

The Source

Information, News, and Resources for Persons with Spinal Cord Injury

Spotlight on...

What motivates an individual to vie for the title of Ms. Wheelchair Virginia? That was one of the questions *SCI Source* recently posed to the current titleholder: Dr. **Pam Clark**. In Dr. Clark's case, the motivation was an unparalleled opportunity to advocate for positive changes for persons with disabilities. As an educator, Dr. Clark, 39, was no stranger to public speaking at the time of a spine-crushing injury in May 2001. In addition to teaching students from kindergarten through college, she has experience with motivational speaking in her role as the college administrator of the Piedmont Tech Prep Consortium. Her job involves working closely with area businesses, Chambers of Commerce, schools, and universities to develop post-secondary job training programs.

As an innovator of educational programs, she has been invited to make presentations across the country. While working full time, Dr. Clark still found time to continue her own education, recently completing requirements



Ms. Wheelchair VA visits VCU RRC

for a doctorate in education administration. Dr. Clark's dissertation was on a subject that hit close to home: developing a model school for students using wheelchairs. In writing her

dissertation, she considered the challenges and obstacles outside the physical plant as well as addressing the instructional needs of all students.

Enthusiastically embracing the Ms. Wheelchair Virginia role, Dr. Clark has met and spoken with individuals and groups across the commonwealth. Her duties have helped her "understand a different and greater perspective." Dr. Clark won her title on a platform of education, awareness, and accessibility. She underscored the importance of education in getting people with disabilities back to work. In terms of awareness, Dr. Clark related that people "want to help, but don't know what to do." Being in the public eye and sharing the Ms. Wheelchair Virginia mission and message helps increase awareness of disability issues.

Dr. Clark expressed an
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HAVE CHAIR, WILL TRAVEL

The summer is winding down and while many folks' vacations have come and gone, future destinations may be on the horizon. To conclude our article on travel for persons with Spinal Cord Injuries, this article's focus will be on identifying accommodations and gathering resources for potential entertainment options.

As in the previous article, the first step begins by identifying your destination. Will you be traveling within the

United States or outside of our borders? How long will your trip last? How far away will the destination be from your home? Let's break down the steps to help reduce hassles on your trip. As always, it will be critical to plan well in advance and gather as much information as you can. Should your trip be within the United States, hotel accommodations have to comply with the Americans with Disabilities Act. (ADA). However, local ordinances and regulations will vary from location to location, therefore it is imperative to ask questions to minimize potential problems. When calling to

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(Ms. Wheelchair VA, continued from page 1)

especial interest in having an effect on accessibility issues faced by persons who use wheelchairs. In particular, she would like to see changes in the minimum standards for parking and for bathroom facilities. She shared the frustration with the scarcity of wheelchair accessible parking, relating a recent experience of being blocked from getting into her van by a car parked too close. Frustrating,

also, is the limited availability of bathroom facilities, the accessible ones often being used by persons who don't need them.

Ms. Wheelchair Virginia will continue to champion her mission in the months to come. She envisions eventually setting up a non-profit organization for providing supplementary assistance for individuals with disabilities – providing whatever resources, help, care, or money they may need to enhance their

quality of life. Dr. Clark expressed thanks for all the support she has received from all over the state, including the Ms. Wheelchair Virginia organization, her family, friends, and church family. Optimistic for the future, Dr. Clark affirmed that she would “keep hoping and believing that something good will happen every day.”

Debbie West

(Have Chair, continued from page 1)

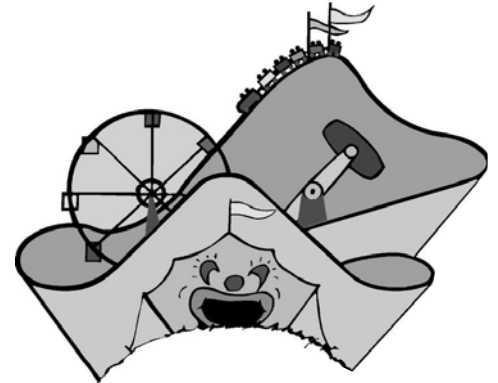
secure reservations at a hotel of your choice, try and call the toll-free (“800”) number to lower expense. When you are talking to the hotel agent, make sure you ask for a wheelchair accessible room. Ask them about shower, benches, or chair availability. You will probably need to talk to the hotel at this point. If so, see if they can connect you while on the line, eliminating steps and reducing phone cost. Once you've contacted the hotel clerk, be prepared: have that list of questions regarding the room such as roll in shower vs. standard tub, raised commodes, bed options and on which floor the room is located. Keep in mind that having your room on the first floor is always safer in case of a fire or other emergency. Make sure you have the agent's name and number should you need to contact them in the future. Many hotel chains have experience dealing with persons with disabilities, but not necessarily with persons who have spinal cord injuries. Assume they don't have the expertise and be prepared to fill in the blanks, making all your needs known upfront.

If your destination is outside the USA, all bets are off. Since other countries don't have to comply with ADA regulations, it will be critical that you speak directly to the hotel to get accurate information regarding accessibil-

ity - especially door widths, shower options, commode heights, and space between beds. As stated earlier, get the name of the agent and make sure you double-check all your concerns. Also try and talk with the same agent in the future to maintain continuity and eliminate mistakes. Some larger hotel chains make rooms wheelchair accessible abroad, but this is the exception rather than the rule. Use the Internet to do some of your homework. Many hotel chains do an excellent job with accessibility information. Also, use the recommendations of other people with spinal cord injuries who may have used the hotels in the past. Some travel magazines have published issues devoted to disability information.

Some people choose cruises as an option for their vacations. If this is the case, gather as much information as you can regarding specific cruise line accessibility. Many cruise lines have websites and/or printed information for consumers with disabili-

ties. Make sure you obtain a wheelchair accessible berth and, as with hotel accommodations, make sure all your needs are made clear from the beginning. As a word of caution, in many cases, excursions or day cruises are not necessarily associated with the cruise line. Therefore, you will need to discuss accessibility options once you board the ship.



If your vacation choice is at a theme park within the USA, contact the park directly. Most theme parks have brochures regarding policies and procedures pertaining to persons with disabilities and accessibility options. Additional entertainment options can be obtained through the Internet; state travel and tourism offices, and Chambers of Commerce.

In conclusion, do your homework, plan well in advance, and gather as much information as you can to reduce or eliminate hassles along the way.

Billy Perkins





Ms. Wheelchair America

A Program of Achievement, Advocacy, and Opportunity

The Ms. Wheelchair America Program was established in 1972 by, Dr. Philip K. Wood, a physician who devoted his career to the treatment and rehabilitation of functionally impaired individuals. This volunteer-run, non-profit, national program serves as a forum for the promotion of the achievements, talents, and capabilities, as well as the needs, of mobility impaired women. Traveling the country and making public appearances, Ms. Wheelchair America helps promote awareness of the need to eliminate architectural and attitudinal barriers and inform the able-bodied public of the achievements of people with disabilities. Not a beauty contest, the Ms. Wheelchair America program judges contestants on such factors as personal accomplishments since onset of disability, communication skills, public relation skills, advocacy skills, poise, and demeanor.

The winner of this year's Ms. Wheelchair America program was Juliette Rizzo. From covering national news stories as a journalist to carrying the Olympic torch, Ms. Rizzo has proven that personal dreams and goals are within reach for people with disabilities when the appropriate supports are in place. With the support of the Vocational Rehabilitation (VR) program, Ms. Rizzo was able to pursue an academic dream of a Master's degree in Journalism from the University of North Texas and a Bachelor of Science degree in Journalism from Texas A&M University. She is also a graduate of Partners in Policymaking, a competency-based national leadership and training program for adults with

developmental disabilities.

Ms. Rizzo, 36, serves as the National Communications Director for the Assistant Secretary for Special Education and Rehabilitative Services in the U.S. Department of Education in Washington, D.C. -- an example to others with disabilities, that high-quality, meaningful, integrated employment is within reach. Using a customized Permobil power wheelchair to minimize chronic pain and maximize performance, Ms. Rizzo empowers others with disabilities daily, sharing personal experiences and resources gained through a lifetime of adventures with juvenile rheumatoid arthritis, scleroderma and fibromyalgia.

A visible leader and speaker at the state and national levels, Ms. Rizzo stays connected to the disability community at the grassroots level as well, serving as an

appointed commissioner to the Montgomery County Maryland Commission on People with Disabilities and the board of the Arthritis Foundation Metropolitan Washington, D.C. Chapter. With an Italian flare for food and fashion, Ms. Rizzo also is passionate about accessible container gardening, sailing solo and looking for that elusive Elvis PEZ dispenser to add to her over 200 plus collection. Ms. Rizzo's favorite thing to do, is to go where she has never been before and to ask others to roll with her.



Juliette Rizzo, Ms. Wheelchair America

the SCI SOURCE

POETRY CONTEST

The Source is sponsoring a poetry contest with a \$50 prize to be awarded to the best entry. Persons with SCI and family members of persons with SCI are invited to submit one or more poems for consideration.*

Submit a copy of your poem to "SCI Source Poetry Contest" by email (ddwest@vcu.edu); fax (804 828-2378); or US mail (VCU Box 980542 Richmond 23298-0542).

The top poems will be published in upcoming issues of the *Source*.

Deadline for submissions is Sept. 15, 2004

**All entries become the property of the VCU MC SCI Model System and cannot be returned. Editorial staff of the SCI Source reserve the right to edit poems prior to publication. All entries must represent original works of art, reflecting an effort of personal creativity and unique artistic vision.*

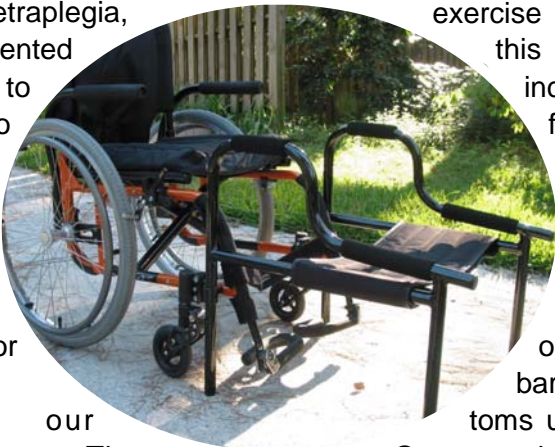
Gizmos and Gadgets

This writer recently had the opportunity to meet Thom DeLilla, program administrator for the Brain and Spinal Cord Injury Program of Florida and inventor of a remarkable new device that allows for increased independence for wheelchair users. As a wheelchair user and individual who has lived for over 30 years with C7 tetraplegia, Thom invented the device to be able to independently transfer from his wheelchair to the floor and back.

During our conversation, Thom brought out his invention - a wheelchair-to-ground transfer system called the Bottoms Up Bars (BUB) system - and demonstrated its use. As I watched, Thom was able to go from his manual wheelchair to a floor in a minute or less. Probably more remarkable though, he was back in his chair in the same period of time. The ease this allows for movement to and from the ground has been said to reduce anxiety and promote greater activity levels.

According to the website (www.enablinginc.com), the system can be successfully used by individuals with C6 and C7 level spinal cord injuries. "If you can lift yourself enough for a pressure release, you can use this product".

Made of aircraft aluminum, the BUB system is lightweight and durable and can be attached with ease to a wheelchair by its users. Once attached, the system helps stabilize the wheelchair so the user can transfer more safely and easily to the ground. The user then places their legs over the Bottoms Up Bars seat and transfers to the seat. The next step is for the user to extend their legs out and lower him- or herself to the ground using the parallel bars for support. Now on the ground, the users can exercise or access this space with increased confidence.



To return to the wheelchair, the user pushes up on the parallel bars to the Bottoms up Bars seat. Once on the BUB seat, the user positions their legs and prepares to push up to ascend to the wheelchair seat. After positioning their hands to ascend up to the wheelchair level, the user pushes up to the wheelchair, brings legs back over the suspension strap, and removes the system from the wheelchair.

For more information about the BUB system, contact Enabling, Inc. 2123 Deerfield Drive, Tallahassee, Florida, 32308. As of publication of this article, the cost of Bottoms Up Bars was \$300. Orders can be taken by phone (1-850-847-1000) or are available through the Concepts in Confidence catalog at <http://conceptsinconfidence.com/catalog/> (under new products).

Michelle Meade

THINKING ABOUT WORK?

Part I

In the long-term, finding and keeping a job is one of the biggest challenges faced by persons with spinal cord injury. Many people who have had an SCI are working successfully and there is much to be learned from their experience. This is the first article in a series to be published by *SCI Source* that will describe and discuss strategies for working and living a productive life. Our discussion will center on helpful ideas offered by successful SCI survivors and experienced professionals.

Are you thinking about finding a job? Answer the questions below to help you make a decision about what kind of job you would like and how work may fit into your life:

- ▶ What did I like most about the jobs I've held in the past?
- ▶ What kind of job would I like to have now?
- ▶ What kind of job would I definitely not like to have?
- ▶ How would working affect my quality of life?
- ▶ Can I work and keep my benefits?
- ▶ How does work affect the way I feel about myself and my life?
- ▶ What skills or qualities do I have to be successful?
- ▶ How can I find an employer who will offer flexible hours, reasonable accommodations, and be sensitive to my other needs?
- ▶ What can I do to increase my chances of success?
- ▶ What resources and supports are available to help me find a job?

The key to finding a job is having an "attitude of success." Having a successful attitude begins with believing in yourself and your power to make the future better. Successful people...

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- ▶ focus on their skills, not their limitations
- ▶ look for opportunities to improve their skills
- ▶ set attainable goals
- ▶ learn from their mistakes instead of blaming themselves and others for problems
- ▶ look for the good in themselves and others
- ▶ look ahead and problem-solve difficult situations before they occur
- ▶ learn to control their negative (and positive) emotions
- ▶ communicate effectively by learning to listen and express themselves clearly

- ▶ appreciate the value of patience and persistence

Understanding how employers think and what qualities they value will help you work successfully. Can you guess what qualities employers value most? Recent surveys have revealed that most employers want the same basic qualities in an employee. They want someone who is:

- ▶ Polite and professional
- ▶ Flexible
- ▶ Reliable
- ▶ Willing to learn
- ▶ Responsible for themselves

In many cases, your willingness to listen and learn will outweigh your lack of experience. Regardless of your physical impairment,

you can choose to show others your best personal qualities.

Understand that finding and keeping a job typically involves a series of steps - thinking about what you want to do and what your skills are.... identifying jobs available in your community and how they are matched to your skills and interests.... seeking and completing training.... interviewing successfully and developing relationships with supervisors and co-workers.

Careful planning at each step will save you time and frustration in the long run. Working successfully takes time, commitment, and learning from experience. Additionally, appreciate the value of good relationships. Ask others you trust for feedback and suggestions to help you stay the course.

Jeffrey Kreutzer



UPCOMING EVENTS



September 11, 2004

Sheltering Arms Community Recreation Services' Adapted Water Sports Spectacular, Lake Anna State Park. 11 am-3 pm, \$10 per person (includes lunch) Space is limited, so please register by September 3. For more information call the CRS office at (804) 560-7230 extension 275.

September 15

Poetry Contest Deadline. Be sure to enter your original work of art to the SCI source by this date to be eligible for the \$50.00 prize. See page 3 in this issue for details.

September 21, 2004

Old Dominion Chapter, National Spinal Cord Injury Association (ODC/NSCIA) Meeting — Sheltering Arms, Midtown 2805 West Broad Street Richmond, VA 23220. Meets the third Tuesday of every month. For more information contact: Shawn Floyd (804) 726-4990.

September 21-25

2004 N.W.P.A. U.S. National Wheelchair 8 - Ball and 9 - Ball Championship — The Playing Field, 7801 West Broad Street, Richmond, VA 23294. For more information contact: Jeff Dolezal (703) 817-1297 or (703) 980-2734 (Cell).

October 13, 2004

Universal Design seminar hosted by The Virginia Housing Development Authority, The Waynesboro Disability Services Board and the City of Charlottesville. 8 am-5 pm — The Doubletree Hotel, Charlottesville, VA. The seminar costs \$50. Registration Deadline is September 12. For registration materials contact: Gail Braham (804)343-5512 — email: gail.braham@vhda.com.

October 15, 2004

Virginia Commonwealth University Medical System Model System Annual *SCI Symposium* — Science Museum of VA, Richmond. This year's theme is "Back to Basics." Contact Brenda Kitchen at 828-0861 or e-mail beagle@hsc.vcu.edu.

October 19, 2004

Old Dominion Chapter, National Spinal Cord Injury Association (ODC/NSCIA) Meeting — Sheltering Arms, Midtown 2805 West Broad Street Richmond, VA 23220. Meets the third Tuesday of every month. For more information contact: Shawn Floyd (804) 726-4990.

October 22-24, 2004

World of Possibilities Disabilities Expo 2004 — Dulles Expo Center, Chantilly,

VA. Three full days of the most extensive selection of disability-related products under one roof including equipment, services and resources in a one stop shopping and learning experience. For more information call (410) 549-5707 or 1-866-227-4644 website www.caringcommunities.org. For free Admit One coupons (\$5 value) contact Shawn Floyd with the ODC/NSCIA at (804) 726-4990.

November 16, 2004

Old Dominion Chapter, National Spinal Cord Injury Association (ODC/NSCIA) Meeting — Sheltering Arms, Midtown 2805 West Broad Street Richmond, VA 23220. Meets the third Tuesday of every month. For more information contact: Shawn Floyd (804) 726-4990.

To include your upcoming events in this section, please contact Debbie West at:

(804) 828-8797
(804) 828-2378 (fax)
PO Box 980542
Richmond, VA 23298-0542
Ddwest@vcu.edu

GLAD YOU ASKED!

QUESTION: What, if any, are the special concerns or issues associated with a woman's health and sexuality after having a spinal cord injury?

ANSWER: There are many important health and sexuality-related issues that pertain primarily to women with spinal cord injury (SCI). Women make up nearly 20% of those with traumatic spinal cord injury (SCI) and usually present, at time of injury, with a relatively young age (mean age in the 30's). Over 50% are married at time of injury. Health and sexuality issues, discussed below, will include: osteoporosis, cancer, sexual activity, menstruation, fertility and menopause.

OSTEOPOROSIS

Osteoporosis is defined as a loss of bone density and has been shown to be a risk factor for long bone (such as the femur) fractures. It occurs in all women following menopause, however, individuals with SCI will also develop osteoporosis below the level of injury, secondary to prolonged immobility and decreased weight bearing. This will begin immediately after SCI and may progress rapidly over the first 3-6 months. Currently there are no proven treatment approaches for halting the bone loss seen following SCI. Hormone replacement therapy remains controversial as potential benefits and risks continue to be studied. Routine management of post-menopausal osteoporosis is recommended, as well as safety issues to avoid risk of fracture to the long bones.

CANCER

Cancer in women with SCI (such as breast, uterine, and colon) continues to present a risk, similar to non-SCI individuals. For

this reason, it is recommended that all women continue to obtain routine (and regular) screening exams for breast (mammogram, breast self-exams), uterine (pelvic exams, Pap smears) and colon (hemocult and blood test) as regularly as non-SCI women. Studies, however, show that women with SCI are less likely to seek out and/or receive these tests.

SEXUALITY

A women's sexuality is an expression of physical and emotional intimacy and reflects physical contact, body image, self- (and partner) satisfaction and the forming of relationships. SCI may affect the experience of sexuality and women with SCI may experience physical and psychological changes that may affect sexual function. Sexuality does not need to change after SCI. It is recommended that women be educated about the effects of SCI on sexual function and about ways to become more at ease with their sexuality and sexual activity.

It has been shown that women can resume active, enjoyable sex lives following injury. Nearly 65% report participation in sexual activity following SCI, compared with 85% prior to injury. Activity increased with the time after injury and with lower levels of injury (lumbo-sacral 80%, thoracic 70%, cervical 60%). Reflex (physical) or psychogenic vaginal lubrication will usually be present, but if not, can be compensated for with lubricants. Problems reported by women during sexual activity included positioning, spasticity, incontinence and autonomic dysreflexia, not satisfying one's partner or oneself, feeling sexually unattractive and lengthy time preparation. Studies have shown that women do report less ability to achieve orgasm following SCI. "Safe sex" for sexually active women for prevention of sexually transmitted disease (STD) continues to be recommended.

MENSTRUATION

A women's menstrual cycle will normally and temporarily stop following SCI, then resume within 3-6 months. Usual characteristics, such as cramping, irritability, emotional instability, water weight retention and pain will continue, though possibly with less intensity. 25% of women note increased spasticity, sweating and flushing during menstruation.

FERTILITY

Following return of the menstrual cycle, women regain the ability to have children, similar to before injury. Thus, it is important to practice birth control techniques, as desired. Due to the estrogen in birth control pills (BCP), there is an increased risk for deep venous thrombosis (blood clots) especially during the first several months after acute injury. Therefore, BCP may be less often recommended. Common methods utilized by many with SCI include condoms, hysterectomy (removal of the uterus) and birth control pills (BCP).

MENOPAUSE

The average age of women with SCI who reach menopause usually occurs at the same time as non-SCI individuals. Menopause may be accompanied by mood disorders, as before injury, as well as increased spasticity, bladder spasms and autonomic dysreflexia.

CONCLUSIONS

It is important for women to be educated and counseled about the effects of SCI on health and sexuality issues following SCI. Additionally, more research is necessary to adequately assess, monitor and provide ongoing recommendations. Life expectancy, in individuals with SCI, is increasing and a better understanding of these factors, as well as those related to aging, will affect women's health, sexual activity and quality of life.

William McKinley

DOMESTIC VIOLENCE AND DISABILITY

Three of the many goals of the Ms. Wheelchair Virginia organization are: (1) to provide education about the frequency of abuse of women with disabilities (2) to facilitate coalitions around the commonwealth to ensure that women with disabilities have access to services and (3) to give a voice to women with disabilities who are being abused. To this end, the committee for Stopping The Abuse and Neglect of Women with Disabilities, or STAND, was created in the spring of 2003.

Domestic violence is defined as "a pattern of abusive behaviors that is used to control someone in the context of an intimate relationship." According to the Colorado Department of Health, upwards of 85% of women with disabilities are victims of domestic violence. Disabled women tend to stay in dangerous relationships/conditions longer than able-bodied women due to a number of factors. Factors include, but are not limited to, a lack of services available to the disabled community and the victim's dependence on the abuser, typically their partner or caregiver,

for their physical needs.

Disabled women experience types of abuse similar to able-bodied women. They also tend to experience unique forms of abuse specific to their disabilities. Unlike their able-bodied counterparts, disabled women have reported abuses such as:

- ▶ being restricted to their beds/wheelchairs
- ▶ being denied meals/strict meal times
- ▶ being exposed to extreme temperatures (not turning on the air conditioner/heat)
- ▶ being denied access to doctors or medical care
- ▶ not given medication
- ▶ being denied access to their own assets
- ▶ purposely being dropped
- ▶ not being turned
- ▶ being left in soiled undergarments for long periods of time

Currently 38 certified Domestic Violence Programs operate residential shelters in Virginia. Some of the mandatory criteria of these shelters are: a 24-hour hotline, cri-

sis intervention and safety planning, temporary emergency shelter/accommodations, supportive counseling, legal advocacy, and children's services. Listed below are wheelchair accessible shelters in the greater Richmond area. For more information on shelters in your area, please visit the Virginians Against Domestic Violence website at www.vadv.org. You may also call:

- ▶ **National Domestic Violence Hotline** - 800-799-SAFE (7233) or 800-787-3224 (TTY).
- ▶ **YWCA Women's Advocacy Program** (Richmond) - 804-643-0888
- ▶ **YWCA Women's Advocacy Program** (Chesterfield) 804-796-3066
- ▶ **Safe Place** (Ashland) 804 - 752-2702

For additional information on disabled women and domestic violence, please contact Virginians Aligned Against Sexual Assault (VAASA) www.vasa.org, the Global Organization for Women With Disabilities, or STAND (Debbie Johnson, Director: 434-846-2146; STANDdj@AOL.com)

Nicole Abdul



ATTENTION:

Persons with Traumatic Spinal Cord Injury

Update for Health... Update for Information... Update for Services...Update to Help

The Virginia Spinal Cord Injury (SCI) Registry was developed to maintain a record of current information about persons living with traumatic SCI in the Commonwealth. This information is used to promote the delivery of appropriate services to improve health, productivity and quality of life.

As part of a study examining the needs of Virginians with traumatic SCI, researchers at Virginia Commonwealth University (VCU) are trying to ensure the completeness and accuracy of the registry. For more information about the project or to make sure that you are represented in the registry, please call 804-828-7962 or e-mail pellenbogen@vcu.edu





Online magazine for women in wheelchairs:
www.mobilewomen.org

Discovering the beauty that exists in every person with a Disability.
www.beautyability.com

A Center on resources and research on parents and children with a disability
<http://www.lookingglass.org>

*National Women's Health Education Center:
Women with Disabilities*
<http://www.4woman.org/wwd/index.htm>

Center for Research on Women with Disabilities
<http://www.bcm.edu/crowd/>

Sexuality for Women with SCI (fact sheet)
<http://www.spinalcord.uab.edu/show.asp?durki=51275>

Pregnancy for Women with SCI (fact sheet)
<http://www.spinalcord.uab.edu/show.asp?durki=22442>

Chatrooms

Women with SCI
<http://health.groups.yahoo.com/group/womenwithsci/>

Pregnancy, mothering and SCI
<http://www.paralinks.net/pregnancysci.html>

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