HAPPY ANNIVERSARY!

It is the 20th anniversary of Pushin’ On! As the current editor, I wanted to honor our long-running newsletter and celebrate our past accomplishments. I decided to look back on past issues for my inspiration and found that the experience was much like looking in my high school yearbook. Everyone pictured is wearing strange clothes, and they have funny hairstyles. It is these humorous images that inspire me in this sometimes fictional tribute to the life and content of Pushin’ On.

The Early Years

The roots of today’s newsletter began in 1981. The staff here at Spain Rehabilitation Center received a grant to publish four issues of a newsletter. The staff held a contest to name the new newsletter. A nurse working at Spain came up with Spokesman and won a blow dryer for her contribution to history. Spokesman was written for former patients of Spain, their families, and staff at Spain. Many of the articles were personal profiles of former patients who had successfully reestablished their lives after injury. Other articles focused on community events such as Ms. Wheelchair Alabama. A few articles also focused on some of the medical services offered at Spain. For example, the first feature article on the cover of Spokesman was about the 1,000th renal scan done at Spain. In 1981, a renal scan was described as "landmark" treatment, but it is a common treatment practice today.

The name, Spokesman, lasted only one year before it was changed. The reason for the name change is a mystery, but I have joked that it happened to avoid a law suit. At the time, some women's groups may have been angered by the name, Spokesman. Plus, there is also the possibility that the once prized blow dryer may have been one of the millions recalled for fear of asbestos.

For whatever reason, Pushing On was published in 1982 with the subtitle, News from Spain Rehabilitation Center. While the content was the same as Spokesman, Pushing On offered a more positive attitude. The new name implied that individuals with SCI are doing things instead of simply talking about things.

The Middle Years

The newsletter began to establish its own identity after a few years in publication. Pushing On soon became Pushin’ On. This change is another
mystery, but my guess is that the editorial staff dropped the letter “g” from the name because no one here in the South pronounces useless letters. We do not go fishing. We go fishin’!

During the late 1980s and early 1990s, SCI research showed the benefits of preventive medicine. This is the idea that it is better to prevent medical problems through self-care. Self-care became a major focus of Pushin’ On. The newsletter began to feature articles to educate individuals with SCI on medical concerns such as the prevention of pressure sores through skin care, bladder management and the prevention of urinary tract infection (UTI). In fact, one of the first of these health related articles to appear in Pushin’ On was on the urinary system. This topic was important because renal (urinary system) failure use to be the leading cause of death for individuals with SCI. However, articles, like the one from Pushin’ On, have helped to educate many individuals on ways to prevent UTIs, which also helped reduce the number of deaths due to renal failure.

More people began reading Pushin’ On during the middle years, and articles focused less on local issues and more on issues that appealed to most individuals with SCI and their families. The newsletter was one of the first to discuss issues of caregivers, caregiver depression and the long-term well-being of individuals with SCI and their family caregivers. Pushin’ On was among the few sources of information on issues of sexual health and fertility. There were articles on methods to improve erectile dysfunction and methods to improve fertility. There were other articles on issues of pregnancy and parenting following SCI.

**Today**

The main focus of the newsletter is now on educating individuals on issues of spinal cord injury. A major concern for many individuals is secondary conditions of SCI. A “secondary condition” refers to medical complications or social issues that can occur as a result of living with SCI.

Medical information is important to the long-term health of individuals with SCI. Some of the more recent medical topics featured in the newsletter include pressure sores, respiratory illness, urinary tract infection, sexual function and fertility. These medical issues have always been of interest, but more individuals with SCI are living longer than ever. As a result, many articles have appeared in recent issues of Pushin’ On focusing on how medical problems can be further complicated by factors related to aging.

Individuals with SCI are also interested in social issues. These issues are important to those who wish to have an active lifestyle after injury. Pushin’ On has addressed issues of social interest with recent articles on stress, nutrition, relationships, employment, accessibility, and bladder and bowel management.

The newsletter also features two regular columns. “Healthy Living” began in 1999 and was originally known as “Questions from the Clinic.” The original column was created to answer common questions from individuals with SCI. Today’s column continues to answer questions on medical complications and other issues, but “Healthy Living” also includes occasional articles on issues of everyday living with SCI and offers suggestions on managing potential problems.

“Research Update” has been a ongoing part of Pushin’ On for 11 years. This column features research studies done here at Spain. These studies are mostly related to secondary conditions of SCI, so they are of great interested to most individuals with SCI and their families. Many of the studies featured in “Research Update” have been very successful. Some studies have helped reduce the number of deaths related to renal failure. In fact, renal failure is no longer the leading cause of death due to research like that done at Spain. Research done in UAB’s sexual health clinic has also been a major contributor in improving sexual function and fertility.

**Conclusion**

The overall goal of this newsletter is to improve the quality of life of individuals with spinal cord injury. Education is the key to reaching this goal, and Pushin’ On offers accurate, up-to-date information of interest to individuals with SCI and their families. If you are educated on medical complications, you are more likely to know how to prevent those complications. If you read about the success of others in managing issues similar to the ones you face in living with SCI, you may find ways to help manage your own issues. Education gives you the opportunity to achieve all those things in life that you desire. Pushin’ On can help give you knowledge, but only you can turn that knowledge into greater independence.
HEALTHY LIVING

20 YEARS AND BEYOND: LIFE AFTER SCI

Individuals with spinal cord injury (SCI) are living longer than ever. It is now common for individuals to live 20, 30, and 40 years or more after injury. Those individuals who have lived 20 years or more after injury have witnessed many medical and social changes for persons with disabilities.

In honor of the 20th anniversary of Pushin' On, two individuals with SCI who are former patients of Spain Rehabilitation Center offer their opinions on the medical and social changes that they have experienced while living with SCI. Shirley is a Program Coordinator. She is living with T-12 paraplegia as a result of a car accident in 1974. Toby is an engineer. He has T-12 paraplegia as a result of a car accident in 1970. They answered three questions.

Q What medical advances in SCI have helped or impressed you over the last 20 years?

"Individuals with SCI are living longer than ever. There’s more information about medical complications that we can expect to experience. There’s more knowledge about how to prevent problems and new treatments to help manage complications. New medications are frequently introduced that help alleviate problems. Many of the medical issues that often made life more difficult in the past can now be managed or even corrected. I believe these medical advancements help people with SCI lead more fulfilling and happy lives." -Shirley

"One of the most shocking medical changes is how quickly individuals who are newly injured return home after their injury. There may be adequate physical preparation and training given in the activities of daily living, but people need more than several days stay in a rehabilitation center to adjust to the unbelievable life changes that occur after injury. There have also been numerous advances in technology that have made life much easier. As a wheelchair user for 31 years, I have seen how lightweight materials, quick release wheels, cushion designs, and even Velcro have made wheelchairs much easier to use, more individually fitted and more aesthetically pleasing." -Toby

Q Have you witnessed much of a change in your attitude, or in the attitude of others, toward persons living with SCI?

"Yes. I believe young people are now more accustomed to seeing people who use wheelchairs. People with disabilities are now more in the public view; you see more people with disabilities on television, more in advertising, and more in the community. I believe many children are now more informed and aware of disability issues. I believe they will become adults who are more likely to view people with disabilities as productive and capable." -Shirley

"Unfortunately, the greatest challenge is still public attitude. In my opinion, the main issue of fair employment gets little attention. I have seen little change in opportunities for individuals with SCI as a result of ADA (Americans with Disabilities Act), and there is very little public visibility or political power held by persons with disabilities. I'd like to see our government provide individuals with disabilities the same support that is given to persons on the basis of their race and gender." -Toby

"There are always new obstacles and challenges that must be overcome. It might be skin problems, urinary tract infection, bowel or bladder accidents, lack of accessible parking, or even well intentioned people who are misinformed. It seems like there is always something. The longer I live with spinal cord injury, the more these things seem to bother me. Maybe it’s because I adjusted to my disability many years ago, but the problem issues continue to be the same. Trying to keep an optimistic outlook is often my greatest challenge. I have learned that attitude is everything. My days can be good or bad depending on how I approach each situation that arises. I can always find an alternative to the challenges I encounter when I am willing to work on it, rather than give up. When I approach problems with a positive attitude, life is a lot better." -Shirley

"Other than the obvious accessibility issues, one of the greatest challenges is facing the effects of aging in areas like skin care, joint problems, increasing fatigue and problems with urinary tract infection." -Toby

Q What has been your greatest challenge in living with SCI?

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When *Pushin' On* was first published in 1982, there was not a lot of money funding research for a cure for spinal cord injury (SCI). Sure, individuals with SCI have always had hope for a cure, but most scientists used to believe that a cure for paralysis was highly unlikely. The notion of nerve regeneration in the spinal cord seemed impossible, so money was more often spent on areas of research that did not focus on a cure.

A cure became increasingly probable as progress toward nerve regeneration improved. Today, no one knows if it will take 5, 10, or even 20 years or more, but most scientists now agree that it is only a matter of time before there is some form of cure. In fact, this promise of a cure has opened the door for a new attitude. There are now millions of dollars spent each year on research with the very real possibility that a cure is within reach.

This possibility of a cure has individuals with SCI asking some very interesting questions. Why is it so hard for doctors to find a cure? When there is a cure, what will it be? Will I be able to get back all my lost motor and sensory functions? What can I do to help?

### What Are the Difficulties in Finding A Cure?

First, every spinal cord injury is different. Some injuries are caused by car accidents and others by falls. Injuries occur at different levels, and some people have complete injuries while others have incomplete injuries. All of these factors mean that some injuries result in a more severe loss of sensory and motor function than others.

Second, further damage to the spinal cord can occur beyond the time of the initial injury. For example, swelling occurs around the injured area of the spinal cord within hours after injury. The swelling causes additional damage to nerve axons and blood vessels. In addition, the regrowth of nerve cells is later blocked by substances that the body naturally produces to inhibit nerve growth. These biological complications are some of the main factors that contribute to the difficulties of finding a cure.

### When There Is A Cure?

When you think about a cure for paralysis, you might imagine many possibilities. You might think that you will need surgery to repair the damaged nerves in your spinal cord. You may be hoping that you can simply take a pill each day and gradually regain function.

Current scientific evidence suggests that there will not be one simple cure. It is not likely that one surgical treatment or one special medication will solve all of the complexities that are involved in restoring function. Instead, a cure will likely involve a combination of different treatments working together. For example, a cure might eventually involve a surgical procedure to enhance nerve regeneration, and various drug treatments may be necessary to promote the reestablishment of nerve connections.

### How Will A Cure Work?

A *Research Review* of the latest research for a cure of spinal cord injury is now available. The newsletter explains that persons who are newly injured and persons who have been injured for many years will likely benefit from different strategies for a cure. However, the newsletter notes four strategies toward a cure that are currently being funded. An eventual cure for paralysis will likely involve the use of one or more of four areas of research.

#### Neuroprotective Agents

When a person is first injured, there is obvious damage to nerves and cells at the site of the injury. This damage is often severe enough to result in spinal shock (a temporary form of nerve paralysis) or complete or partial paralysis of the person's motor and/or sensory function. In addition, further damage to the spinal cord's nerve cells and its protective covering (myelin) continues for days or even weeks after the initial injury.

Researchers hope to solve this problem by using specific types of medications that prevent or counteract the death of nerve cells after injury. Some examples of these medications include Methylprednisolone, GM-1 Ganglioside (Sygen), Interleukin-10, and Gluamate (AMPA) Receptor Blockers.

#### Regeneration

Regeneration, or getting nerves to grow, is a difficult process. Unlike many peripheral nerves that flow from the spinal cord throughout the body, central nerves within the spinal cord do not usually regenerate when damaged. The reason...
is that spinal cord tissue contains certain chemicals that actually stop nerve regeneration.

Based on laboratory success, researchers believe that they can promote nerve regrowth and block the chemicals that prevent spinal nerve growth. However, their attempts to reestablish the correct “connections” on both sides of the injury have been unsuccessful thus far in humans. Researchers are studying the effectiveness of many different possibilities to solve the many problems of regeneration.

Transplantation
When damage occurs to nerves outside the central nervous system (the brain and spinal cord), those peripheral nerves sometime regenerate. Researchers are trying to replace damaged central nerve cells that do not regenerate with peripheral nerve cells that do regenerate. Their belief is that the transplanted nerve cells will continue to regenerate and become a part of the central nervous system.

One transplantation option has recently generated a lot of debate. Fetal Central Nervous System Tissue is believed to help with nerve regeneration. The tissue contains stem cells, progenitor cells and other substances that support nerve growth. These stem cells can develop into several cells depending on the types of signals they receive. Researchers hope that transplanting stem cells into the spinal cord will result in nerve regrowth and connection.

Rehabilitation
An essential element of any hope for a cure is rehabilitation. No one is going to simply get up and walk. It will take time. You will have to work extremely hard to regain strength, stamina, and balance. Your brain may need time to relearn how to communicate with your body to improve function. All of this work will require a number of different therapies to be most effective.

What Kind of Return Will I Have?
As an individual with SCI, you may be hoping that research for a cure will result in a full recovery from your injury. You may expect to return to your old, "normal" self. You might image yourself doing daily activities with the same ease as before your injury. This is the goal of research for a cure, but it will take a long time to reach that goal.

Although this image of a full recovery may become a reality in the future, it is much more likely that you will first benefit from research that improves your current function or gives you partial recovery. For example, researchers are working to improve function in parts of the body such as the bladder and bowel. There is also a lot of work currently in the area of Functional Electrical Stimulation (FES). FES is the process of sending electrical stimulation to muscles to improve function. These are only two examples of work being done to improve current quality of life.

What Can I Do?
Most all individuals with spinal cord injury want to benefit from a cure for paralysis. It is only logical that you want to get as much benefit as you can from treatments to improve quality of life. You can help improve your chances for benefitting from scientific advances by doing everything possible to take care of your body and stay healthy.

The single most important thing that you can do to benefit from research for a cure is to prevent medical problems.

As an individual with SCI, you are at risk for medical complications such as pressure sores, urinary tract infection and respiratory infections or illness. If you do not take care of your health, you put yourself at an even greater risk. Many medical problems can severely limit your ability to exercise and lead an active life. Some complications are also life-threatening.

The single most important thing that you can do to benefit from research for a cure is to prevent medical problems. Take care of your body, and stay active. It is recommended that you get regular, annual checkups from your doctor to help prevent long-term health problems.

Losses in bone density and muscle mass are two other obstacles that need be considered when thinking about walking. You have likely lost muscle and bone mass due to a lack of use. This loss is common after injury. Unfortunately, the natural physical changes that come with aging and menopause can result in added bone and muscle loss.

You may not be able to completely stop the loss of bone

To continue, see Cure on page 7

1 Craig, M; Lindsey, LL. Research Review. Spring 2002. To receive a copy of this newsletter, go to www.spinalcord.uab.edu/show.asp?durki=19803.
All women experience a loss of bone density. This loss occurs as women get older. Plus, they experience an additional loss of bone density during menopause. These periods of bone loss put women at risk for developing osteoporosis, which is a disease characterized by low bone mass and structural deterioration of bone tissue, leading to bone fragility and an increased susceptibility to fractures of the hip, spine, and wrist.\(^1\)

Women with spinal cord injury (SCI) are not immune to this risk for developing osteoporosis. Instead, they may be at a greater risk. Women who are newly injured experience an additional loss in bone density due to a lack of use in many parts of their skeleton. Although the amount of bone loss levels off over time,\(^2\) the loss for women after injury is an added complication to the normal loss of bone density that occurs during menopause and as they get older.

**Methodology**

This current cross-sectional study compares the overall degree of musculoskeletal abnormality and factors related to the degree of musculoskeletal abnormality in (1) postmenopausal women with SCI, (2) men with SCI, and (3) postmenopausal women without SCI. The study examines the spinal, postural, and osteoporotic changes in women with SCI who have undergone menopause after injury. These women will be matched and compared to men with SCI by age and time following injury. The study will also look at the hormonal, nutritional, urological, dermatological, psychological, pain, and functional changes of women with SCI. These findings will be compared to women without SCI and matched by bone density to determine if women with SCI develop a greater degree of secondary disability than women without SCI.

**Participants**

Women participating in this study must meet certain requirements. They must be at least 5 years post-injury and have a T-10 level of injury or higher. They must also have experienced menopause at least 2 years ago and are not on any hormone replacement therapy.

The women are also offered incentives for participating in this study. They are given free medical examinations, which includes a bone density scan and follow-up. The women also receive a financial incentive for participating.

**Anticipated Results**

By understanding the effects of menopause in women with SCI, it is believed that this secondary disability condition can be recognized and treated early. Early interventions, which might include medications, diet and exercise programs, and equipment and wheelchair adaptations, will be pilot tested for development and initiation. More importantly, this study also aims to address whether women with SCI need therapies soon after injury to delay or lessen the later aftereffects of menopause. Finally, menopausal women participating in this study will be given information on, and membership in, the UAB Osteoporosis “Tone Your Bones” program offered by the UAB Health System. This is a peer support group for women with osteoporosis. The group meets weekly and receives education on self care. Women who choose to participate in this program will be asked to evaluate the effectiveness of the program. They will also be asked to recommend modifications, if needed, that can be made in the program to best benefit women with SCI. Then, all women with spinal cord injury who are post menopausal and later treated by the UAB Model SCI System of Care will then receive information on the program.

This is an update on an ongoing study by Drs. Amie B. Jackson, Steven Thiess, and Sarah Morgan. Call 205-934-3330 for information on participating in this study.

and muscle, but you can help minimize your loss. First, talk to your doctor and establish a healthy diet and exercise program. These programs can help you stay healthy and active. Plus, proper diet and exercise programs can improve your chances of getting the most from possible treatments to improve function.

**Participating in Research**

You may want to participate in some current or future research in spinal cord injury. Researchers are almost always recruiting individuals with SCI to participate in clinical studies to determine the effectiveness of treatments. Researchers will also one day recruit persons to participate in research for a possible cure for paralysis. If you want to participate in any kind of research, you should understand the realities of research. It is logical to think that researchers will almost certainly want those individuals with SCI who will offer the best hope for success. Therefore, it is likely that researchers will first accept participants who are healthy and active. If you are not active or if you have medical problems, you may not get the opportunity to participate in research.

**Registration for UAB RRTC Teleconference on Pain after SCI**

**Agenda:** Speakers will address topic for about 45 minutes followed by up to 30 minutes of Questions & Answers.

**Sponsors:** UAB Department of Physical Medicine & Rehabilitation, UAB Rehabilitation Research and Training Center on Secondary Conditions of Spinal Cord Injury, and the UAB Model Spinal Cord Injury Care System.

**Cost:** Registration is free. Callers are only responsible for the cost of long distance telephone charges to area code 205.

For more information or to register via Email, send to: sictc@sun.rehabm.uab.edu, type in Subject, “Registration for Teleconference,” and include the information that is asked for in the registration form below in the body of the Email.

Register online at www.spinalcord.uab.edu/show.asp?durki=35335

**Topic:** Pain Management following SCI (for consumer audiences*)

**Speakers:** J. Scott Richards, PhD, Professor & Director of Research at the UAB Department of Physical Medicine and Rehabilitation.

Laura Kezar, MD, Assistant Professor & Director of the SCI Pain Clinic at the UAB Department of Physical Medicine and Rehabilitation.

**When:** March 4, 2002 [5pmET] [4pmCT] [2pmPT]

*Pre-registration is required!* Professionals may participate if space is available. Teleconference phone number will be provided after Registration Form is received.

**Mail To:** RRTC on Secondary Conditions of SCI 619 19th Street South - SRC 529 Birmingham, AL 35249-7330

**Fax Registration Form To:** 205-975-4691

Individuals with SCI will always hope for a cure for paralysis. Today, medical advances have led to the likelihood that some type of cure is within reach. It is now up to you to prepare yourself for the cure. What you do today may have a direct impact on how well you will benefit from research to improve some, or all, of your body's functions. You want to do everything you can to help improve your chances of benefitting from research for a cure. It is up to you to be ready when there is finally a cure for spinal cord injury.
**Are You Pregnant?** - UAB is looking for women with SCI living in Alabama who have recently become pregnant to participate in a video program documenting the process of pregnancy after injury. Women who participate can receive up to $1,125. For details, contact Phil Klebine or Linda Lindsey at rtc@uab.edu or 205-934-3283.

**Sexuality and Women with SCI** - UAB needs women with SCI for a 16 week study on the effects of a specific drug treatment on improving sexual function. Participants must have had SCI for more than 1 year, age 19 and older, and available to make office visits to the Spain Rehabilitation Center clinic. Call Alice Johnson at 205-934-9494 for more details.

**2 Month Study in Reducing UTIs** - Individuals with SCI over 19 years of age and in reasonably good health are needed to evaluate three solutions for bladder irrigation to determine which is most effective in reducing UTIs. Participants must use Foley or Suprapubic method of bladder management. For more information, contact Kay Canupp at 934-0355.

**SCI Health Education Multimedia Series** - UAB is offering a multimedia CD with a series of slideshow presentations on topics related to SCI. Those topics include Functional Goals Following SCI, Prevention of Pressure Sores Through Skin Care, Prevention and Treatment of UTI, Understanding and Managing Respiratory Complications, and Challenges of Spastic Hypertonia. Call 205-934-3283 or email rtc@uab.edu to get the CD, or go to www.spinalcord.uab.edu/show.asp?durki=28921 for viewing the presentations online using a web browser or download the multimedia series to your personal computer.

**SCI Email Distribution** - You can be notified via email as new and updated SCI material from UAB becomes available; email scirtc@sun.rehabm.uab.edu and type, "subscribe to SCI email distribution list."

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**Research for the Cure**

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