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- **Ziconotide: A Non-Opioid Alternative for Chronic Neuropathic Pain, A Case Report**
- **The Road Back to SCI**
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## Editorial

### On Global Nursing Leadership

Verena Briley-Hudson, MN, RN, CNA



When I think about nursing leadership, I think about what is unlike anything that we might experience or may not know now, but what others will need to know in the future. AASCIN's goals are to:

- Provide, promote, and enhance the care of individuals with SCI.
- Develop and promote education and research related to SCI nursing.
- Provide educational opportunities for nurses who specialize in SCI nursing.
- Facilitate an exchange of information and collaborate with other professionals involved in SCI care.
- Serve as a resource to other nursing and health care individuals and organizations, government agencies, educational facilities, and consumer groups.
- Recognize nurses committed to the care of individuals with SCI.
- Advance SCI nursing as an area of specialty nursing practice.

We are an organization that has characteristics of empowerment, highly skilled and educated, resourceful with specialized nursing and health care expertise, and with an eagerness to share our commitment. As we prepare others for the future, it can be exciting to experience and understand SCI nursing leadership in a global way. Every nurse is a leader! Our thoughts of what nursing leaders around the world can share with us and what we can share with them as we learn from others stimulates our thoughts for a bonding of common themes. We all realize that there are global nursing concerns for improving health care. It might be with merely getting to know other nurses through many interesting ways: technology, electronic web sharing, traveling, and visiting with other nurse leaders around the world, or by learning just a little of the language.

I was very fortunate to be able to join a group of talented nurse leaders on two exciting nursing delegations, one to Russia, and another to China. While exploring global nursing leadership involvement, I found that we share many commonalities among many other nurses around the world. Many of you know that AASCIN has international nurse members from Canada and that several nurses from other countries do join us in our annual meetings as presenters and as conference attendees. At our last conference in Orlando, six Canadian nurses joined us.

I can tell you that the language of nurses caring in any country is through the eyes of kindness and their motivation of sharing information to improve health care for others. So, in October 2005, taking the quick language travel book basics and essentials; bathroom, eat, drink (vodka), yes (da), and hotel, off to Russia I went! So, I just wanted to share a little of the information that I learned with you.

Embarking upon on a different journey in a quest for knowledge, many nurses in Russia also struggle with the challenges of quality health care systems and staff shortages. We seek opportunities to learn more, develop a different approach to what we do, and implement new ideas, and so do the Russian nurses, particularly the nurse leaders. Many of us seek new knowledge and share experiences as we participate and attend local, state, and national meetings, as do the Russian nurses. Moreover, we become re-energized in our commitment to quality and patient care, yet there are less often opportunities for this sort of participation there.

By the end of this experience, I had traveled from Moscow to Novgorod and to St. Petersburg. Seeing the cultural heritage of Russia, visiting a university and three hospitals, and discussing nursing with our Russian colleagues, what became obvious early on is that nurses, regardless of where they practice or in what country they work, share the same values and commitment to patient care.

Traveling in Russia was an experience. I was escorted around mainly by bus but did have an overnight trip by train from Moscow to Novgorod.



**A night train from Moscow to Novgorod was a night to remember!**

Train stations in Russia are not exactly the “plush Amtrak” as in the United States. Regardless of what city we visited, the housing structures are a combination of the elaborate palaces from the past and the rectangular and plain structures from the era of communism. The Russian Orthodox religion has played an important role in Russia. Most cities were built around monasteries and many have been destroyed or are being used for other purposes. Churches and magnificent cathedrals were everywhere, yet some churches were destroyed because of many wars; others were being refurbished while others are a showcase of history. Historical treasures are also in museums so large that it would take weeks to see it all (i.e., the Hermitage in St. Petersburg being one of the most famous).

Russian lifestyle has changed dramatically over the past 10 years. Things that we take for granted such as grocery stores were nonexistent 10 years ago. Now, all types of shopping are available. Shopping malls, specialty shops, European and American cuisine restaurants, and even gambling casinos are found in the larger cities.

### **Nursing in Russia**

So what was the best and most refreshing news to hear around the world? It was hearing that, “to be a nurse is very prestigious”. The Russian educational system for nursing is structured, and all nurses are educated in a university setting. The course work is very similar to our nursing education curriculum. It is divided into four blocks of study: Natural Sciences, Biological Sciences, Liberal Arts, and Leadership Development.

Completion of course work takes 3 years, and then nurses work in hospitals under the guidance of a senior nurse for at least 1 year. Skills labs are set up at universities for students to have hands-on experience in anatomy and physiology and develop necessary skills to provide patient care. All nurses involved in teaching or holding management positions are educated to the equivalent of our Master’s degree and require two additional years beyond the initial RN educational requirements. In an effort to provide access for more students, some universities are using long-distance computer learning with a requirement that students be on site for observation and testing at the university for 1 week per quarter.

RNs licensure is a combination of a written test, clinical test, and oral examination. Nursing practice is legislated by the government. License renewal cycle is every two years with the same requirements each time. Since practice is legislated, nursing is struggling with autonomy. Several nursing organizations in Russia are affecting change in nursing practice. The Russian Nursing Organization is playing a leadership role at the governmental level to transform nursing standards into practice. I did not find a similar organization to the AASCIN, but did learn that the organization of Perioperative Nurses is

focusing on standards related to that specialty. As with many of our organizations, information and new research is shared at regional meetings.

Recruitment and retention problems are also evident. Salaries are very low for both nurses and physicians. For nurses, salaries range from \$500 to \$800 per month. Since nurses and physicians can make more money in fields other than health care, many leave the profession. Both professions are experiencing shortages due to international recruitment. Russian culture limits diversity in the workforce especially for men. Their role is limited to the operating room and to areas where they are not direct care providers.

### **The Hospitals**

We visited three hospitals that are mostly public and supported by the national health care system. One specialized in cardiac surgery and the other two in general medical surgical services. Many hospitals are 500 beds, located in urban cities, and specialize in an area of practice. Mini-hospitals with 16 to 42 beds are located in smaller towns. The hospital administrative structures are very similar to ours and consist of the president, who is a physician, and the chief nurse. Computers on nursing units and at the bedside were limited. Other equipment, especially related to care of patients at the bedside, was state-of-the-art. Unlike most mandates in our health care systems, there was no evidence of disposable equipment such as bedpans, and in some instances, sterilization of needles and syringes were routine. The hospitals were quiet with no overhead paging. As we toured the units, we were able to observe the interaction between the physicians and nursing staff. There was a genuine respect between them. As stated by one of the presidents, “We work very hard on relationships.”

The patient care units we toured in the cardiac hospital were actually critical care wards. The beds were occupied with patients’ ages 6 weeks to 13 years. It was an emotional moment to witness the caring of the team. The highlight of our visit was to observing cardiac surgery of a 2-year-old in the operating room. It was a breathtaking experience to see the little heart pumping.

### **The Health Care System**

While I did not experience or learn about any SCI wards, the current health care delivery system in Russia is based on four principles: every citizen has a right for health care; preventative medicine is a priority; the state is responsible; and care should be based on medical science. The current system supports the role of the specialist. As we visited the hospitals, and spoke with the presidents, this was obvious. The two presidents who met with us were surgeons who maintained a part-time surgical practice and a full-time president’s position. As Russia is moving forward, they are looking to the United States to adopt our model of family practice and chronic disease management in caring for patients. The model will provide a significant salary increase to any nurse or doctor who will commit to a primary care focus. Nurses will have a significant role in this model as teachers.

### **Challenges**

For Russia, there are many challenges to face, particularly in health care. Nursing has outlined their goals: increase nurses’ role in the health care system; increase nurses’ role in health care policy; increase nurses’ role at the international level; and take the standards of nursing practice and put them into law. Does that sound all too familiar?

### **Lasting Impressions**

As I reflect upon those 12 days in October, it seems that only yesterday that I started on a journey that led me to a new understanding of nursing at the international level. There is so much to learn from others. Our challenge is to develop the pathways of success in sharing and recognize nursing for the global profession that we represent.

Stay tuned for another upcoming Editorial on global nursing about my trip to China this past August and September 2007, that is, if I make it back from Cape Town and Johannesburg, South Africa this coming August! Oops, sorry to miss our AASCIN Conference again this year! This article will feature an extensive review about how Chinese nurses are educated and the manner in which that compares to the American system, including the role of nurses in both countries; how nursing associations are influencing the professional development of Chinese nurses; hospital organization and the role of nursing leaders; and

basic concepts of patient safety and infection control and how they have evolved in Chinese health care organizations.

As nurses, we are all nurse leaders; it is time to move to a global focus and place greater emphasis on multiple health care initiatives that affect a changing world. We must embrace the art of foresight as we do the art of nursing for the element of success, because without both, we cannot prepare for what we need to know now and to prepare others for the future. If nurses investigate potential global alliances with other international nurse leaders, together we create a powerful world of health care opportunities to improve quality and mutual nursing concerns.

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## President's Message

### AASCIN is Making History

*Diane Reinhard, MBA, BSN, RN, CRRN*



Change your thoughts and you change your world.

#### Norman Vincent Peale

*US clergyman (1898 - 1993)*

Changes in society have been observed through slow, gradual modifications in mindsets and beliefs as well as through dramatic action. History is one of the tools used to document change. (Wikipedia)

At AASCIN, we are making history. Effective October, 2008. AASCIN, AASPSW, APS and the TLC (therapy leadership council) will receive funding for 5 years to support our annual conference from Paralyzed Veterans of America (PVA). We will also receive support for organizational management and pro bono services from a legal firm to help with our organizational merger efforts. We are making history in our organizations through our actions. We have one Joint Program committee leading the efforts to coordinate the 2008 conference and develop the 2009 conference, in Dallas. We are making history through our efforts to merge our four SCI organizations, listed above. We will become the biggest SCI professional organization in the world. We are making history through our partnership with the American Spinal Injury Association (ASIA) to co-sponsor the 2009 conference. We are making history by our representation with the Spinal Cord Leaders Council. We are making history by offering the first SCI boot camp developed by AASCIN.

We want you to be are part of our history! Remember to renew your membership. Get other professional colleagues to join you as a member. Experience an amazing interdisciplinary experience at our conferences. Participate in list serve discussion. Develop relationships and opportunities with other organizations to benchmark your organizational data or share policies. Be a leader!

Our partnerships and future direction of our organization may appear risky to some of our member. Our risk was making no changes. Our organizational world was changing around us and we could not stand still. We will remain strong with the changes we have accepted and endorsed.

I look forward to many more years of being a member of a dynamic and future thinking organization.

See you in Orlando!!!!

*Diane Reinhard, MBA, BSN, RN, CRRN, is the director of Nursing at Craig Hospital in Englewood, Colorado, and the current president of AASCIN.*

## Feature Article

### Stories of Feeling Independent

Mario R. Ortiz, RN, PhD, CNS-BC



#### Abstract

*Feeling independent* is a universal experience. Each person has a sense of what it is like to feel independent, a feeling or sense that may be changed with the occurrence of a spinal cord injury. For persons living with a spinal cord injury, feeling independent is a particularly important concept that may reveal much about how they experience health and quality of life. These descriptions of health can be used to guide nursing practice and further research in regards to what it is like to live with a spinal cord injury. The purpose of this paper is to present five selected stories of persons' experiences of feeling independent. These *feeling independent* stories had themes of (a) a strong will to think and act as one chooses, (b) living with limitations and opportunities, and (c) living what is important and cherished. It is important to understand how persons with spinal cord injury live their lives and how they want their lives to be.

**Key Words:** spinal cord injury; patient stories; practice applications

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#### Stories of Feeling Independent

*Feeling independent* is an experience that all persons live in some way and at some moment in time. It is inherent in living day-to-day life as persons choose what to do, how to do it, where to do it, and with whom to do it with. For persons with spinal cord injury (SCI), such decisions are lived in a unique way with different challenges and opportunities. For this researcher, bearing witness to a family member who has lived with a SCI for many years has shifted the researcher's view of what it means to feel independent. The researcher has seen how his family member and the family member's friends with spinal cord injuries have lived feeling independent by focusing on doing what was important for them in unique and challenging ways. So, knowing more about feeling independent enhances understanding of the meaning of health and quality of life (Parse, 1994) for persons being served by health professionals.

The purpose of this paper is to present selected stories of persons living with SCI and their experience of feeling independent. These stories were constructed from a qualitative research study that sought to uncover the structure (i.e., to describe) of the lived experience of feeling independent for persons living with SCI in the community. These structures depict patterns of feeling independent. These persons lived within a large Midwestern, metropolitan community. They each were willing to speak about their experience of feeling independent. These stories may assist health care professionals to have a better understanding of what the experience of feeling independent is like, especially for persons living with a SCI in the community. Increasing understanding about feeling independent can aide professionals to be more aware of how to participate in the lives of individuals with SCI. Health care professionals may gain an appreciation for the way persons with SCI are determined to live what is important in their own unique ways while living with the restrictions and limitations inherent in their situations.

#### Relevance to Spinal Cord Injury

The idea for constructing these stories emerged from living with a family member who has SCI and from the researcher's belief that persons with SCI experience feeling independent in distinct ways in relation to the unique challenges and opportunities they live moment-to-moment and day-to-day. Moreover, this belief emerged from insights gleaned from the findings of two studies (Mitchell, 1995; Parse, 2001a). In Mitchell's (1995) study, the core concept "anticipating limitations" emerged as one of the major findings. It captured the ways the participants in the study described what is good for them in light of what they are apprehensive about doing or trying. As they spoke about their experiences of restriction- freedom "the participants each talked about what was important to them as they simultaneously described "not feeling

like moving”, “wishing there was some place closer”, “limiting desires to do only what he is able to do”, and “appreciating living, even when it is difficult” (p. 169-170). The difference in Mitchell’s study is that it focused on the experience of older persons. It did not focus on the experience of persons living with SCI. Although Mitchell’s study was pivotal in establishing restriction-freedom as an important concept related to health and quality of life, it does not address the unique ways of living for persons with SCI.

In Parse’s (2001a) study, feeling independent emerged as a recommendation for future research based on the findings of the study on the lived experience of contentment. In this study, ten women over the age of 65 were asked to talk about what contentment or feeling content meant to each of them. One of the major findings of the study was “resolute liberty, as an unwavering determination to be independent, is integral to contentment” (p. 336). This finding means that the participants were “unwavering in affirming their self-reliance” (p. 335).

Statements like “being able to do what I want to do” and “keeping busy on my own” were prevalent in the descriptions (Parse, 2001a). Another participant said that being independent is most important to contentment. While another participant said she enjoys being alone and not going along with others. These statements show that for these participants, independence is important for contentment and thus to health and quality of life (Parse, 2001a). The findings of this study are important in that they show a link between health, quality of life, and the concept of feeling independent, as outlined in Parse’s study. The participants, however, were not persons with SCI and thus more research was needed to uncover what feeling independent is for persons living with SCI.

### Related Literature

**Feeling independent is a multidimensional, dynamic, and universal aspect of the everyday living of all people (May, 1981; Mitchell, 1990, 1994, 1995; Tillich, 1952). Parse (1981, 1998) stated that all persons live both opportunities and restrictions in all situations and with all choices. For every situation, there are limits that cannot be passed and there are opportunities that are taken. For a person with a SCI, one may choose to become adept at maneuvering a wheelchair so that he or she may spend time out with family and friends. With this opportunity of being with loved ones, the person with SCI is still limited in certain activities due to the wheel chair. Hence, opportunities and restrictions are lived all at once. Similarly, Mitchell (1995) writes of “anticipating limitations” (p. 171), which was one of the core concepts of her study. She says “anticipating limitations was described by participants as a process of reflecting on restrictions in the now, as well as on how restrictions might be experienced in time to come” (p. 171). A second core concept of Mitchell’s study was “unencumbered self-direction” (p. 172). She writes that this core concept is “related to the various meanings assigned to freedom and choice”. The concept was described in relation to daily routines and patterns of living (p. 172). In light of feeling independent, participants in Mitchell’s study spoke of “not being pinned down, confined, or dictated to”. Persons who lived alone liked not having to consult others about decisions and activities (p. 173). One man spoke about having the freedom to restrict his own actions in order to do what he thought was best (Mitchell, 1995). The last core concept in Mitchell’s study was “yielding to change fortifies resolve for moving beyond” (p. 173). This is related to how participants spoke about deciding to accept, adjust, and go along. They said such things as “you just have to live day-by-day, and what you can’t do you just have to learn to live with; it’s a matter of adjusting to change” (p. 173-174). In yielding to change, there emerged a fortified resolve to move on with the living of one’s life. Participants in the study decided to laugh, to learn new ways, to count blessings, and to have a different attitude in order to keep going. One participant said:**

*I’m not going to worry about the many things I can’t do. Many times I’ll get upset but I’m not going to let it throw me. I’ll just sit down and wait till I’m able to cope with it. You can choose to sit down and cry over spilt milk and go crazy, but you have to fight, fight back instead (p. 174).*

Hence, the restrictions and freedoms inherent in the every day living of one’s life are unique and important to health and quality of life. People live feeling independent in ways that are known to them and in ways that are new and must be learned. A person can only know what feeling independent is like by asking and listening to others.

### Construction of the Stories

All of the stories were from ten persons living with SCI who were 18 years of age and older. The participants were willing to speak about feeling independent (in English). Participants were recruited through personal contacts and through advertisements in community newspapers. Once they agreed to participate, participants met with the researcher in a convenient setting conducive to private discussion. They signed a consent form. Verbal consent was obtained from participants who are unable to write their name. These procedures were approved by a University Institutional Review Board (IRB) for the Protection of Human Subjects. A phenomenological-hermeneutical method (Parse, 2001b) was used to learn more and construct stories about the lived experience of feeling independent. Each participant was asked to: “Describe your experience of Feeling Independent”. After this initial statement, the researcher would use phrases such as, “Go on” or “Tell me more about how what you say relates to your experience of feeling independent”. There were no other probing questions. After the tape-recorded dialogue with each participant about *feeling independent*, a story was constructed that depicted the essential ideas about *feeling independent* from each participant’s dialogue. Then, the researcher dwelled with each story to construct themes or “essences” that utilized the participants’ words to capture their fundamental experiences of feeling independent.

### Significance for Nursing

To date, there have been no work published that focuses on feeling independent from a human science, human becoming (Parse, 1998), perspective. There was also no evidence of research to discover the meaning of the lived experience of feeling independent, or to describe the themes of feeling independent, even though it is important in understanding health and quality of life (Parse, 1994). These stories enhance understanding of persons’ experiences of *feeling independent* in general, and of the experience of feeling independent while living with a SCI in the community in particular. The findings provide nurses and other health care professionals with an opportunity to use the themes of these stories to change ways of practice.

### Selected Stories

Ten persons living with SCI in a Midwestern urban community shared their stories, but five stories that speak to the meanings of all the stories will be shared here (see **Table 1** for major story themes of all ten participant stories). The participants’ ages ranged from 33 to 65, three were women and seven were men, and all had been living with SCI for at least 5 years. The participants’ stories are presented in this section.

### Douglas’ Story

Douglas says that feeling independent is “being complete as the next guy.” There are things he knows he needs help with, but says, “I know who’s the boss. As far as I know, the boss is still me.” He makes sure that whoever is helping him listens to him and understands that feeling independent is important to him. Feeling independent runs his life. He would rather try things on his own and take a risk of being hurt, than always rely on someone else. He says, “You take a chance going outside, that’s the way things are today. I have burnt myself a couple of times cooking for myself. Things like that happen, I learn from that. Even though I got hurt by myself, I still did things my way.” Feeling independent is “living the way I want and then figure out how I can do it. It is taking your time.” He says that if he could not live on his own, he’d feel like he was in prison, again. “I had the option of going to a nursing home, but it seems like prison to me. I have been a prisoner, you know. I did 2.5 years in the state penitentiary. I got bossed around every minute, but I still knew I was the boss. I still was independent, I guess. Feeling independent was up to me.” Douglas says sometimes when people keep trying to tell him what he needs, he feels like he’s losing his mind, so he tells them to stop, even if it offends them. He says, “feeling independent is to live the way I want to, I just keep going no matter what, I just have to do it, it’s so important for me to keep going.”

### Themes: Participant’s Language

1. Feeling independent is being complete like everyone else. It is running his life the way he feels right for him. It is making a choice to feel independent no matter what the circumstance. He says it is the way he wants to live. He just has to do it.

2. Feeling independent is taking risks at times. It is doing things for myself, even though I may get hurt. It is very important for him to keep going.

***Loanna's Story***

Loanna says that “feeling independent is unexplainable, but good.” She says that sometimes she feels independent and other times she does not. It is preparing meals with her sister and nieces in her own apartment. She says that she likes living alone because having too much structure makes her feel like what she says and wants to do does not matter. She states, “Last year I was in the hospital at this time. It was such a structured environment. I could not say that I wanted to just lay around all day or tell them I wanted to get up and make myself pretty.” Loanna says that feeling independent is a blessing from God that she has chosen to accept and make the most of. She believes that God knows what is right, and she will do what she can to live life to its fullest, no matter what may come her way. Feeling independent is doing what she loves, like cooking for her family and spending time with them.

**Themes: Participant's Language**

1. Feeling independent is doing what she wants, spending time with family, and living on her own. It is doing what is important to her when she wants to do it. She wants the freedom to choose when she wants to do something even though she is unable to do everything.
2. Feeling independent is a blessing from God she has chosen to accept and is living life to the fullest no matter what happens. It is unexplainable but good.

***Jake's Story***

Jake says that feeling independent “feels really good, just being able to get around by myself and do what I want.” He goes on to say that feeling independent “is something I try to keep control over, you know. People will try and take it away from me, but they can't because I'm the one who says what it is and how I want it.” Jake says that he knows there are things he'll never be able to do and that it's ok to get help when he needs it. He is very focused on living his life his way, no matter what may come his way or who may say he cannot do something. He says he “really appreciates people around him who want to help, but there's nothing like being alone”. He adds, “feeling independent is a feeling that I love. I guess I am my feelings, so I am independent”. He believes that feeling independent isn't what you cannot do, it's what you choose to do and then making a plan to get it done.”

**Themes: Participant's Language**

1. Feeling independent feels really good. It is being in control and doing what he wants. It is being able to do some things and not do other things. Feeling independent is what he says it is.
2. Feeling independent is a choice. It is choosing to do something and then making a plan to get it done. Feeling independent is something he loves. It is who he is.

***Claire's Story***

Claire says that feeling independent “makes me feel whole. I feel great—it feels great. I feel calm, relaxed, and peaceful.” She goes on to say, “Sometimes, in the past, I've done hiking in my wheelchair, and being out in nature, up in the mountains, where it really feels calm and peaceful, I feel like I'm part of that, like I just kind of blend with nature.” She adds, “I'm able to go wherever I want to go. I can go outside when I choose to; some people in nursing homes and prisons cannot go outside and get fresh air when they want to. But I can.” She was in an abusive relationship, but says she was still independent despite not being able to walk and living with someone who kept trying to control her. She says, “. . . even though I was living and feeling independent, he was living there too. I was finally able to put him out. I was living for myself and there was nobody there.” Claire said it was scary after he moved out because now she had to get help to get some things done. There were many times when she'd be in bed all day or up in her chair all night

because the health aids did not show up, or the nurse could not get to her until later. However, she says that, “I did not care though because I was still independent even though I could not control those things. I was still living my life my way. No matter what I can’t control, I always feel independent.”

**Themes: Participant’s Language**

1. Feeling independent is being whole. It is a great feeling that is calming, relaxing, and peaceful. It is being out in the fresh air and the mountains where she can blend with nature.
2. Feeling independent is a choice. It is doing what she wants to no matter what obstacles are in her way. Feeling independent is living for her self even though she cannot control everything.

***Richard’s Story***

Richard says that feeling independent is “physical security of knowing that I have the ability to get my needs taken care of . . . I feel very secure or more independent when I have a good attendant or a good temp”. He goes on to share that feeling independent is “a dichotomy between my professional life and my personal home life. Because as a judge you’re totally in charge, I have my staff here and they are always there to support the judge—whatever I need done, gets done. When I’m in the court room I run the court room, the attorneys are representing their clients and all that, but I make the decisions, and court starts when I get there, not when the attorneys get there, and we break when I say we are breaking.” He adds that “then I go home, I’m dependent on maybe a twenty-year old college student, who I just hired two weeks ago and I’m hoping will be there to take care of me, take care of the house, take care of the food and that kind of stuff, so it’s a really interesting dichotomy.” He goes on to say “there are times when I get frustrated and wish I could do more and I feel I have the ability and talent to do more, if I were more independent and had less restrictions.” He shares that “a feeling of independence is probably getting my physical needs taken care of, that is a baseline for me; if that’s taken care of and I don’t have to worry about that, then my disability becomes almost obsolete.” He also says “a feeling of independence is to be able to out in the backyard and enjoy that.” Richard adds, “for me independence is being able to focus on what’s important in my life and getting it done.”

**Themes: Participant’s Language**

1. Feeling independent is focusing on what is important in life and getting it done. It is sitting out in the back yard and enjoying it. Feeling independent is being frustrated and wishing I could do more. It is having the ability and talent to do more, if there were less restrictions.
2. Feeling independent is a dichotomy between your personal and professional life. It is feeling totally in charge at work and totally dependent at home.

**Table 1:** Story Themes for All Participants (See Next Page)

<b>Douglas</b>	<ul style="list-style-type: none"> <li>• Feeling independent is being complete like everyone else. It is running his life the way he feels right for him. It is making a choice to feel independent no matter what the circumstance. He says it is the way he wants to live. He just has to do it.</li> <li>• Feeling independent is taking risks at times. It is doing things for myself, even though I may get hurt. It is very important for him to keep going.</li> </ul>
<b>Loanna</b>	<ul style="list-style-type: none"> <li>• Feeling independent is doing what she wants, spending time with family, and living on her own. It is doing what is important to her when she wants to do it. She wants the freedom to choose when she wants to do something even though she is unable to do everything.</li> <li>• Feeling independent is a blessing from God she has chosen to accept and is living life to the fullest no matter what happens. It is unexplainable but good.</li> </ul>
<b>Jake</b>	<ul style="list-style-type: none"> <li>• Feeling independent feels really good. It is being in control and doing what he wants. It is being able to do some things and not do other things. Feeling independent is what he says it is.</li> <li>• Feeling independent is a choice. It is choosing to do something and then making a plan to get it done. Feeling independent is something he loves. It is who he is.</li> </ul>
<b>Claire</b>	<ul style="list-style-type: none"> <li>• Feeling independent is being whole. It is a great feeling that is calming, relaxing, and peaceful. It is being out in the fresh air and the mountains where she can blend with nature.</li> <li>• Feeling independent is a choice. It is doing what she wants to no matter what obstacles are in her way. Feeling independent is living for her self even though she cannot control everything.</li> </ul>
<b>Richard</b>	<ul style="list-style-type: none"> <li>• Feeling independent is focusing on what is important in life and getting it done. It is sitting out in the back yard and enjoying it. Feeling independent is being frustrated and wishing I could do more. It is having the ability and talent to do more, if there were less restrictions.</li> <li>• Feeling independent is a dichotomy between your personal and professional life. It is feeling totally in charge at work and totally dependent at home.</li> </ul>
<b>Mae</b>	<ul style="list-style-type: none"> <li>• Feeling independent is a great feeling that she needs to live. It is freedom and being free.</li> <li>• Feeling independent is staying strong to do the things she wants to do. It is taking a step forward and five steps back to do what she wants. It is never giving up. Feeling independent is being like everyone else because every one needs help with something.</li> </ul>
<b>Lila</b>	<ul style="list-style-type: none"> <li>• Feeling independent is being in charge and doing what she needs to do everyday, just like a normal person. It is coming and going as she pleases. It is not relying on others.</li> <li>• Feeling independent is a great feeling. Feeling independent gives her a spunk in how she lives. It is how she chooses to live; it is an attitude and not just actions.</li> </ul>
<b>William</b>	<ul style="list-style-type: none"> <li>• Feeling independent is moving on with my life, despite hard work or his accident. It is choosing, planning, and coordinating to do something he finds important. Feeling independent doing what he wants with the limitations he has.</li> <li>• Feeling independent is symbolized in the freedom his motorcycle gives him. It is being out in the open air. Feeling independent is spiritual. It is choosing to have hope and faith, and to love God.</li> </ul>

<b>Tyler</b>	<ul style="list-style-type: none"> <li>• Feeling independent is a choice. It is living life for the things that are important. Feeling independent is being there for family. It is an inner strength that some people have more close to the surface than others do.</li> <li>• Feeling independent is being normal. It is something all people share since every person can do some things and not others.</li> </ul>
<b>Andrew</b>	<ul style="list-style-type: none"> <li>• Feeling independent is very meaningful; it hurts when not able to be independent and is rough. It is often a feeling of wanting to give up. Feeling independent is stepping out of the bed, hoping tomorrow will be a better day, and it is weeping at night and having joy in the morning.</li> <li>• Feeling independent is more like being free, it does not mean that you do as you please, but it means you can do things that you want to do, by not having to depend on someone.</li> </ul>

### Discussion of Stories and Implications for Practice

Each person's story is reflective of a strong will to think and act as one chooses (Parse, 1998). It is a way the participants described their experience of feeling independent. Participants talked about things like "having the freedom to cook, clean and make myself look nice when I want to"; "whatever I need gets done"; "come and go as I see fit"; "doing things on my own"; "taking risks in living on my own"; and "doing what's important to me". This is how the participants experienced the freedom that comes with making choices for one's self and carrying them out. It is related to how they view and live independently no matter what may come their way. The participants discussed how they had certain "techniques" and "ways" of doing certain things that work best for them. They also discussed how they are also trying to figure out new ways and better ways to do what they need now and in the future.

Implications for nursing practice for persons living in a strong willed way focuses on listening to persons to develop a life and care plan that is meaningful and important. This means that the nurse and person can focus on useful and meaningful health patterns that support the person in continuing to live and feel independent. The nurse offers information and direction when the person with SCI requests it, and it is done under the person's direction. So, a person may want to focus on health patterns such as self-perception, coping-stress tolerance, role-relationship, or activity-exercise. At the functional health pattern level, the nurse with the person could focus on and discuss anxiety and fear, family coping and enhanced coping, role function and family processes, or situational adaptive capacity and physical mobility

Another pattern within the stories was living with the limitations and opportunities that are present everyday for persons with SCI. It is another way the participants talked about feeling independent. Participants talked about things like: "At work, I'm totally in charge and at home, I need help with almost everything"; "sometimes I feel I can do anything, while at the same time I have to be practical about what I do"; "doing things on my own is what keeps me going, but I also know that no matter what I do, I can't do them like everyone else"; and "I need help with lots of things, but I say what it is because I like to do lots by myself".

This pattern in the stories reflects how the participants experienced the self-reliance that comes with being limited by certain physical traits, while being free to choose what they believe is important to them despite challenges (Parse, 1998). The participants discussed not being able to get around as they always wanted, they discussed what it would be like to have to live with a helper, while they were currently living alone, and they talked about fighting, laughing, and struggling to get through and press on. The participants discussed how they know that they have limitations, but that they choose to focus on the autonomy and strengths they possess.

Implications for nursing practice for persons living with the limitations and opportunities with SCI focuses on bearing witness to how persons live the limitations and opportunities in every choice and physical goal and movement. It is exploring with persons the whole context of a situation, instead of what they "cannot do" or what the nurse believes would "be best" for them. Persons with SCI usually know what they are up against and how to accomplish a task with their own unique abilities. The nurse may ask such questions as: "How have you done this before?"; "How did that work out?"; "How would you do that differently next time?"; "What do you like to do?"; "What challenges do you face when you try that?". In

this way, the nurse creates an environment where persons guide the way activities can be accomplished within their view of what they can and cannot do. The activities are based on what is important to the person, and not on what the nurse has “assessed” to be true. Important health patterns may include cognitive – perceptual pattern and health perception – health management. At the functional health pattern level, the person with the nurse could focus on and discuss decisional conflict, sensory perception, unilateral neglect, energy field disturbance, ineffective protection, or environmental interpretation.

The third pattern within the stories was a focus on living what is important and cherished. It is living with loved ones, prized ideas and goals, and activities that persons relish in everyday living. It is another way the participants talked about *feeling independent*. Participants spoke about things like: “traveling with my family”; “making myself look pretty”; “going to the grocery store”; “cooking meals for my family in my kitchen”; “sitting on my motorcycle just for a couple of minutes”. This pattern was how the participants experienced living what is important to them with a constant goal and plan to support what they value. It is how they live independently with their own goals to achieve and maintain what they love and like to do. The descriptions by the participants accounts of being involved with, yet feeling separated from others and activities that were important to them. Participants talked about things like: “getting what I need done”; “always pushing myself to do what I want”; “living on my own and loving those who love me”; “being with my niece as she picked out a new prom dress”; and “living with my wife and son at home”.

Implications for nursing practice for the pattern of living what is important and cherished focuses on what persons with SCI value and hold as important over the years and from moment-to-moment. The nurse listens to persons explore what they hold dear for now and the future. It is exploring the possibilities the person deems as important knowing that with what is chosen brings new possibilities that also brings the person to letting go of other ways of living. The person and nurse create what can be according to what the person views as important. The nurse may ask such questions as: “Tell me what you enjoy doing each day”; “What do you like about doing that”; “What are your plans to be able to continue to do that”; or “Tell me more about what’s important to you”. The nurse is with people as they live with change that they value and holds importance for them. By exploring options in the presence of the nurse, the person moves from what is to what could be. Persons may focus on health patterns such as coping – stress tolerance patterns and self-perception – self-concept patterns. At the functional health pattern level, the person with the nurse could focus on and discuss individual coping, family coping, adjustment, personal identity, self-concept, hope, and body image.

### Summary

The purpose of this paper was to present five selected stories of persons’ experiences of feeling independent. These feeling independent stories had themes of (a) a strong will to think and act as one chooses, (b) living with limitations and opportunities, and (c) living what is important and cherished. Stories about the lived experience of feeling independent have the potential to add to a general understanding about how persons with a SCI live and feeling independent, and contribute to knowledge unique to nursing. These stories may be useful for nurses and other health care professionals who are concerned with the lived experience of health for persons living with a SCI.

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## Feature Article

### Ziconotide: A Non-Opioid Alternative for Chronic Neuropathic Pain, A Case Report

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#### Abstract

**Background:** Chronic neuropathic pain is a serious problem for patients, caregivers, providers, and the entire health care system. Given the high costs associated with managing chronic neuropathic pain, and the fear of contributing to narcotic dependence, providers are looking for an effective analgesic that has an acceptable side effect profile, and can be administered on a long-term basis without addiction. This is a case report about a hospitalized patient with severe chronic neuropathic pain, who agreed to a trial of intrathecal Ziconotide in combination with low dose morphine, to achieve better pain management without side effects.

**Case presentation:** PS, a 67-year-old male paraplegic patient, hospitalized for the treatment of pressure ulcers and osteomyelitis, developed an exacerbation of his chronic neuropathic pain related to a history of L-2 radiculopathy and spinal arachnoiditis. He was treated with a combination of drugs including intrathecal and systemic morphine, gabapentin, pregabalin, and clonidine. Twice, he developed granulomas at the tip of the intrathecal catheter, which obstructed the flow of medication through the catheter and interrupted pump delivery of the morphine. The granulomas were likely related to the high dose of morphine being delivered through the pump. The patient agreed to a trial of intrathecal ziconotide in combination with a lower dose of morphine, and 6 months later, is demonstrating improved pain control and increased alertness without side effects.

**Conclusion:** Ziconotide, in combination with low dose morphine, was shown to be effective in managing chronic pain and improving quality of life without significant side effects.

**Keywords:** ziconotide, chronic neuropathic pain, spinal arachnoiditis

#### Background

Chronic neuropathic pain is a serious and problematic issue for patients, caregivers, providers, and the entire health care system. The amount of suffering in patients with neuropathic pain is due to its chronicity and the inability to provide effective pain relief without significant and unacceptable side effects. There are many definitions for neuropathic pain, but the International Association for the Study of Pain defines neuropathic pain as “pain initiated or caused by a primary lesion or dysfunction of the nervous system” (as cited in Cavenagh, 2006). Alterations in the processing of sensory signals from the affected body region can induce spontaneous pain with abnormal pain sensations of varying characteristics. In the 21st century, the most common pain problems in the Western world are chronic low-back pain and pain arising from failed back surgery syndrome. In some of these patients, there is a neuropathic pain component present, especially when there is a radiological (post-operative fibrosis, arachnoiditis) or electrophysiological evidence of radiculopathy, or when previous surgery appears to have entrapped nerve roots in scar tissue (Vissers, 2006). Chronic neuropathic pain can persist for months or years beyond the originating cause. There are multiple origins of neuropathic pain including peripheral nerve trauma, other mononeuropathies such as diabetic neuropathy and connective tissue disease, polyneuropathies related to diabetes, alcoholism and other causes, root/dorsal root ganglion such as post herpetic neuralgia and arachnoiditis, and central sensorial deficits related to infectious, chemical or ischemic insults (Vissers, March 2006).

#### Case Presentation

PS is a 67-year-old male with a 40-year history of chronic low back pain and multiple laminectomy surgeries in the 70s, 80s and 90s. An L2–3 disc herniation resulted in L2 paraplegia in 1995. Over the last 12 years, his pain treatments have included epidural steroids, oral medications, transeletrical neurostimulation (TENS), physical therapy, and electrode spinal cord stimulation. He has described his back and bilateral leg pain as being “achy” and “shooting, stabbing” pains and his pain scores have been documented anywhere from 5 to 10. He was diagnosed with L2 radiculopathy in 2003, and was started on intrathecal morphine for pain control. Intrathecal opioid therapy through implantable drug delivery systems (IDDS)

has been an option for the treatment of chronic pain since the early 1980s (Turner, 2007). The advantage of IDDS over other modes of opioid delivery includes using a lower dose of medication for pain relief resulting in less severe side effects. The programmable system consists of a pump implanted into an abdominal subcutaneous pocket, a catheter inserted into the intrathecal space of the spine and tunneled under the skin, and an external programmer that controls the infusion rate. The pump requires filling at regular intervals via subcutaneous port injections. The most commonly reported pharmacological side effects with opioid use and an IDDS include nausea/vomiting, urinary retention, and pruritus. Hardware complications include catheter migration or dislodgement, catheter obstruction or occlusion, and mechanical failure of the pump or battery. There are also reports of intrathecal granulomas that form at the tip of the intrathecal catheter, some large enough to cause spinal cord compression and neurologic dysfunction (Turner, 2007). Despite the usefulness of intrathecal (IT) morphine, there is a need for more effective alternatives for pain management when opioids are not effective or when complications limit their use.

During hospitalization in 2007 for treatment of pressure ulcers with osteomyelitis, PS developed an exacerbation of his low back pain most likely related to arachnoiditis, a complication of multiple surgeries and radiographic myelograms. Spinal arachnoiditis is caused by an inflammatory process of the arachnoid membrane resulting from many possible causes, including myelograms with oil-based radiographic contrast agents and multiple back surgeries. It is characterized by inflammation and scarring of the arachnoid membrane of the spinal cord. Three membranes, arachnoid, the dura, and the pia cover, protect and provide cushion for the spinal cord and spinal nerve roots. Damage occurs when an inflammatory response triggers fibrinous exudates, which results in the nerve roots adhering to themselves and/or the thecal sac. The arachnoid membrane is extremely thin and fragile and does not have innervations or vascularization which makes the healing process difficult. The constant flow of cerebrospinal fluid also interferes with the healing process because it washes away the phagocytes and enzymes that prevent the formation of the scar tissue precipitated by inflammation. Diagnosis is based on symptoms and magnetic resonance imaging. Arachnoiditis symptoms are sometimes difficult to distinguish from other types of neural compressive diseases because many of the symptoms are similar and the disease onset can be months to years from the initial injury. Some of the common symptoms include burning pain in the low back radiating down the legs; pain that persists even at rest; urinary urgency, frequency and incontinence; spasms of the back and legs; burning in the ankles and feet; skin rashes and itching; loss of sensation below the affected area; partial or complete paralysis of the lower extremities; and neurologic deficits (Wright, 2003). The prognosis is poor for patients with spinal arachnoiditis because there is no cure and surgical intervention may provide only temporary relief, with scarring returning after a short period of time. These patients are at risk for depression, suicide, and drug and alcohol dependence as a result of enduring pain for years at a time and the disabilities associated with the disease. It is an incurable disease that can cause minor to severe symptoms and treatment is difficult because complete pain relief and the alleviation of symptoms are sometimes impossible.

PS was treated with a combination of drugs for pain management including intrathecal morphine, initially delivered at a rate of 2.0 mg/24 hr, but requiring titration up to 5.0 mg/24 hrs for adequate pain control. Intrathecal morphine is accepted as the gold standard analgesic and is an appropriate first-line choice in most patients requiring IT analgesia therapy. A number of poorly opioid-responsive pain states, however, exist. Although most side effects of IT morphine are of mild or moderate severity and are amenable to symptomatic treatment or dose adjustment, endocrine effects of long-term IT morphine administration may include a variety of serious effects. Additionally, tolerance may lead to the use of higher drug concentrations in attempts to maintain pump refill intervals and preserve the life span of implanted IT pumps. High doses or concentrations of IT opioids may result in hyperalgesia or the formation of inflammatory masses at the IT catheter tip (granulomas) with potentially severe neurologic results (Ellis, 2008).

The IT morphine delivered at a rate of 5.0 mg/24 hrs was given in combination with IT clonidine delivered at a rate of 253 mcg/24 hrs. In addition, systemic gabapentin, pregabalin, desipramine, venlafaxine, and oxycodone with acetaminophen was given to maximize pain control. Subsequently, the patient developed a granuloma at the tip of the intrathecal catheter which obstructed delivery of the medication through the pump and required the pump to be discontinued for a period of time to allow the granuloma to dissolve. During this time he was placed on IV systemic morphine through a patient

controlled analgesia (PCA) pump. He required high doses of PCA for pain control and, although he did achieve moderate pain control, he was unhappy about the heavy sedation that came along with it. A few weeks later, after the granuloma had resolved and the IT catheter was patent again, the morphine was restarted and the PCA morphine was discontinued. Less than 3 weeks later, the patient again developed a granuloma at the tip of the catheter and the IT morphine was discontinued requiring the PCA morphine to be resumed. Due to the high risk for this patient to develop granulomas at the tip of the intrathecal catheter, the interventional pain consultant recommended he be placed on a trial of ziconotide, a potent, non-opioid analgesic being used for treating chronic neuropathic pain.

Ziconotide is a synthetic version of a peptide isolated from the venom of the marine snail, *Conus Magus*, a predatory sea creature that attacks its prey with harpoon-like tenacles loaded with a paralytic poison (Stix, 2005). It is the first in a new class of non-opioid analgesics known as N-type calcium blockers which target pre-synaptic calcium channels on nerves that ordinarily transmit pain signal. Ziconotide blocks the N-type voltage-sensitive calcium channels and prevents release of the excitatory amino acid, glutamate, from the presynaptic terminal, thereby reducing the amount of stimulation at the dorsal horn neurons. The dorsal horn of the spinal cord is a critical integration site involved in processing signals resulting from a variety of noxious stimuli including thermal, mechanical, and inflammatory. Evidence suggests that the N-type channels targeted by intrathecal ziconotide are not directly implicated in most acute thermal pain sensation but rather play a more significant role in inflammatory and chronic neuropathic conditions (Snutch, 2005). Furthermore, ziconotide does not interact with opioid receptors, so it will not prevent withdrawal symptoms in patients being weaned from opioids. This patient, PS, unhappy with the side effects of his current pain regimen, agreed to try intrathecal ziconotide for pain management.

The patient was started on intrathecal ziconotide 0.5 mcg/24 hrs in combination with 0.5 mg/24 hrs IT morphine. Although ziconotide was initially approved by the FDA to be used in monotherapy, many physicians are using it with success in combination with intrathecal opioids and non-opioids. Following the initial delivery dose of 0.5 mcg/24 hrs for this patient, the ziconotide was increased 0.5 mcg per week during the first 3 weeks. The patient experienced no side effects to the drug and, as the ziconotide was titrated up, the morphine was reduced. Two months after starting the “snail juice”, a name the patient affectionately gave to ziconotide, he rated his pain level at a 4, was sitting up in his wheelchair, and was more alert. He also demonstrated increased mobility and was able to be return home and be followed in the outpatient clinic. Six months following initiation of IT ziconotide, this patient is currently receiving 4.50 mcg/24 hrs and 1.5 mg/24 hrs of IT morphine and continues to report a pain level of 4 with no reported side effects.

## Discussion

The use of ziconotide as an alternative for patients who are refractory to other pain therapies is associated with a number of challenges. This includes ensuring adequate pain relief for patients as they are being weaned off opiates, and controlling adverse side effects and opioid withdrawal symptoms. The FDA approval of ziconotide in 2004 was based on three clinical trials with patients from a variety of populations, including cancer pain and neuropathic pain (Thompson, Dunbar & Laye, 2006). The most commonly reported central nervous system side effect with intrathecal ziconotide during clinical trials were dizziness, confusion, nystagmus, ataxia, abnormal gait, somnolence, impaired speech, and abnormal thought processes (Staats, 2004). The ziconotide safety profile warns that severe psychiatric symptoms and neurological impairment may occur during treatment with this drug. Patients with pre-treatment psychiatric disorders may be at an increased risk, and ziconotide may cause or worsen depression with the risk of suicide in susceptible patients. The efficacy and safety of ziconotide have been studied in three randomized, double-blind, placebo-controlled trials. In the first two trials, 111 patients with refractory cancer-related or acquired immunodeficiency syndrome-related pain and 257 patients with inadequately managed nonmalignant pain were continuously infused with IT ziconotide or placebo for 5 to 6 days (Rauck, 2006; Staats, 2004). Ziconotide was associated with significant pain relief, as measured by the percent reduction in Visual Analog Scale of Pain Intensity (VASPI) scores from baseline, in patients with malignant pain (53%, ziconotide, versus 18%, placebo;  $p < 0.001$ ) and nonmalignant pain (31%, ziconotide versus 0%, placebo;  $p < 0.001$ ). Some of the adverse events such as dizziness and nystagmus were observed with a  $\geq 15\%$  difference in incidence between the ziconotide and placebo groups. The third trial included 220 patients and used a lower-dose, slower-titration regimen than that used in the previous studies.

After 3 weeks of treatment, mean percentage improvement in VASPI score from baseline was significantly greater in the ziconotide-treated group (14.7%) than in the placebo group (7.2%,  $p=0.0360$ ) (Wallace, 2006). Although the degree of pain relief in this study was less than that seen in the previous trials, the low-dose, slow-titration regimen resulted in a lower incidence of serious adverse events and a smaller proportion of discontinuations for adverse events than did the higher-dose, faster-titration regimen used in the previous studies. In a study of the safety and tolerability of ziconotide in an open-label long-term trial, 119 patients received ziconotide for  $\geq 360$  days; total exposure was 350.9 patient years. Median duration of ziconotide therapy was 67.5 days (range, 1.2-1,215.5 days); mean dose at last infusion was 8.4 (range, 0.048-240.0). Median VASPI scores at baseline, month 1, and the last available observation up to month 2 were 76 mm (range 4-100 mm), 68 mm (range 0-100 mm), and 73 mm (range 0-100 mm), respectively. Most of the patients (99.7%) experienced mild (43.5%) or moderate (42.3%) adverse events with 58.6% of adverse events considered unrelated to ziconotide. The most commonly reported adverse events ( $\geq 25\%$  of patients) included nausea, dizziness, headache, confusion, pain, somnolence, and memory impairment. No drug related deaths, IT granulomas, or permanent adverse sequelae occurred with ziconotide therapy (Wallace, 2008).

While this case report demonstrates that ziconotide can be successful and efficacious with a combination of intrathecal morphine in a carefully selected established pump patient, this practice has not been studied in blinded, placebo-controlled trials. This treatment decision is associated with a number of challenges, including providing adequate analgesia to patients as they are weaned from intrathecal opioids, controlling adverse medication effects, and managing potential opioid withdrawal symptoms. In a Phase II multicenter trial assessing the safety and efficacy of adding intrathecal ziconotide to intrathecal morphine, 26 patients were included in a study that included a 5-week titration phase and an extension phase. During the titration period, intrathecal morphine dosing remained constant, while the ziconotide therapy began at 0.6 and was increased to a maximum of 7.2. During the extension phase, ziconotide and intrathecal morphine dosing were adjusted at the investigator's discretion. The data showed that of the 26 patients, fewer than 15% reported drug-related treatment-emergent adverse events, and side effects were generally mild or moderate. The mean percentage improvement in visual analog scale pain intensity scores was 14.5% (95% confidence interval, -9.4% to 38.5%) from baseline to week 5 and varied during the extension phase (Wallace, 2006).

### Conclusion

Neuropathic pain following a spinal cord injury is a challenge for every caregiver. Some of the existing treatments for chronic neuropathic pain deliver inadequate pain relief, unacceptable side effects, or both. There is still a need for an effective analgesic with an acceptable side effect profile that can be administered on a long-term basis. Opioids such as morphine have shown to be effective in treating chronic pain, but high doses are often required which narrows the therapeutic index. Neuropathic pain is often maintained by activity in peripheral primary sensory neurons, making modulation of this activity attractive for drug developers. Ziconotide has shown to be effective in combination with IT morphine in this unusual case of chronic pain, but there continues to be a great need for further research into pathophysiological mechanisms of the induction and maintenance of neuropathic pain, and the use of biological and other agents with fewer side effects in an effort to achieve effective analgesia for these patients.

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## Leadership Circle

### The Road Back to SCI: From Informatics Nurse to Nurse Manager Via a Clinical Nurse Leader Residency

*Heather N. Weckman, MS, BSN, RN-BC, CNL*



As I reflect on this Memorial Day, I am reminded of the patients with spinal cord injuries and disorders (SCI/D) we serve at the James A. Haley Veterans' Hospital in Tampa, Florida. Many of these veterans' have borne the battle for our country.

When I left SCI in February of 2001, it was to serve nurses as the Clinical Nursing Informatics Coordinator and to merge my former career of bank data processing with my clinical nursing experience. While I was proud of becoming the first ANCC certified Informatics Nurse at the Tampa VA, I never forgot the passion toward my clinical setting in SCI. Even after I took my new role, I presented at AASCIN on "Using Informatics to Empower SCI Nurses" when clinical documentation systems were emerging. I remained a member of AASCIN until I was unable to be directly involved with SCI patient care, although I continued to serve SCI nurses for their computer access and

documentation needs.

I continued my education and received my BSN in May of 2001 and began work on my graduate degree in Nursing Informatics at the University of South Florida. As challenges at work arose, I was unable to continue graduate school at the pace I had originally intended. I learned of a new graduate program which introduced the concept of a Clinical Nurse Leader (CNL). This program was endorsed by our Nurse Executive. The CNL is the first new nursing role introduced in 35 years. Through the partnership between the American Association of Colleges of Nursing (AACN) and the Department of Veterans Affairs (VA) that began in 2003, the VA's Office of Nursing Service has played a pivotal role in implementation of the Clinical Nurse Leader role. A goal is application of the CNL as an integral component of the patient care model at every VA medical facility by 2016. After exploring the CNL curriculum at the University of South Florida (USF), I decided to transfer from Nursing Informatics to the CNL program. This allowed me to practice at the unit level during my residency by making small cycles of change to impact the clinical care of patients. Additionally, it augmented my collateral role of Bar Code Medication Administration Coordinator. The clinical component consisted of a minimum of 300 hours spent in residency, although I spent many more hours during my initial evaluation of the unit. I became the first CNL student to choose SCI as my clinical setting and was the first Informatics Nurse to pursue this unique role. I obtained permission from USF faculty and began my unit assessment using the Essentials of Magnetism. As we are the first Magnet VA hospital, I valued the opportunity to discover on an SCI unit the essential elements that allowed our hospital to achieve and maintain Magnet status.

As I studied performance measures and worked with staff to improve processes at the point of care, I realized I could affect change at this level and share "best practices" with other units. This also supported our organization's Transforming Care at the Bedside (TCAB) initiative. I was already a member of the SCI TCAB Interdisciplinary Team serving as an alternate Informatics Nurse for SCI cycles of improvement. I also called a former quadriplegic patient and asked if he would become the SCI TCAB Patient Representative. He agreed and is now an active member of the team.

During my first CNL semester, my assignments reconnected me to the interdisciplinary team in SCI (social worker, pharmacist, providers, dietician, psychologist, nurse manager, recreation therapy, and staff nurse). Many of the providers were the same but there were others that had no recollection of my SCI expertise and background. I also needed to renew my contacts with the staff in a role other than staff nurse or Clinical Nursing Informatics Coordinator.

The leadership residency immersion experience included elements of self-evaluation that align with our facility's high performance development model. I planned education for all three shifts on handheld pocket personal computers used for medication administration and vitals entry (and soon for all specimen collection) to improve medication administration outcomes at the unit level as identified by pre and post Bar Code Medication Administration (BCMA) surveys in November 2007 and March 2008.

With guidance from my preceptor, an SCI Nurse Manager, I was able to view her role from a unique perspective and discover yet another area where I might continue to expand my skills and knowledge. The CNL experience led me back to the SCI unit, bedside clinicians and patients. Some of the ventilator-dependent patients I originally cared for are still in our inpatient setting and may be eligible to transfer to my new long-term care SCI Ventilator Unit once it officially opens. It is gratifying to know the patients remember me as a staff nurse years ago and are eager to transfer to my long-term care vent unit.

Using my unique combination of experience in SCI, Nursing Informatics and newly acquired leadership skills from the CNL program combined with the guidance of my preceptor and clinical nurse leader faculty facilitator, I was able to study process issues and explore the possibility of improving patient medication delivery in an isolation setting.

My journey to the Nurse Manager role would not have been possible without my recent clinical experiences in SCI. By initiating, managing, and evaluating projects related to patient safety, I may have helped improve the patient/family satisfaction scores by becoming a valued member of the team and modeling the CNL role. By establishing and maintaining a high level of collegiality, I was able to serve as a liaison between physicians and staff. While my former role in Informatics required me to effectively manage human, environmental, and material resources, I am looking forward to the challenge of learning even more to become an effective Nurse Manager. I graduated in December of 2007 and became certified as a CNL on May 19, 2008. This credential will allow me to serve as a CNL resource in SCI as we explore implementation of this new role.

I can now turn my attention to my new role of Nurse Manager on a brand new SCI long-term care unit. I am thrilled at the prospect of nurturing nurses in the unique SCI long-term care setting. We will have the opportunity to serve our “residents” in a beautiful, home-like setting.

I still remember my first day as an SCI Ventilator nurse and how uncertain I was of my newly acquired skills. I am confident I can inspire nurses to dedicate themselves as I have to our SCI residents in a supportive environment. I am glad to be “home” where my clinical passion lies.

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## Innovation Station

### Helping Parents Cope during Recovery of the Adolescent Spinal Cord Injured Patient

Christy Stackhouse, RN, CRRN



#### Introduction

Working with patients with spinal cord injuries (SCI) can be very challenging for even the most skilled rehabilitation nurse. When dealing with adolescent patients, clinicians may find that they have two patients instead of one, the other person being the parent. When adolescent patients are admitted to the hospital their parents are usually right by their side, and it is often the mothers who try to shield and protect them as much as they can. One often encounters palpable feelings of sheer agony in the mothers, and the look of despair on their faces, when they first come in with their child, may stay with one for a very long time.

#### The Stages of Grieving

When adolescents with SCI are admitted to the rehabilitation unit they are very likely to be going through the process of grieving their new injury. The stages of grief are inclined to mirror those described by Elisabeth Kubler-Ross. Kubler-Ross, in her landmark publication *“On Death and Dying,”* identified five distinct stages of grief that a person experiences after any catastrophic event; these are denial, anger, bargaining, depression, and finally acceptance. SCI can certainly be classified as a catastrophic event, and the loss may be just as great for the parent as it is for the patient who has been injured. Even though they are not dealing with death, they are dealing with a huge sense of loss; there is loss of control, loss of independence, loss of normal bodily function, and perhaps loss of a whole way of life.

Many believe that a person cannot heal until they have experienced these five stages. The nurse, however, should accept that every person goes through the stages at different paces and progression cannot be forced; in fact, the patient may not go through all five stages, and a person may become stuck in one stage for a longer period. The first step for the patient with SCI will perhaps be denial that the injury happened or believing that it will go away. Anger at the fact that this could have happened to them may soon follow. This is quite often projected on the persons closest to them and those who take care of them; quite often nursing staff and parents are the ones who bear the brunt of that anger. Despair and sadness may then set in, and may be manifested in symptoms of depression and preoccupation with how much their life has been disrupted. Hope soon follows as they start to work hard on their therapeutic rehabilitation program and possibly the dream of someday walking. Finally, acceptance of their injury is possible as grieving comes to an end and they look toward the future.

#### The Nurse’s Experience

I have witnessed throughout my years of being an adolescent SCI nurse that parents often go through these stages with their child. To feel pain after a loss such as this is quite normal. The once fiercely independent adolescent may revert back to a child-like state and the parent then feels compelled to be always present to protect and dote on the “child”.

During the first few days of their inpatient stay, the parent may experience a similar sense of denial and anger before they accept that their child is out of immediate danger and start to look ahead to their life using a wheelchair. Often the mother/father may reflect the same feelings as the patient and state that “my child WILL walk out of here”. One fear that is frequently voiced is that of who will take care of their child when they are gone, especially if there is no other family support.

At our facility, the patient and family members have a psychiatrist and counselor available for emotional counseling and support, and this helps a great deal with the healing process. As a nurse, however, I see my role as also supporting the patient and parent to deal with their sense of overwhelming grief. By listening and sharing experiences, I try to bring the adolescent patients out of their sad cocoon, as well as help the parents deal with the myriad of emotions. Sometimes I will pull a parent aside and give them a reassuring hug to let them know things will get better, while sustaining the reality of the experience

and without giving false hope. Another coping mechanism that I have found helpful for these parents is the support of other parents who have sons or daughters with SCI. Introducing a new parent to one who has been at the center for a while helps them both. These families gain a lot from each other as they all have experienced tremendous loss. They seek each other out for refuge and are able to open up their feelings to each other without their children knowing of their fears and despair. A strong support network is sometimes born of these encounters and often carried on for many years. The facility also has a peer counselor who puts current patients in touch with others who have had similar injuries.

### Case History

Jo is a 15-year-old football player who was injured and admitted to the center. His mother Gina came in with him. Jo had sustained an injury at the C-5 level and was still on a ventilator. For the first few weeks, Gina would not leave Jo's side, not even to get a drink of water. It was in these few weeks that I saw constant fear and despair on Gina's face. She expressed that she was a woman of strong faith and was not sure why this was happening to her son. Jo went through many challenges during his inpatient stay. Vent weaning was trying, he had to receive several blood transfusions, and he also contracted a number of urinary tract infections; it seemed as if he would never get better. Mother and son both had frequent and regular sessions with the assigned counselor and nursing would communicate to the therapist if either of them demonstrated the need for more intense intervention. Many times I spoke with Gina one-on-one while Jo was in therapy and she would share some amazing stories about her young son. He had done well in school, was an amazing athlete, and did youth ministry for their church. I reassured her that though he might have to adapt and do things differently, they could certainly find avenues to continue with his interests. The recreation therapist worked to identify and introduce him to activities that suited him.

Gina was also going through a divorce after 17 years of marriage. She went through many challenges with her son's injury, but always kept a positive face around him. When Jo finally turned the corner about 1 month after his admission, they both seemed to be happier and more accepting of his injury.

As Jo improved he began to do a lot more on his own and became as independent as he could be for his level of injury. He is now back at home and he and Gina are both coping well. They continue to hope for a cure that may someday come, but in the meantime have learned to deal with his injury. I hear from them from time to time and I am always impressed with their hope and perseverance.

### Conclusion

It is perhaps impossible for a nurse to imagine the devastation that parents feel as they watch their child lie helpless in a hospital bed. This is probably one of the most devastating events that a family could experience and the strength that they often demonstrate is amazing. Watching and helping families pull together can be one of the more rewarding parts of our job; instilling hope while guiding them through this difficult time is part of what I see as the role of the rehabilitation nurse.

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## Research Corner

### The Pilot Study

Matthew Sorenson, PhD, RN



Conducting a research study is a complex process often fraught with problems. One of the best ways to minimize problems and issues is conduction of a pilot study. Pilot studies are probably best viewed as a stepped down version of a larger study. This by no means diminishes their importance. A pilot study can help determine the feasibility of a larger research study, provide information regarding the issues and problems that could be encountered during a larger project, and help in instrument development by providing information on reliability and validity.

#### Advantages of a Pilot Study

Conducting a pilot study allows the researcher to get a feel for the issues and problems that may arise. It is generally run with fewer subjects and for a shorter time frame than the intended larger study. This allows for identification of problems and issues that will arise during the course of a larger study. It also helps determine whether the planned procedures are adequate in completing the proposed study. A pilot study can aid in determining whether resource issues exist such as: how much time is being spent with each subject? How many subjects are available and how many of them are willing to participate? What efforts need to be made in terms of recruitment, and what kind of attrition is expected? The use of medical records in a pilot study could help determine if the information present is adequate in answering the research questions prior to embarking on a larger study.

A pilot study also allows the investigator to gather initial data to establish proof of the concept or data supporting instrument reliability or validity. In terms of instrument development, the pilot study provides a chance to investigate the usability of the tool and the data that it provides. A pilot study provides information regarding the time that is taken to complete the tool and the readability of the instrument. As well, a pilot study allows for identification of items that are not being completed in the intended manner or that subjects are having difficulty with. One can also determine if the data provided by the tool fully represents the intended construct, or answers the research question. The derived data can also be used in calculating a power analysis to determine the appropriate sample size necessary for a fuller exploration of the concept.

#### Funding for Pilot Studies

Several private and federal funding mechanisms provide monies for pilot studies. In general, these mechanisms may not provide salary support but they do provide money for collection of data. Two examples would be the National Institutes of Health R03 or R21 mechanisms which provide limited support for the collection of pilot data or the conduct of studies with a novel research question. The R03 (Small Research Grant Program) provides two years of funding for the collection of data, with no salary support. The program intent is a brief limited project in terms of time and scope. The hope is that generated data may lead to a larger, more developed project appropriate for a R01 level research grant. The R21 mechanism (Exploratory/Developmental Research Grant Program) is intended to fund novel, high risk studies that may be using less traditional or more experimental research approaches.

#### Limitations of a Pilot Study

All research studies have limitations and the same holds true of pilot studies. Perhaps it may be more appropriately said that the limitations lie within what the investigator chooses to do with the data, rather than the study itself. These projects often have small numbers of subjects, and one must be careful in drawing firm conclusions based on such data. Not all study related issues may be revealed by the pilot study since it is often conducted in a short period of time and using a smaller number of subjects. If an intervention has been done, it then needs to be decided whether or not the subjects from a pilot study will be included in the analysis of a larger project. If the conduct of the pilot study reveals the need to include a different instrument or modify the intervention, then the data sets may not be truly compatible. The investigator needs to think through the ramifications of all decisions made using such data.

### **Conclusion**

The pilot study can provide valuable information necessary to the conduct of larger or future investigations. The preparation of a pilot study, however, is no small feat. The investigator still needs to conduct a thorough review of the literature and ensure that the methodology and design are sound. Also, in order to actually collect data, the approval of an institutional review board will be necessary. Yet, the pilot project or study provides a chance to walk through procedures upfront and can be helpful in avoiding study related pitfalls. While the general belief may be that such material does not see the light of publication, the articles by Wardell (2006) and Warms et al., (2004) prove that there is indeed a place for such efforts.

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## **Aging with SCI** **SCI Caregivers: An Important Part of the Picture**

*Angela Starkweather, PhD, ACNP, CCRN, CNRN*



Caring for the caregiver is a well established concept for health care providers managing patients with cancer, stroke, and dementia. It has not been as widely applied, however, for those with spinal cord injury (SCI). With more than 40% of people with SCI fitting within the older adult category, many of these patients will have an older adult spouse or family member on whom they depend for care. As health care professionals, we are in a prime position to assess the support system of the person with SCI; prepare, identify risk factors, and provide resources for SCI caregivers; and strengthen the social support network of the individual and family.

The Caregiver Health Effects Study, conducted by Schulz and Beach (1999), compared the rate of mortality among older adult caregivers and non-caregivers. This study collected data over a 4.5 year period among 392 caregivers and 427 non-caregivers age 66 to 96 years old who were living with their spouses. The results demonstrated that those who were providing care and experiencing caregiver strain had mortality risks that were 63% higher than non-caregivers, and that caregivers who reported mental or emotional strain had a higher rate of mortality compared to their non-caregiving counterparts. Since then, there has been a focus in research on the caregiving role to gain more insight into the positive and negative outcomes associated with caregiving, interventions that may decrease the negative consequences associated with caregiving, and the resources that can improve the quality of life and health of the caregiver.

Assessment of the person with SCI should include his/her assistance needs and equipment and resources required to help them achieve maximal functioning. Consideration of the individual(s) who provide care, and resources that can optimize their ability to continue caregiving is vital. Although some research has shown that older adult caregivers are just as likely to seek and adhere to preventative health practices as non-caregivers, encouraging them to take the time to take care of themselves can often lead to a more open discussion concerning their needs (Matthews, Dunbar-Jacob, Sereika, Schulz, & McDowell, 2004). If family members are the primary caregivers, an assessment of the family dynamics can help to illuminate potential or actual risk factors associated with the caregiving role (Yajima et al., 2007). Offering respite care for caregivers, either through in-home care, daycare, or through other means, can also be empowering for the caregiver. Mason et al. (2007) found that among older adults, daycare respite was associated with greater satisfaction, albeit higher costs, than other types of respite. Options for respite care are usually dependent upon several factors, such as financial resources, insurance coverage, and/or community resources. At times, creative solutions may need to be sought in order to find appropriate respite solutions.

Preventative and supportive care for the caregiver is an important area for individuals with SCI and their families. Not only can this improve the care and outcomes of the patient, but it can strengthen the family and/or social support network. There are many resources freely available to caregivers. Resources may include information on caregiving, support groups, or how to access financial assistance. There are several general caregiving resources Web sites on the internet, including:

Caregiver.com

<http://www.caregiver.com/>

Caregiver Resource Network

<http://www.caregiverresource.net/>

The National Family Caregivers Association

[http://www.nfcares.org/about\\_nfca/](http://www.nfcares.org/about_nfca/)

The National Family Caregiver Support Program

<http://www.aoa.gov/prof/oaoprogram/caregiver/caregiver.asp>

With a growing population of older adults with SCI who will require more assistance as they age, identifying ways to support the caregiver should become a part of routine practice. As noted by Kim and Schulz (2008), the development of social policy and resources for SCI caregivers specifically needs to be addressed. SCI nurses are in a key role to provide a holistic, family-centered approach to the older adult patient with SCI, by not only addressing the needs of the individual, but of the social network.

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## Book Review

**Lengnick-Hall, Mark (Editor) (2007). Hidden Talent: How Leading Companies Hire, Retain, and Benefit from People with Disabilities. Westport, Connecticut, London: Praeger Publishers, ISBN: 13:978-0-275-99289-7, 156 Pages, \$39.95.**

*By Jessie Dickerson, RN, MSN, CWON-AP, CFCN*



“Hidden Talent: How Leading Companies Hire, Retain, and Benefit from People with Disabilities” is a long overdue informative book that tells the story of how several leading companies hire, retain, and benefit from people with disabilities. The editor, Lengnick-Hall, has managed to dispel many of the myths and stereotypes typically associated with hiring people with disabilities in the employment arena. This book also addresses the misconceptions that people have as it relates to persons with disabilities inability to function effectively in the workplace.

This most interesting book gives amazing insight into how these companies hire, retain, and ultimately benefit from having people with spinal cord injuries or other disabilities in their workforces. Any organization that is currently reluctant to hire people with disabilities, will have a definite change of heart after reading this book. There are a number of easy steps listed in the book that anyone can utilize in order to capitalize on the extraordinary talents of people with disabilities.

The format of this book is organized into three main sections which are listed below:

Section 1: The Problem and the Opportunity: People with disabilities need jobs and Employers need workers consist of two chapters. A brief overview of each chapter is provided.

Chapter 1 - describes labor and demographic trends that demonstrate the underutilization of people with disabilities in the labor market and how this is an important untapped human resource.

Chapter 2 - reviews the common myths and misconceptions many employers use to not hire people with disabilities. As a result, employers consequently ignore this valuable source of labor.

Section 2 - Solutions: What some leading companies are doing to hire and retain people with disabilities consists of seven interesting and compelling chapters.

Chapter 3 - provides explicit examples of how Hewlett-Packard (H-P) incorporates people with disabilities into their workforce. H-P has successfully utilized people with disabilities by focusing on making their own products accessible to people with disabilities. They also involve people with disabilities in the development of accessibility guidelines and in the design and testing of products and services.

Chapter 4 - describes how Dow Chemicals create opportunities for people with disabilities world-wide.

Chapter 5 - illustrates how Sun-Trust Bank uses Disability Councils to be responsive to employees with disabilities. Sun-Trust incorporates a great marketing strategy by having persons with disabilities visible at all levels of the business. This strategy has resulted in significant financial growth for this business.

Chapter 6 - describes a unique small company that has totally integrated persons with disabilities into its workforce.

Chapter 7 - describes how Giant Eagles Supermarkets, headquartered in Pittsburgh, Pennsylvania uses the community rehabilitation organizations to provide job coaches to assist new employees with disabilities.

Chapter 8 - describes how Microsoft, a multinational Company, also uses Employee Disability Councils to assist with the integration of employees with disabilities into their worldwide work force.

Chapter 9 - describes the Marriott Foundation and how it employs persons with disabilities in its “Bridges Program” and nationwide network of hotels. The foundation and the hotel corporation emphasize the acceptance of disability in the workforce and in service to its customers with disabilities.

Section 3 - lessons learned about hiring and retaining people with disabilities consists of three chapters.

Chapter 10 - describes how companies can gain a competitive edge by hiring a diversified workforce.

Chapter 11 - gives examples of proven methods that any organization can use to create an organizational culture that is receptive to hiring and retaining individuals with disabilities.

Chapter 12 - pulls all three sections together in order to make some general conclusions from research and organizational practices as it relates to hiring people with disabilities.

Hidden Talent is well researched and should be required reading, in my opinion, for anyone dealing with human resources and the dynamics in the workplace. It also contributes to the knowledge base of anyone knowing and/or working with persons with disabilities. This book will definitely provide you with the necessary tools to explore the hidden talents of those with disabilities.

*The editor of Book Reviews welcomes your input. Please contact Jessie Dickerson at Jessie.Dickerson@va.gov with comments, questions, and suggestions.*

## Abstracts from Selected Literature

**Abel, R., Bazzocchi, G., Christensen, P., Coggrave, M., Hulting, C., Krogh, K., Laurberg, S., & Media, S. (2006). A randomized controlled trial of trananal irrigation versus conservative bowel management in spinal cord injured patients.**

*Gastroenterology 131(3), 738-747.*

*John Morawski, RN, BSN, CRRN*



It is difficult to overstate the importance of bowel regularity in persons with spinal cord injuries (SCI). There are many publications that speak to this. The research publication being reviewed outlines the results of a clinical trial that has been underway in Europe since 2003. The study was designed to test the Peristeen Anal Irrigation system, a product that is a transanal irrigation system. The results of which could lead one to believe that there may be a new way to effectively manage the bowels of a patient with SCI.

The study was well designed and executed. The trial patients were randomly selected, and were comparable to the control group. The trial group received the transanal irrigation device, and the control group received a program similar to the PVA guidelines. The results for both groups' outcomes were measured using the Cleveland Clinic constipation scoring system, the St. Mark's Incontinence Score and the Neurogenic bowel dysfunction score. The results indicate that the transanal irrigation system shows favorable results when compared to the more conservative methods.

Overall, the article is outlining a method of bowel management that holds some promise. Some of the weakness of this study was a lack of mentioning the possible bias of the Cleveland Clinic constipation scoring system as it relates to SCI management. The system has several criteria and one of them is going to skew the results of this study, but this would not account for the improvement in the incontinent scores, and the neurogenic bowel dysfunction scores. Essentially, this experimental method of evacuation showed to have outcome advantages over the more traditional methods, but more research into this is needed.

*John Morawski, RN, BSN, CRRN, is an SCI Nurse Educator at Shepherd Center, Atlanta, Georgia. John is the editor of the journal reviews column. Contact John at [john\\_morawski@shepherd.org](mailto:john_morawski@shepherd.org)*

## Selected Abstracts from the 2008 SCI Conference in Orlando, Florida

### #35 Wheeling Into Life with Recreation

*Jane A. Thomas, BSN, RN*

Participation in meaningful recreation is one of the best ways for individuals with spinal cord injuries to adjust to lifestyle changes. Research shows that a positive recreational experience can increase health, fitness, self-confidence, development of new skills, social interactions, overall quality of life and well-being. Recreational activities provide people with disabilities an opportunity to participate in activities that challenge expectations and stereotypes.

Education and opportunity for involvement will help motivate these individuals to carry out the physical fitness and health program that can bring each of them to their highest possible state of functioning and well-being. Nurses are at the front line and have the power to help motivate by educating and presenting possibilities.

This presentation will highlight interviews with several Paralympic athletes. These individuals are members of the USA Wheelchair Rugby Team. Interviews will focus on experiences and accomplishments demonstrating how interactive sports can restore control and normality in the life of a person with a physical disability.

Recreation and interactive sports can lead to a more meaningful, productive and healthy lifestyle. Initiation into the various sports and community reintegration should begin as early as possible. Experience individuals "Wheeling into Life" through sports and recreation.

#### Objectives

- The participant will be able to discuss how recreation promotes a healthier lifestyle.
- The participant will be able to describe how recreation and fitness increases quality of life.
- The participant will be able to discuss the nurses role in developing self confidence and fostering motivation.

### #36 Start a Research-based Injury Prevention School Program

*Debby Gerhardstein, MA, BSN, RN*

ThinkFirst For Kids and ThinkFirst For Teens are programs of the ThinkFirst National Injury Prevention Foundation, founded by America's Neurosurgeons. They are based on the Health Belief Model, helping students understand the realities of permanent disability caused by injury, the consequences of their actions, and the ability they have to choose behaviors that can easily protect them from becoming injured. See results of efficacy studies, and learn how you can start a chapter.

#### Objectives

- Gain understanding of the Health Belief Model.
- Learn about research-based injury prevention programs.
- Learn how to be a provider of educational injury prevention programs.

Funding Source: Illinois Department of Transportation; Central DuPage Hospital Foundation

### #37 A Conceptual Model for Stress Research in Individuals with SCI

*Matthew R. Sorenson, PhD, RN*

Recently nursing research has begun to investigate the connections between stress and health. The conduct of such research requires an examination of both environmental stress evoking factors and the physiological response mechanisms which may contribute to the development of disease dependent upon health status and vulnerability of the individual. The development of illness relies to a great degree on the

health status, both physiological and psychological, of the subject. In the individual already at risk, or vulnerable, changes induced by stress may worsen an already existent disease condition. Just such a scenario may occur within individuals with an autoimmune disease such as multiple sclerosis, or those living with spinal cord injury. Here we discuss a potential model for research into the interplay between stress perception and physiologic responsiveness using an integrative model combining aspects of a physiologic approach to stress (Allostasis) with a model of family stress (Double ABCX). We review the major physiologic pathways through which allostasis may affect health and summarize the influencing psychological variables of which researchers need to be aware. We then discuss how this model may be utilized in investigations of the effects of stress on individuals with spinal cord injury or other neurologic conditions.

### Objectives

- Discuss the relevance of stress research to spinal cord injured populations.
- Identify the major physiological pathways involved in the response to stress.
- Summarize psychological variables that may influence stress appraisal and perception.

## #38 Spinal Cord Injury and Disorders Family and Caregiver Education: Conquering Challenging Situations

*Jo Ann Wells, MSN, RN, CRRN*

Providing training and education for the families and caregivers of persons with spinal cord injuries and Disorders may prove to be a difficult challenge at times. Complex medical issues and high levels of injury may dictate the need for complicated care to be learned by the caregiver. As persons with other spinal cord disorders are also added to the scope, the issues may become more complex shadowed by existence of degenerative conditions that add the component of constantly facing potential new losses. As an SCI Center for thirteen VA hospitals, patients may come from long distances, leaving their families. Homesickness and transportation of caregivers who need to learn are two of the complicating issues.

Patients or caregivers may also present with cognitive issues or mental health issues that provide an additional challenge. The medical issues and age of family members may require special considerations. With interdisciplinary teamwork, successful family and caregiver education and training can be accomplished to achieve a discharge down the street or across the country.

### Objectives

- Identify common patient conditions or situations that may signal a difficult or complex situation exists.
- Identify family and caregiver issues that may complicate the educational process.
- Describe interventions that may assist in completing successful education and training for persons with SCI and their care givers.

## #39 Developing an Initial Sitting Program Using an Interdisciplinary Approach

*Paula K. Morris, BSPH, PT*

One of the most challenging factors facing the interdisciplinary team during the acute phase of care of the patient with SCI/D is achieving a successful initial sitting program. Staff members from all disciplines are involved in this phase and must be able to recognize potential limitations for successful upright tolerance. These may include level of injury, comorbidities and psychological components. The process for developing a sitting program will be discussed.

It is crucial for staff to be comfortable and familiar with identifying the necessary equipment that will make the transition to the upright position as smooth as possible for the patient with SCI/D. Devices and equipment to minimize blood pressure issues will be identified. The staff should be able to recognize and make informed decisions regarding the appropriate wheelchair and cushion type to be used to ensure skin protection and assist with preventing skin breakdown. Other issues to be discussed include methods of pressure reliefs as well as appropriate positioning and support for the patient in the wheelchair.

Failure to consider the necessary components of the initial sitting process will likely interfere with quality medical management of the patient.

#### **Objectives**

- The participant will recognize potential limitations of the patient that impact upright tolerance.
- The participant will identify the components needed to achieve a successful and effective upright sitting position.
- The participant will identify appropriate devices and equipment useful in establishing an effective sitting program.

### **#40 Home Alone? Not Anymore! Using Telemedicine to Reduce Complications in Spinal Cord Injury Patients**

*Sherril S. Porterfield, MSN, RN, CRRN, CWOCN*

The annual incidence rate of spinal cord injury in the U.S. ranges from 30-50 injuries per million people. The average number of people living with SCI in the U.S. is 200,000, and this number will continue to grow as medical advances reduce mortality from SCI and extend the life span of SCI-survivors.

The average annual South Carolina (SC) incidence rate of SCI is 67 per million, which is 22% higher than the national average. The total economic impact of SCI in SC is estimated at \$25,765,812 per year in 1997 dollar values.

The challenge of surviving a SCI is surmounted only by the challenge of living with the injury for the rest of one's life, especially when the average age at the time of injury is 32. Those living with SCI commonly develop serious, often chronic, life-threatening and costly secondary complications. These complications include pressure ulcers, urinary tract infections, spasticity, deep venous thrombosis, chronic pain and depression.

The exorbitant health care costs associated with treating secondary complications of SCI exact a profound economic toll on the community at large: health care costs for a SCI-injured individual amount to \$200,000, on average, for the first year after injury. Secondary medical complications present a multifactorial challenge to the SCI-injured population in terms of disability, increased mortality, financial burden, and quality of life issues like mental health, community reintegration and caregiver burnout.

Adequate outpatient SCI care has been limited by several factors, including a patient's ability to evaluate their own wounds / status from home, lack of patient initiative in seeking medical care proactively, and transportation problems (availability, cost, need for assistance when traveling, etc.). This is especially true in rural populations, the primary populations served by Roger Peace Rehabilitation Hospital.

One direct, effective economical way to address such life-threatening secondary complications in SCI is via a telemedicine program linking spinal cord injured individuals with ongoing medical evaluation / resources from the comfort and convenience of their home. Telemedicine interventions have been credited with fewer hospitalizations in the first year of injury, an increase of 18 days of quality-adjusted survival per year, preventing pressure ulcers, and treating pressure ulcers. Telemedicine programs have also been shown to facilitate a smooth transition from inpatient rehabilitation to the community, improve quality of life and allow limited health care resources to be used more efficiently. This presentation will demonstrate the use of a SCI telemedicine program at Roger Peace Rehabilitation Hospital. Through use of a videophone system, the Clinical Nurse Specialist / CWOCN has been able to monitor patients functional level, assess / make recommendations for wound care issues, manage bowel and bladder programs, and make other appropriate recommendations to keep the SCI patient from being readmitted to the hospital within the first 2-3 months after discharge from rehabilitation.

#### **Objectives**

- At the end of the presentation, the participant will identify the cost of secondary complications of SCI.
- The participant will identify telemedicine options used for early identification/prevention of SCI complications.

- The participant will learn to implement a telemedicine program that will improve quality of life and decreasing readmission rates.

### **#41 Pain Syndromes in Spinal Cord Injury**

*Angela R. Starkweather, PhD, RN, ACNP, CCRN, CNRN*

1. Review the pathophysiology of pain  
Define pain terminology
2. Provide criteria for various types of pain: musculoskeletal, inflammatory, neuropathic, psychogenic  
Relate to pathophysiology of SCI
3. Discuss the use of medication, physiotherapy, and complementary and alternative medicine in the treatment of pain syndromes associated with SCI

#### **Objectives**

- Discuss the pathophysiology of pain.
- Contrast the various types of pain encountered in SCI.
- Relate the type of pain syndrome to appropriate pain treatment therapies.

### **#42 Using an Evidenced-based Order Set “Appendix” to Enhance SCI Care**

*Peggy R. Guin, PhD, RN, ARNP, CNS*

Since our institution became a level one trauma center, patients with SCI have been admitted to the trauma service and subsequently transferred to neurosurgery, if SCI is their only injury. Coordinating care for patients with SCI is challenging and requires that standards are met in a timely fashion, regardless of what service the patient is on. Specificity in clinical care and ensuring the appropriate consultation of required disciplines within a specified timeframe are required. The order set for spinal cord injury care was not “hardwired” for consistent use by the trauma service and delays in required care occurred. In order to eliminate redundancies, assign accountability, and ensure consistency across services, members of the SCI committee developed a “SCI appendix.” The appendix is used as a supplement to the “generic” order sets used by the trauma service or the neurosurgery service, regardless of where the patient is in the care continuum, e.g., ICU, general unit. Much negotiation between services and members of the SCI committee was required to clearly identify agreement in content, accountability and ownership, and consistency in the process needed for successful implementation. This presentation describes the work of the interdisciplinary committee to implement this new care management system.

#### **Objectives**

- Identify three goals of the order set process.
- Discuss two barriers related to implementation.
- Describe one example of negotiation of content related to “standard of care” where discrepancies in evidence across populations exist.

### **#43 Enhancing Learning for Patients with SCI: The Rehabilitation Learning Readiness Assessment Guide**

*Barbara J. Olinzock, EdD, RN and Mary Helen Elliott, MSN, RN*

With changes in healthcare policy and reimbursement patterns, patients with SCI are now expected to learn and direct complex self-care regimens within a shorter period of rehabilitation. These changes pose significant learning challenges for patients and teaching challenges for nurses. The Rehabilitation Learning Readiness Assessment Guide (RLRAG) is offered as an evidence-based method to enhance learning readiness for SCI patients. The RLRAG is a product of the Rehabilitation Learning Readiness Model

(Olinzock, 2004) focusing on five stages of learning readiness; dependent, involvement, engagement, self-initiation and self-direction. Stages correspond to five nursing roles; authority, guide, motivator, mentor and consultant. The nursing goal is to assess the stage of learning readiness of the patient and assume the corresponding teaching role. In a preliminary study, the assessment guide proved useful in depicting learning readiness challenges characterizing a learning trajectory for SCI patients during rehabilitation. An orientation to the RLRAG, worksheets, and how it can be used will be presented. The assessment guide is currently being piloted with undergraduate nursing students participating in a rehabilitation case study project. Findings suggest that the RLRAG may indeed be useful in orienting novice nurses as well as reaffirming the multi-faceted teaching roles and activities of expert SCI nurses.

### **Objectives**

- Identify five stages of learning readiness and five corresponding nursing roles.
- Describe nursing learning readiness challenges and nursing activities for each stage.
- Describe benefits of using the RLRAG for clinical practice.

## **#44 Fifteen Years in the Life of a Tetraplegic Couple**

*Susan P. Crawford, BA, RN, CRRN*

Fifteen years ago, Cheryl and Ken were a young couple moving on the fast track to success in the Silicon Valley of California. On a beautiful, carefree and sunny day, they went for a drive in their new convertible sports car. Cheryl lost control of the car, crashing into a ravine in a remote area. For 16 hours they hung upside down in their car, clinging to life and to each other, praying to survive, unable to move or call for help. The couple was discovered by a hiker and his dog the following day. They were airlifted to SCVMC, both alive, both tetraplegic. This is their story. A story of courage, heartache, triumph and the strength of the human spirit.

### **Objectives**

- Provide insight into the world of tetraplegic husband and wife.
- Provide insight into the grieving process after a catastrophic injury such as SCI.
- Provide an inspiration to all health care workers in the field of SCI rehab.

## **#45 SCI End of Life A Brighter Future? A Follow Up**

*Vernadine Hampton, MSN, RN*

Death and Dying! What's the Difference? What to Do? Imagine the anger and frustration! This presentation is a follow up and will discuss end of life issues that impact the in-patient, SCI Long Term Care resident who receives a death sentence due to a terminal illness. What does it mean to die? Most people would quickly change the subject, if it were raised at all. It is said that in knowing how to die, one also knows how to live? Nurses are strong advocates for self-determination in caring for the terminally ill. When cure is no longer possible, a host of psychological, physical, and spiritual stressors arise therefore it is essential for effective interventions to be developed and implemented by the interdisciplinary team. Communication, pain control and comfort care are examples of interventions to maximize positive patient outcomes and resources for nursing staff. The case study will include interdisciplinary interventions, patient outcomes, discussions about spiritual freedom, dying on patients own terms leading to independence in a brighter future after life. I. The Difference between Death and Dying II. Physical and Psychological Changes III. Knowing How to Die IV. Interventions V. Closure VI. Case Study.

### **Objectives**

- Describe the difference between death and dying.
- Identify end of life issues impacting terminal care on a Spinal Cord Injury Unit.
- List Interdisciplinary Interventions to manage death and dying in a Long Term SCI setting.

## **#46 Knowledge and Practice of Caregivers Concerning Special Care of SCI Patients**

*Shanta P. Subedi, BN, RN*

Spinal cord injuries (SCI) are the leading causes of morbidity and mortality. Especially in the developing countries, the lack of adequate prevention programs and therapy facilities carry an enormous personal and economic cost. In Nepal, because of the geographical complexity, a high number of Nepalese suffer from SCI resulting from falls. Though an adequate treatment is beyond the capabilities of most Nepalese, Spinal Injury Rehabilitation Center aims to educate the caregivers concerning the special care such as physical and psychological support and help them to live the best quality of life even after the injury. With a survey research comprising questionnaires and interview, this study assessed both knowledge and practice among caregivers in Nepal, and the degree to which acquired knowledge was transformed into practice. This research found that the caregivers' duration of stay in hospital during primary care is significantly related to the level of knowledge and practice. This study also found the lack of understanding of importance of diet, skin care, bowel movement and maintaining proper positioning. This study has greater implications in understanding the caregivers' knowledge and practice in the context of developing countries, and help reshaping the treatment plan of patients with SCI.

#### **Objectives**

- To assess knowledge of the caregivers towards the special care of the patients with SCI.
- To assess practice of the caregivers towards the special care of the patients with SCI.
- To identify the degree to which the knowledge is transformed into practice when caring the patients with SCI.

#### **Film: Almost Home**

*Susan Thomason, MN, RN*

This 1hour 20 minute DVD showcases select residents of St. John's on the Lake, a Long Term Care (LTC)/Independent Living facility in Milwaukee, Wisconsin. In this film, which is co-produced and co-directed by Brad Lichtenstain and Lisa Gildehaus (INDEPENDENTLENS), residents, family and staff provide their perspectives on residential living in the facilities. Residents are elderly and many have dementia. In this thoughtful and provocative video (PBS Broadcast Date: February 21, 2006), there is a LTC cultural shift to "person first" and quality of life issues. In a medical model, activities such as bathing times, are regimented with minimal flexibility; in the social model, which is adopted in this LTC facility, there is a commitment to individualizing activities. The entire interdisciplinary team is dedicated to empowering residents to making the facility "almost like home." The team uses strategies like being flexible with the time the resident arises in the morning, medication administration, diversional activities (e.g., music, pet, community outings), opting out of uniforms, and multiple other cultural shifts. Although persons with spinal cord impairment are not showcased, those attending the Film Festival will gain insight into how a meaningful sense of community may be attained in LTC settings.

#### **Objectives**

- Differentiate between medical and social long term care (LTC) delivery models.
- Identify three means of empowering elderly LTC residents to make choices.
- Cite strategies for managing LTC residents on a person first basis.

#### **Film: Intimate Relationships and Spinal Cord Injury: The Client's Perspective**

*Susan Thomason, MN, RN*

This 24 minute DVD profiles 3 men and 1 woman with spinal cord injuries (SCI) and describes their challenges in establishing sexual relationships. G.F. Strong Rehabilitation Centre, Vancouver, British Columbia, has addressed concerns and myths, experiences with dating, the role of the rehabilitation team, and other aspects of sexuality.

This video provides an excellent overview that would serve as an invaluable introduction to a sexuality rehabilitation program, particularly with single persons who are preparing to relaunch into dating.

The solo presentations of those persons profiled differentiate between physical contact and establishing a deeper level of communication and sexuality. Presenters are casual and candid.

Content focuses on both physical (e.g., leg bag leak) and emotional challenges (e.g, fear of the unknown). Body image, self-image, fear of rejection, self-esteem, the rush to “get back on the horse,” and other psychosocial issues are addressed. A peer mentor discusses various aspects of sexuality pre- and post -marriage. Supporting a family, having children, dependency, and other broader perspectives are offered.

Those attending the Film Festival will cultivate a more in-depth understanding of the person with SCI as related to the physical and psychosocial aspects of sexual relationships.

**Objectives**

- State two common myths related to persons with spinal cord injury and sexuality.
- Describe the difference between physical sex and an establishing an intimate relationship.
- Identify strategies used to overcome barriers to establishing sexuality relationships.

## AASCIN News Summer 2008

### AASCIN Committee News

Mary Ann Reilly, MS, RN

#### Summary of BOD Reports for the Third Quarter of 07-08



*The Nominating Committee* has developed an exciting group of candidates for the 2008-09 BOD. Ballots have been mailed. The candidates include: Laura Johnson, Nurse Manager SCI Clinic at the Charlie Norwood VA in Augusta, GA; Robin Nolan, Nurse Manager, SCI Clinic at the Tampa VA; Lisa Beck, CNS in the Outpatient SCI Program at the Mayo Clinic; Katherine Van Dyke Hayes, Professor of Nursing at Holy Family University, Philadelphia. You are encouraged to submit your ballot.

*The Aging Committee* is awaiting the pilot study for the 'Motorized Mobility Devices Assessment Check List' which will be held at the Hines AV, Tampa VA and OSU. Members of the committee sit on the ANA Geriatric Committee. Our members

are defining the Scope and Practice of the Geriatric SCI Nurse.

The Treasurer has been intricately involved in the Tri-Association plans for our association's merger with AASCIPSW and APS. Our Treasurer has been seeking information on grants to support our projects.

*The Editorial Board* has posted the 25.1 issue of the AASCIN Journal. Please take time to read the excellent articles on the management and care of osteoporotic fractures in the SCI population, causes of fever in SCI, prevention and health maintenance, and leadership. Manuscripts are continually being sought. Articles have been reviewed and the 'Best Article Awards' have been selected.

*The Membership Committee* has reviewed the nominees for the James A Peters Award. The committee has reviewed and refined the definitions of membership. Guidelines are being written to allow Student Nurses to join our association. Thank you cards have been sent to all members who have renewed. A special thank you is being extended to all members who have sent in monetary donations. A New Member Campaign is being developed. The plans for the 25<sup>th</sup> Anniversary of AASCIN are in progress.

All members are encouraged to attend the 2008 Congress of Spinal Cord Injury Medicine and Rehabilitation Conference in Orlando on August 11-13. Check our web site at [www.aascin.org](http://www.aascin.org) for more information.

### Call for AASCIN Committee Participation

Now is the time for you as an AASCIN member to take action. Become involved in AASCIN by participating in one of our six standing committees and editorial board. Descriptions of the committee/board are listed below. If you are interested, please contact the AASCIN office for a committee interest form and return it with a current resume or curriculum vitae. Remember, it is your organization. AASCIN needs YOU!

#### Aging Issues Committee

Oversees the American Nurses Association/Specialty Nursing Association Partners (ANA-SNAP) grant activities within AASCIN. Promotes education and research related to aging. Identifies ways to help members of AASCIN enhance the care of individuals with SCI as they age both chronologically and with the impairment. Maintain latest knowledge base for dissemination and communication of information on aging with SCI.

### **Clinical Practice Committee**

Identifies and assesses clinical practice trends related to SCI nursing practice and implements strategies to promote quality care for individuals with SCI. Clinical practice issues encompass the areas of prevention, health promotion, health maintenance, and restoration. Members should be knowledgeable about nursing practice trends.

### **Editorial Board**

Publishes the quarterly online journal and other selected materials related to AASCIN activities. Serves as a consultant to AASCIN committees/task forces in the production of publications. Publishing experience is preferred.

### **Membership Committee**

Coordinates activities related to AASCIN membership. Develops and implements a membership survey when requested by the Board of Directors. Activities related to public relations and/or membership solicitation are planned, implemented, and evaluated. Reviews renewal applications for membership status. Sets guidelines for and selects recipients for three awards: James J. Peters Award for Distinguished Service, the Staff Nurse Award for Excellence in SCI Nursing, and the Expanded Role Award for Excellence in SCI Nursing.

### **Nomination Committee**

The Board of Directors appoints the Nomination Committee on an annual basis for a one-year term. Look for the Board of Directors' "Call for Nominations" if you are interested in providing leadership to AASCIN.

### **Program Committee**

Plans, implements, and evaluates the Annual AASCIN Conference for the general membership, thus promoting exchange of knowledge, skills, and ideas related to SCI care among nurses, other health care professionals, and consumers.

## **Bulletin Board**

### **Annual Conferences**

#### **34<sup>th</sup> Annual Scientific Meeting of ASIA**

June 19 -22, 2008

Loews Coronado Bay Resort, San Diego, California

ASIA - Phone: 404-335-9772

Email Address: ASIA [OFFICE@SHEPHERD.ORG](mailto:OFFICE@SHEPHERD.ORG).

#### **35<sup>th</sup> Annual Meeting of ASIA**

September 22-26, 2009

Adam's Mark Dallas (to be reflagged as the Sheraton)

Dallas, Texas

#### **21<sup>st</sup> World Congress Rehabilitation (RI)-Quebec 2008**

August 25-28, 2008

Quebec City Convention Center

[www.riquebec2008.org](http://www.riquebec2008.org) or [www.riglobal.org](http://www.riglobal.org)

***Toronto Rehabilitation Institute***

***Spinal Cord Rehabilitation: Innovation, Impact, and Future Directions.***

November 6-8, 2008

Hilton Toronto Hotel

**[www.torontorehab.on.ca/education/sci.08index.htm](http://www.torontorehab.on.ca/education/sci.08index.htm)**

*Submitted by Jesse L. Dickerson, RN, MSN, CWON-AP, CWON, CGCN*

## **The Consortium for Spinal Cord Medicine Clinical Practice Guidelines**

*Linda Love, MS, RN, CRRN*



The Consortium for Spinal Cord Medicine, in partnership with PVA's research and education team, strives to improve care of persons with spinal cord injury by making their care more research and evidence based through publication of The Consortium for Spinal Cord Medicine Clinical Practice Guidelines. The Consortium also publishes companion consumer guides to provide information to consumers of SCI related health care.

Clinical Practice Guideline topics include:

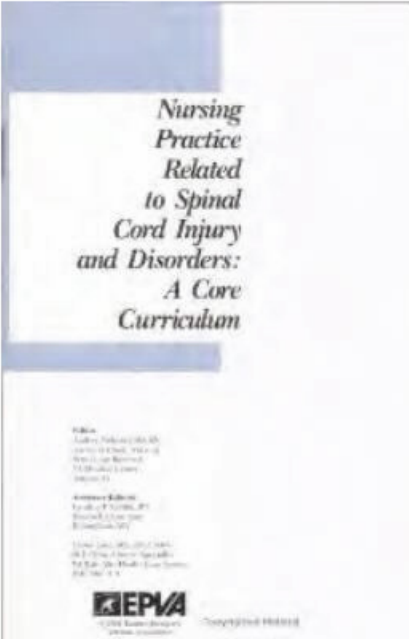
- Bladder Management
- Preservation of Upper Limb Function
- Respiratory Management
  
- Thromboembolism
- Autonomic Dysreflexia
- Pressure Ulcers
- Expected Outcomes
- Depression
- Neurogenic Bowel

Consumer Guide topics include:

- Depression
- Expected outcomes
- Pressure Ulcers
- Autonomic Dysreflexia
- Neurogenic Bowel

*..... and more.*

Check the PVA website [www.pva.org](http://www.pva.org) under "Publications." Downloads are free. Select publications are available in print and in Spanish.



**“SCI Core Curriculum” Offer**

Widely considered a “must-have” text for all SCI nurses and edited by longtime AASCIN members, Audrey Nelson, PhD, and Linda Love, MS, RN, CRRN, *Nursing Practice Related to Spinal Cord Injury and Disorders: A Core Curriculum* is now available to AASCIN members at a significant discount. Thanks to an arrangement with Demos publishing, AASCIN members may order the book directly at a 35% discount, with free shipping. Go to [www.demosmedpub.com](http://www.demosmedpub.com) and enter “AASCIN” as a discount code. Demos generously donated two copies for the book draw at the annual SCI Conference in Florida last year.

### **Attention Nursing Professionals!**

*SCI Nursing* encourages manuscript submissions from all interested nursing professionals and we welcome a wide variety of topics and research approaches. Manuscripts must be submitted electronically and conform to the *Publication Manual of the American Psychological Association*, Fifth Edition. For information on style and content requirements, please visit our Web suite at [www.aascinc.org](http://www.aascinc.org) and click on the “AASCIN” box, located at the bottom of the home page, and then click “*Get Published in SCI Nursing.*” Share your insights with colleagues around the world. Publish in *SCI Nursing*!

# Congress of Spinal Cord Medicine & Rehabilitation



This is the largest annual gathering of professionals working in the field of spinal cord injuries and disorders in North America. Sponsored by American Paraplegia Society, American Association of Spinal Cord Injury Psychologists and Social Workers, American Association of Spinal Cord Injury Nurses, Therapy Leadership Council in Spinal Cord Injury, and hosted by United Spinal Association.

- Qualified attendees are eligible for continuing medical education credits

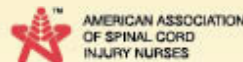
### Congress highlights include:

#### Polytrauma and War Injuries

by renowned experts: Paul F. Pasquina, MD  
Lauren G. Doloresco, MN, RM, CNA, BC  
Steven G. Scott, DO

#### Wheelchair Fall Risk Assessment

featuring: Audrey L. Nelson, PhD, RN



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