It All Adds Up! research + YOU = results

Individuals with spinal cord injury (SCI) are always looking for new and better ways to do things. If you think something is better, you try it. It might be trying a new computer program to make your job easier. It might be trying a new medication to ease the pain in your shoulder. If it makes your life easier or less painful, you stick with it. If it does not work, you look for something else.

It is the same with research. The purpose of research is to find answers to questions about whether or not something works. Researchers in SCI hope that they can find answers that will help make a difference in your life.

In 1975 the National Spinal Cord Injury Data Research Center was created. Now known as the National Spinal Cord Injury Statistical Center (NSCISC), the center collects and combines information from Model SCI Care Systems across the country. Researchers use the NCSISC information to see what areas of SCI care need improvement. They look at medical issues and other areas like employment, marriage, and survival after SCI.

Information from NSCISC shows research has already made a difference. In the first 4 years of collecting information, there was a relatively high death rate during the first year after spinal cord injury. This fact lead researchers to focus on ways of improving the survival rate. Now the risk of dying in the first year after SCI is 67% lower than it was between 1973 and 1977.

Today’s research focuses on a number of issues related to SCI. Some research projects are searching for a cure. Some are looking for ways to improve quality of life.

At the UAB Rehabilitation Research and Training Center (RRTC) the focus is on secondary conditions of SCI. These areas of research include pain, spasticity, urinary tract infections, respiratory problems, and other secondary health issues.

“Our research focuses on problems that occur as a result of the spinal cord injury,” says Michael J. DeVivo, DrPH, a researcher and co-director of NSCISC. “The cure research is important. It is what we are all working to achieve. However, some people with...
Table 1  The 18 Current Model Regional Spinal Cord Injury Care Systems

<table>
<thead>
<tr>
<th>Model SCI System</th>
<th>State</th>
<th>City</th>
<th>Phone Number</th>
<th>Model SCI System</th>
<th>State</th>
<th>City</th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northwest Regional SCI System</td>
<td>Seattle, WA</td>
<td></td>
<td>(206) 685-3999</td>
<td>Rocky Mountain Model SCI System</td>
<td>Englewood, CO</td>
<td>(303) 789-8308</td>
<td>Southeastern Michigan SCI System</td>
</tr>
<tr>
<td>Georgia Regional SCI System</td>
<td>Atlanta, GA</td>
<td></td>
<td>(404) 350-7580</td>
<td>No. California Regional SCI System</td>
<td>San Jose, CA</td>
<td>(408) 295-9896</td>
<td>UAB Model Regional SCI System</td>
</tr>
<tr>
<td>Texas Regional SCI System</td>
<td>Houston, TX</td>
<td></td>
<td>(713) 797-5946</td>
<td>Regional SCI Care System of So. California</td>
<td>Downey, CA</td>
<td>(562) 401-7161</td>
<td>Midwest Regional SCI System</td>
</tr>
<tr>
<td>Missouri Model SCI System</td>
<td>Columbia, MO</td>
<td></td>
<td>(573) 884-7972</td>
<td>Regional SCI Center of Delaware Valley</td>
<td>Philadelphia, PA</td>
<td>(215) 955-6579</td>
<td>NE Ohio Regional SCI System</td>
</tr>
<tr>
<td>VCU Regional SCI System</td>
<td>Richmond, VA</td>
<td></td>
<td>(804) 828-0861</td>
<td>Model for Community Integration in SCI</td>
<td>Milwaukee, WI</td>
<td>(414) 259-2126</td>
<td>U of Michigan Model SCI System</td>
</tr>
<tr>
<td>Mount Sinai Model SCI System</td>
<td>New York, NY</td>
<td></td>
<td>(212) 659-9369</td>
<td>New England Regional SCI Center</td>
<td>Boston, MA</td>
<td>(617) 638-7358</td>
<td>No. New Jersey Model SCI System</td>
</tr>
</tbody>
</table>

SCI are experiencing secondary complications. Our research can help ease those problems until a cure is found.”

A more recent trend is research on “Psycho-social” issues. This is the study of the everyday issues related to living with SCI. Some areas include the relationship between individuals with SCI and their caregivers and/or family members. The RRTC at Rancho Los Amigos Medical Center in California is studying aging with SCI. These areas include the course of aging, depression, employment and other issues of daily living.

No one knows what future research will uncover. But one thing is sure. Researchers need you, the consumer with SCI, to help find the answers. Consumers have a big role in research. They are participating in research projects and serving as advisors. It is a good partnership that helps keep the focus of research on the current needs of the consumer.

UAB recently held a focus group of researchers and consumers to talk about problems and solutions of persons with disabilities. One participant was Emily Perkins. She has C4 tetraplegia following a car accident in 1994. “People with disabilities should not hesitate to become involved in research if it can benefit them and so many others,” says Emily. “If an individual wants to make others aware of important issues and concerns, what better way than to work with someone who is already curious about our lives and is willing to help.”

Finding participants like Emily is not easy. Many people with SCI find it hard to get involved in research. Some have problems with transportation. Some have health problems. But researchers recognize these problems. There are working to make it easier for you to get involved. Now you can be a part of many studies without leaving home.

With a little effort you can get involved in research. It only takes your willingness to participate. Table 1 provides the name and telephone number of current Model SCI Care Systems that are studying issues related to SCI. These centers are not alone. A few private organizations are also funding research. They include the Paralyzed Veterans of America, the Miami Project to Cure Paralysis, and the American Paralysis Association, which recently merged with the Christopher Reeve Foundation.

These and other organizations have many studies going on right now, but you need to be careful. Do not get involved in a study until you read the informed consent that describes the nature of the project's potential risks and benefits to you. Ask questions if you do not understand something. Only participate if you know the facts.

You may find a research project that is focusing on problems that concern you. By participating you can help yourself and help to improve the quality of life of everyone with SCI.

The Rancho Los Amigos RRTC, the UAB RRTC and the Model Regional SCI Care Systems are federally funded through the National Institute on Disability & Rehabilitation Research (NIDRR) by the United States Department of Education.
HEALTHY LIVING

Finding a doctor close to home

Most doctors will generally agree that preventive medicine can reduce your chances for future health problems. For persons with spinal cord injury (SCI), preventive medicine means maintaining good health by practicing proper daily care and keeping regular check-ups with a doctor. It is recommended that you get a check-up every year at your rehabilitation clinic whenever you can.

Unfortunately, many persons with SCI do not visit their clinic or doctor at least once a year. According to one UAB study, three of the main reasons for this lack of preventive care include problems with transportation, the distance to travel to receive care, and the inability to find a good local doctor. If any of these reasons are keeping you from regular check-ups, here are some steps you can take.

1. Learn how you can find a local doctor.
2. Learn how you can choose the doctor that is best for you.

Having a doctor close to home will help reduce problems with transportation, eliminate the need to travel long distances, and give you the opportunity to get the care you need to live a longer, healthier life.

Unless you live close to a rehabilitation center, you are likely not going to find a physiatrist, a doctor who specializes in spinal cord injury, close to home. Therefore, a general family physician is probably your best choice. This is okay. Individuals with SCI can still receive regular check-ups and other preventive medical care from a local doctor if you only make the effort.

You can start to look for a good doctor by asking others in your community for recommendations and making a list of those suggestions. If there are others with SCI or other disabilities in your community, contact them to find out if they have a local doctor. If they do, ask them about their relationship with their doctor and how he or she deals with their special needs. You may find others who are not seeing a local doctor. They may also prefer to see a doctor close to home and join you in your search. The more people searching for a good doctor the more likely you are to succeed.

Remember that you are an expert on you, and you should know about the common problems that can occur in persons with SCI.

Second, call the doctors on your list to find out if their office is accessible. This includes parking, doorways, hallways, bathrooms, examination rooms, and examination tables. You may also want to ask whether or not the staff is trained in transferring and if they can help you if necessary.

Finally, select a doctor you trust. Once you make your selection, establish a good relationship with the doctor that will grow over time. Give him or her your full medical history and find ways that you both can stay current on medical information concerning persons with SCI. After all, you and your doctor are a team working for your good health.

Note

Overuse of wrist extension or the muscles of the thumb can also cause pain in the upper forearm and elbow. Tendonitis, bursitis and myofascial pain can also occur at the elbow. The repeated pressure of your arms on the armrest of your wheelchair can cause this swelling. It can be dangerous if this fluid filled sac becomes infected with bacteria.

Nerve entrapped pain occurs when the ulnar nerve becomes pinched at the elbow. This usually causes pain along the inner forearm and hand. You may have numbness and tingling in the hand, weakness of hand, grip and fingers. Carpal tunnel syndrome has similar effects but is caused by a trapped nerve in the wrist. It occurs as a result of direct pressure or repetitive motion.

Some people experience pain due to the damage to the spinal cord itself. This pain can be located in the parts of the body where there is no sensation or muscle function. It is typically burning or stinging but can also be dull and aching. Some patients with this type of pain report that it is more disabling than the loss of function from SCI.

Pain after SCI is very common and should not be ignored. It can be a signal of a more serious problem. Pain can also be very difficult to treat because the source of the pain is not always known. However, you should not be discouraged from talking to your doctor about ways to relieve your pain. You can get help, whether it is musculoskeletal pain, nerve pain, or pain from another anatomic source.

Pain due to spinal cord damage can be treated with a variety of medications. A few of the other common treatments for musculoskeletal pain include stretching and strengthening muscles, massage and trigger point therapy, anti-inflammatory medicines, or resting the area of pain. In the rare cases when these methods are not effective, surgical options are available. Often, this is an attempt to try to mask, or block, the pain signals. If these signals are prevented from reaching the brain, you will not likely feel the pain.

**Note**

**Shoulder & Joint Pain and Posture Changes After SCI** are articles adapted from presentations given at the RTC’s SCI Research Update Conference for individuals with SCI, families and providers on September 25, 1998 in Birmingham, AL. For additional information and resources on pain, see "Resources" on page 8.
It is important for persons with spinal cord injury (SCI) to maintain good posture. Many individuals with SCI come into the clinic with a pressure sore or red spot. They say, “I’ve been sitting on this cushion for 20 years, and it’s never given me a problem. I can’t understand why, all of a sudden, I’m having a problem.” There are two reasons for this. First, your skin changes elasticity and thickness as you age; it is simply not as sturdy as you get older. Second, changes in muscle bulk can cause problems. There is atrophy, or shrinking, of the muscle after SCI. It essentially leaves you without all those muscles padding the pelvis. Another physical change that may cause problems with posture is scoliosis, or curvature of the spine. This can cause you to put more weight on one side of your pelvis.

With these types of physical changes, you may not have adequate muscle strength or balance. You probably need some type of external support to make up for your loss of muscle strength. But how do you really know whether or not you have a problem with your posture? Ask yourself?

* Do I have problems with pressure areas or red spots?
* Do I look crooked or look like I am sitting sideways in my chair?
* Do I loose my balance and fall over when I raise my arms?
* Do I have pain in my neck or shoulders?

If you say “yes” to one of these questions, you need to talk with your doctor about a referral to consult a physical or occupational therapist about your seating and posture. There are some steps that you can take to improve your posture, but you need a professional that can help you find the right method for you.

The first step is often making adjustments to your wheelchair. If you have a chair that is easily adjustable, there are a few things that can be done to improve posture. The proper height of your backrest depends on your level of injury and how much trunk musculature you have to assist you with your balance and posture. If the back of your chair is too high, sometimes it can feel as if you are being pushed forward. If the back is too low, you may tend to slump down in your chair because you do not have enough support.

People with a higher level of SCI may want to adjust the tilt of the chair. Moving the axles up in relation to the frame can actually tilt the whole chair back. This tilt allows gravity to help push you back in the chair rather than pushing you over forward. A lot of times, a little bit of tilt can really help in terms of balance and positioning. Otherwise, you may try to compensate for the feeling that you are falling forward by sliding your bottom forward, slumping down, and essentially lowering your center of gravity to help with balance. Although slumping down may help with balance, it does terrible things to your posture. Another adjustable part of some chairs is the armrest height. If the height is too low, you are going to end up leaning forward in order to rest on the armrest. This can also lead to poor posture.

The second step in improving posture is choosing the right seat cushion for you. There is lot of variety on the market, but it is an individual choice on which you prefer. Some companies will now allow you to try a cushion out before you buy it. Two cushions that are commonly used are the Roho and the Jay cushions.

If you have skin and pressure problems, you might need a cushion that gives you more pressure relief. An air cushion like the Roho does a very good job of pressure relief. The adjustment is critical for this type of cushion. To be effective it must be adjusted so that you sink down into the cushion to within about 1/2 inch of the bottom. It should not be as hard as a rock.

With the Jay cushion there is a “flolite” material that feels like a gel, but it is a gel-type material that offers pressure relief as it forms around your body. This cushion has a lot of little extra pads that you can add underneath one side of the gel pack to help with your position.

Above all, the one thing to remember with a cushion is pressure distribution. Do not create high-pressure areas! Eliminate them! The pressure distribution can be checked with a pressure mapping system like the Force Sensing Array, a system of 144 sensors that determine pressure points while you are sitting on your cushion.

In addition to wheelchair adjustments and seat cushions, there is one more suggestion to help you maintain good posture. Some problems may be prevented with exercise. It is important to stretch and maintain your flexibility. If you are sitting all day, you need to try to get out of your chair at the end of the day, lie on your stomach, and stretch your hips and knees. Find a way to stretch your ankles daily. If you need bed rest for any reason, try to maintain your stretching exercises.
This column provides readers with updates on current research and activities conducted by the UAB Rehabilitation Research & Training Center (RRTC) on Secondary Conditions of Spinal Cord Injury (SCI) and the UAB Model Regional Spinal Cord Injury Care System. For additional information contact the Training Office at 205-934-3283 or email: rtc@sun.rehabm.uab.edu.

Training, dissemination/distribution and technical assistance are vital components of the UAB Rehabilitation Research and Training Center (RRTC) on Secondary Conditions of Spinal Cord Injury (SCI). Information and findings from RRTC research activities are available for a target audience of individuals with SCI, their family members, service providers and health care professionals.

To better direct the RRTC staff in developing projects that meet the needs and issues of the target audience, various people from the target audience serve on a Consumer Advisory Team. The team meets twice a year with the training staff to offer ideas and feedback based on their personal experiences.

During the five year grant cycle, there are 17 training and dissemination projects in three areas.

I
Conduct training on SCI research methods and experiences in applied research provided through...

* Increasing rehabilitation research as a field of study to undergraduates with disabilities.
* Teaching basic rehabilitation research design and methodology to pre/post-doctoral students.
* Exposing students and rehabilitation providers to the latest RRTC research results to improve care of persons with SCI.

II
Provide SCI knowledge to individuals with SCI, their families, service providers and others through…

* Conference and seminars held annually.

III
Publish and disseminate SCI information through …

* Research Review Information Sheets. Topics for 1999 are on Respiratory Complications and Sexuality.
* Pushin’ On. An SCI newsletter published twice a year for individuals with SCI, their family members, service providers and health care professionals.
* Research Update. An annual newsletter for researchers that focuses on the results of a research project from this RRTC.
* FAX Information System.
* Technical assistance requested via phone, email, and correspondence.

The RRTC Training Office is located at Spain Rehabilitation Center within the Department of Physical Medicine and Rehabilitation at the University of Alabama at Birmingham. This Training Office and the RRTC are funded by a grant #H133B980016* from the National Institute on Disability and Rehabilitation Research (NIDRR) of the United States Department of Education. This RRTC also works in cooperation with the UAB Model SCI System, UAB Traumatic Brain Injury Model System, and the National Spinal Cord Injury Statistical Center (NSCISC), located at UAB.

Note
For details on the current research projects funded by this grant, see the previous issue of Pushin’ On or the UAB Department of Physical Medicine and Rehabilitation webpage on RRTC research projects at http://main.uab.edu/show.asp?durki=8861.
### 1999 UAB RRTC Teleconference Schedule

<table>
<thead>
<tr>
<th>Topic:</th>
<th>Spinal Cord Dysfunction: Complementary and Alternative Medicine</th>
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</table>
| Speakers: | S. Laurance Johnston, Ph.D.  
Roberta Trieschmann, Ph.D. |
| Time: | Sept. 14, 1999, 2pm ET (Professionals)  
Sept. 21, 1999, 8pm ET (Consumers/Family) |

Based on an ongoing series of articles in Paraplegia News, this teleconference will focus on a variety of alternative medicine approaches relevant to spinal cord injury/dysfunction.

Dr. Johnston will discuss some of the reasons that over 40% of Americans now routinely use alternative medicine. The discussion will include:

- acupuncture, a traditional Chinese medicine therapy;
- craniosacral therapy, a gentle hands-on treatment that focuses upon the semi-closed physiological system that encompasses the brain and spinal cord;
- homeopathy, a non-pharmaceutical form of medicine;
- chronologically controlled developmental therapy, a physical therapy program that attempts to switch on inactivated neurons; and
- therapies associated with spiritual healing and human energy fields.

<table>
<thead>
<tr>
<th>Topic:</th>
<th>Aging With Spinal Cord Injury</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speaker:</td>
<td>Daniel P. Lammertse, M.D.</td>
</tr>
<tr>
<td>Time:</td>
<td>Oct. 26, 1999, 5pm ET (Consumers/Family)</td>
</tr>
</tbody>
</table>

It is now believed that spinal cord injury influences not only the rate but also the quality of the aging process. In this teleconference, Dr. Lammertse will briefly discuss the nature of aging in general, the effects of aging in various organ systems, and changes in long-term care and survival needs for persons with spinal cord injury. Other areas of focus will include:

- risk factors for heart disease and other cardiovascular conditions;
- musculoskeletal concerns including shoulder pain and osteoporosis;
- respiratory issues including diminished respiratory reserve;
- neurological issues such as bladder cancer; and
- nervous system problems including progressive cysts in the spinal cord.

Please Select Desired Teleconference

- [ ] Complementary & Alternative Therapies for Professionals. Sept. 14, 1999 at 2pm Eastern Time*
- [ ] Complementary & Alternative Therapies for Consumers & Family. Sept. 21, 1999 at 8pm Eastern Time*
- [ ] Aging with Spinal Cord Injury for Consumers & Family. Oct. 26, 1999 at 5pm Eastern Time*

Complete and return this registration form at least 2 weeks prior to the desired Teleconference.

Do you wish us to reply by Mail [ ] Email [ ] Fax [ ]

*Registration is Limited to 150 Callers*

Informational handouts and the Teleconference phone number will be provided after Registration Form is received. Approximate time of each Teleconference is 75 minutes.
Do You Have Sleep Apnea? If you are experiencing symptoms like daytime sleepiness, frequent interruptions of sleep during the night, loud snoring, high blood pressure, poor concentration, depression, morning headaches and a tired feeling when you wake up in the morning, you may have Sleep Apnea. UAB RRTC needs volunteers living in the Birmingham, AL area to participate in a study of Sleep Apnea, a type of breathing disorder whereby a person has absent breathing usually during sleep. If you are a person with SCI between the levels of C-4 and T-3, been injured over 5 years and interested in participating, call Karion Waites at 205-934-3330.

SCI Email Distribution- Receive notices via email as new and updated SCI material from UAB becomes available; email klebine@uab.edu and type in subject or body of email, "subscribe to SCI email distribution list."

For FREE InfoSheets related to topics covered in this issue of Pushin' On, #10 "Pain after a Spinal Cord Injury," #13 "Preventing Pressure Sores," & #18 "Review of SCI Research," send your specific request with a Self Addressed Stamped Envelope to the return address below.

Web Resources

Seating & Posture
- www.newmobility.com/query/magazine/frame-detail.cfm?recID=45&date=
- www.craighospital.org/c2q_posture.html

SCI Research
- paralysis.apacure.org
- www.pva.org
- www.miami.edu/miami-project/HOME.HTM

Pain
- www.ampainsoc.org/
- www.pva.org/pn/9811pain/index.htm

Finding a Doctor Close to Home
- www.craighospital.org/c2h_choosingYourDoctor.html

All articles that appear in Pushin' On are also available on the Spinal Cord Injury Information Network at www.spinalcord.uab.edu.