005

8:30-9:30	Registration and Exhibits
9:30-10:30	Welcome Keynote address: "Optimism in SCI Research: Progress Towards New Treatments"
10:30-11:00	Break and exhibits
11:00-11:45	"Nuts and Bolts of Wheelchair selection and seating" lecture
11:45- 12:00	Break
12:00- 1:00	Lunch with SCIRF funded abstract presentations Door Prizes
1:00-1:45	Break and Exhibits
1:45-2:30	"Getting what you need through effective advocacy"
2:45-3:00	Break
3:00-3:45	"News You Can Use: Update on Prevention and Medical Management of Common Complications after SCI"
3:45-4:30	Ask the experts: Q & A of speakers
4:30-4:45	Closing Remarks, Evaluations, Door Prizes

WHAT TO DO WHILE WAITING FOR A CURE



Many people were deeply saddened by the death of SCI activist Christopher Reeve. After his injury he spent his life advocating for research related to a cure for spinal cord injury. Many people criticized him for not being involved in other issue related to spinal cord injury like health benefits and payment for attendant care. But his work should not be criticized, he had the right to work for the cause that he was most interested in.

Mr. Reeve was a strong advocate for changes in laws regarding stem cell research. This whole issue is an emotional one for people on both sides. Both sides agree, though, that even if the laws were changed, a cure would be found immediately. So what do we do while waiting for a cure? A few good ideas come to mind. First of all, we should take charge of our health. Too many of us risk illness and injury every day because we don't do the things that we've been taught. You know, like drinking extra water and cleaning our hands and equipment before and after catheterizing. Eating the right foods and quitting smoking. Pressure releases.

We know all this stuff, we just don't do it. Another thing we can do while waiting for a cure is to help somebody else who has SCI. Many of us have information, ideas and equipment that somebody else could use. We could all do something for someone who is where we have been.



One of the most important things we can do while we are waiting for a cure is to advocate for changes in the way people with SCI are treated. There are still people warehoused in nursing homes. There are people with no insurance. There are people who are able and willing to work that can't find a job. There are people whose own homes have accessibility issues that prevent them from getting in and out. Public parking and buildings are inaccessible. Medicaid and Medicare benefits needed to help us with our daily living are decreased creating barriers. The list goes on. So, what can you do while you are waiting for a cure? Educate, advocate, and help a friend. Write letters and emails to elected officials.

FLU VACCINE SHORTAGE AFFECTS PEOPLE WITH SCI

Because of the storage of flu vaccines this year, many people with spinal cord injury might find themselves without protection against the flu, and therefore at risk for pneumonia. The US Surgeon General has announced that millions of doses of flu vaccine will be available by the end of the year, but this may be too late for many at-risk patients. There have already been confirmed cases of flu in many counties in SC. It takes a few weeks after injection of the flu vaccine before it is effective in preventing the flu. Since the flu season peaks shortly after the first of the year, it may be too late to be protected by the time the vaccine is available.

The thought of getting the flu is a scary one for many people with spinal cord injury because of their increased risk of getting pneumonia. If you are unable to get a traditional flu vaccine, there are still some things that you can do to protect yourself. First of all, ask your doctor about the nasal flu mist vaccine. If you are healthy, it may be safe for you to use this live, weakened virus vaccine. You can also ask your caregivers to use the flu mist vaccine to prevent them from getting the flu and giving it to you. Make sure that each time your caregiver enters your home that they wash their hands before touching you. You might want to avoid crowds during the flu season to avoid being exposed to the virus. And finally, get a pneumonia vaccination. There is no shortage of this vaccine, and even though it will not prevent you from getting the flu, it can protect you from the most serious complications of the flu. If you have been vaccinated against pneumonia, you should get a booster every five years.

