

The Source

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

Volume 8, Issue 1

Fall 2003

NEW NAME, NEW LOOK, NEW FEATURES

We gladly announce exciting changes in our newsletter, formerly known as *SCI Update*. The Virginia Commonwealth SCI Model System is pleased to introduce our new name, *The Source*. The name change reflects a greater commitment to consumer-oriented service-delivery. We have worked hard to provide practical information and news for persons with Spinal Cord Injury. Regular features will address quality of life issues such as mobility ("Have Chair, Will Travel"), medical or emotional well-being ("Glad You Asked"), and accommodations for everyday living ("Gizmos and Gadgets"). The *Source* will also highlight progress on Model

System projects, important events in the region, human interest stories ("Spotlight On..."), and resource management ("Getting There From Here"). Reader input is encouraged.

Do you know a person with SCI whose story would be of interest to others? Do you have a question you keep meaning to ask your doc, but never get around to? Have you heard of some promising new device or gadget that others might find of interest? Let us hear from you! Contact: Debbie West, Dissemination Coordinator

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Richmond, VA 23298-0542
Phone: 804-828-8797

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VCU AWARDED COMMONWEALTH NEUROTRAUMA INITIATIVE (CNI) GRANT

STUDY TO ASSESS NEEDS OF PERSONS WITH TRAUMATIC SCI

The Department of Physical Medicine and Rehabilitation, in collaboration with researchers from African American Studies and The Survey and Evaluation Research Laboratory at Virginia Commonwealth University, has received an exciting grant from the Commonwealth Neurotrauma Initiative (CNI) which we hope will improve the range and quality of services available to SCI patients and their families. The project involves a statewide needs assessment of Virginians with traumatic Spinal Cord Injury (SCI) and its purpose is to identify the current met and unmet needs of people living with SCI in Virginia. The principle investigators for this project are Drs. Michelle Meade, Njeri Jackson, and Kirsten Barrett.

There are actually three parts to this ambitious project. First, we will be updating the Virginia SCI Registry. The Virginia Spinal Cord Injury registry was created in 1978 based on legislation from the state government. This legislation mandates hospitals to report persons with Spinal Cord Injury, or suspected spinal cord injuries, within 7 days of identification. This information is used to determine health care costs and to justify and improve the delivery of rehabilitative services by the Department of Rehabilitative Services and other agencies. Persons listed on the registry, which is now operated through the Department of Rehabilitative Services, are sent information about Spinal Cord Injury and resources avail-

able in Virginia and may receive periodic newsletters, announcements and be contacted to evaluate their current status or their satisfaction with services.

Second, a series of focus groups and individual interviews will be conducted to gain a better understanding of the issues, needs and concerns of Virginians with SCI. We will be conducting these groups and interviews primarily with women, children and members of minority groups (primarily African - Americans/ blacks and Latinos(as), because research has shown that these groups are underserved. Individuals selected to participate in these two-hour groups will receive \$50 to cover the costs of their travel and expenses.

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Gizmos and Gadgets



Welcome to Gizmos and Gadgets! In each newsletter, this column will focus on different technological advances that can improve the life of those with SCI. This time around we will look a common assistive pointer device for the personal computer, the trackball mouse.

A trackball is essentially a traditional mouse that's lying on its back. To move the pointer, you move the ball with your hand and then use the buttons that are usually near the ball, just as you would the buttons on a regular mouse. However, there are as many different configurations as there are manufacturers – and there are a lot. Most major companies that make peripherals for computers now offer some type of trackball and some have a couple of different types. The options can be endless. The ball can be located in all sorts of positions within the mouse. Most commonly it is in the middle or slightly forward on the mouse, but some can be placed closer to one side to be moved with the thumb. There can be communication to your computer through serial or USB connections, or in the case of wireless mice, use infrared or radio waves.

One of the biggest advantages over the traditional mouse is that because it is stationary, it does not require much space to use. Trackballs have also been gaining popularity in the general population because they offer ergonomic relief from Repetitive Strain Injury (RSI) and Carpal Tunnel Syndrome (CTS) that have been associated with computer use. While they can be a convenience and offer pain relief to the general population, they may be a necessity for those with limited hand function due to a SCI.



Trackball Mouse

One company in particular, GPK, Inc., has designed a trackball specifically for those with limited or no hand or finger function called the Quadtrac. It was designed by a C4-5 quadriplegic for use by others with disabilities due to arthritis, CTS, RSI or paralysis. The one way in which this is very different from other trackballs is that there are two large remote buttons that perform the same functions as the buttons on the mouse. This makes it much easier for those without full use of their hands because they can use one hand to click and the other to move the cursor. According to their website, "This is particularly helpful in situations where it is necessary to hold down the left or right button and move the pointing device at the same time. The remote switches make it possible to use one hand to click and the other to move the cursor." The Quadtrac is available for either serial or USB connections and requires no specialized software or drivers.

If you have been struggling trying to use a traditional mouse because of limited hand function or pain, or if you are just looking to try something a little bit different without a huge investment, maybe a trackball is for you. For more information, check out your local computer shop, or office supply store. For more information on the Quadtrac GPK can be reached online at www.gpk.com. or at 1-800-468-8679.

Shawn Floyd



Traditional Mouse

UPCOMING EVENTS

September, 28-29

12th Annual VCU MCVHP SCI Symposium, "What's Best for Our Patients? An Ongoing Search for Answers". This event has been rescheduled for March 28 - 29, 2004, due to Hurricane Isabel. Please see page 5 for details.

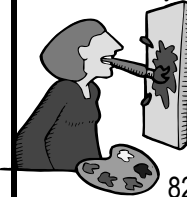
Sunday, October 12th:

Sheltering Arms 11th Annual Different Strokes Golf Classic
 Birksdale Golf and Country Club; 12 noon registration; 1 pm shotgun start \$60 (greens fee, cart, box lunch, dinner and awards). Each 4-some will consist of 3 non-disabled and 1 physically challenged golfer. Registration deadline 10/3/03. Rhonda Riggelman 804-915-1174., ext. 254



Wednesday, October 15th

PosAbilities Unlimited, an organization supporting adaptive recreation for persons with disabilities, meets on the 3rd Wednesday of each month at 6 pm. The next meeting is at Sheltering Arms on Broad Street on October 15th. For more information, contact Dr. Michelle Meade at 804-828-5401 or mameade@vcu.edu



October 21st 5:30 – 6:45p.m

Old Dominion Chapter, National Spinal Cord Injury Association Meeting
 Tuesday, October 21st 5:30 – 6:45p.m
 Sheltering Arms, Midtown
 2805 West Broad Street
 Richmond, VA 23230
 For more information contact: Shawn Floyd 270-1793

Saturday, October 11th All Day

Wheelchair Basketball Tournament
 Monticello Area Community Action Agency (MACAA)
 1025 Park Street
 Charlottesville, VA 22901
 For more information contact: Rick Shifflett at The Independence Resource Center (434) 971-9629



VCU'S SCI MODEL SYSTEMS PARTNERS WITH GOODWILL INDUSTRIES



Virginia Commonwealth University's Regional Spinal Cord Injury Model System is proud to announce its partnership with Goodwill Industries throughout Virginia.

Goodwill has graciously allowed VCU the use of their computer labs and other facilities so the "Introduction to Computer Skills and Job



Search Training" course may be made available to those in Richmond, Fredericksburg and the Hampton Roads/Peninsula areas.

Most recognize Goodwill Industries by their retail stores and large green trailers that are their collection sites. What we don't often know is where our donations go or what is done with the money raised by the sale of those items in the retail stores. Goodwill's mission is to serve people with

workplace disadvantages and disabilities by providing job training and employment services. To fund that mission, they collect

donated clothing and household goods to sell in their retail stores. The proceeds of these sales are combined with financial donations to support essential social services. People receiving Goodwill job training, who

may not be ready to join the competitive labor force, process donated goods for eventual resale.

As these people are empowered to work, they cease to be recipients of tax dollars (through welfare or disability, for example) and become tax-paying members of the community. The



business community in turn, receives a steady stream of motivated workers, trained in fields where job openings exist.

Goodwill Industries offer a full array of employment services such as situational assessment, job skills training, an open to the public job resource room (Richmond branch), transitional employment and job placement assistance. Approximately 20 percent of all persons served by Goodwill each year are individuals with disabilities who are referred

to them by state vocational rehabilitation agencies. These programs at Goodwill provide a perfect "next step" for those who take the Introduction to Computer Skills and Job Search Training course.

Shawn Floyd



MS. WHEELCHAIR VIRGINIA SEEKING CONTESTANTS AND SPONSORS

It is time to register to be a contestant in the "Ms. Wheelchair Virginia Pageant," a three day weekend March 12-14, 2004 at the Omni Hotel in downtown Richmond, Virginia. Applications are available on-line or by mail.

Participants must be between the ages of 21 and 60, use a wheelchair as their primary means of mobility, be a resident of Virginia for the last 6 months and a U.S. citizen. Contestants must possess good communication abilities and be

willing to travel the state as an "Ambassador" for disabled Virginians. Registration and application fees are required.

This is NOT an outward beauty pageant. This is about the beauty inside. Women are judged on advocacy, accomplishments, self-confidence, and ability to speak with others about disabilities.

Each contestant must have a platform, a personal conviction that is important to her that she will present to the judges. This

winner will be a role model for disabled Virginians and go on to the National Ms. Wheelchair America Pageant.

Please visit our web-site at www.mswheelchairva.com or call Debra Willis at **673-6500** or **800-247-7636**, e-mail mwheelchairva@yahoo.com

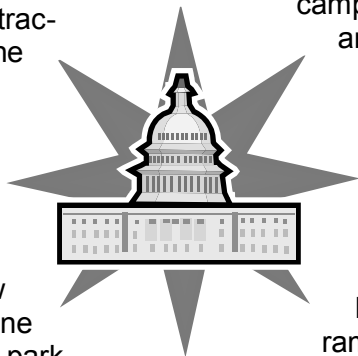
Affiliated with Ms. Wheelchair America Organization



HAVE CHAIR, WILL TRAVEL

Did you know that Virginia has a travel guide that can make it easier for people with mobility impairments to make plans for either brief or extended trips within the state? Published by *The Opening Door, Inc.* in cooperation with the Virginia Tourism Corporation, The Virginia Travel Guide for Persons with Disabilities, is now in its fourth edition. While some restaurants and lodging accommodations are reviewed, the focus appears to be on attractions throughout the Commonwealth.

Want to find about the accessibility of the State Capital? Page 200 of the guide, printed in large type, lets you know that the capital has one wheelchair accessible parking space at least 96 inches wide, as well as a public phone at wheelchair level. Paths around the building are apparently either brick or paved street and have no steep grades. A public restroom, with a heavy 38" door that opens in, is on the first floor. Additional measurements are given for the width



of stall doors, toilet seat and sink height, and the amount of distance between the commode and the wall. An elevator is available (27" door width with 54" control buttons) to all floors. In addition, both the snack bar and the gift shop have accommodations for persons in wheelchairs.

In addition to providing the specifics about places, the guide provides information and contact phone numbers for travel resources throughout the Commonwealth. These include airports, bus stations, and equipment rental companies. Information about the accessibility of recreational areas, campgrounds and fishing and boat ramps are also provided. For example, Quarry Pond in Richmond's Belle Island Park has an accessible fishing pier, while Back River in Hampton's Fox Hill has an accessible boat ramp and pier, as well as accessible restrooms.

While not comprehensive, the Virginia Travel Guide for Persons with Disabilities is at least a good place to start when considering travel within Virginia. To request a copy, call 1-800-742-3935 or access it on-line at: <http://www.travelguides.org/index.html>.

Michelle Meade

SITES TO SURF

Spinal Cord Injury Resource
www.wheelweb.com

National Spinal Cord Injury Association
www.spinalcord.org

Disabled Sports USA
www.dsusa.org

Wheelchair Sports USA
www.wsusa.org

Assistive Technology
www.enablemart.com

Magazine Websites
www.disabilityworld.org
www.360mag.com


National Council on Disability
www.ncd.gov

Society for Accessible Travel and Hospitality
www.sath.org

These websites and many more like them may be found in VCU Health System SCI Community Resource Directory available at: www.sci.pmr.vcu.edu/Resources/SCIResourceGuide.pdf

Shawn Floyd

GETTING THERE FROM HERE



It is our hope to provide individuals with spinal cord injury, family members and healthcare professionals with resources that will enable the individual to achieve their highest level of independent functioning. Resources will be discussed relating to emotional, financial, social, spiritual, and vocational rehab. Through the management of resources, individuals with spinal cord injuries and their families will find it easier to get from here to there.

The **RRC SCI RESOURCE GUIDE** was developed by the RRC special interest group from an interdisciplinary approach. The goal of the guide is to educate patients, family members, and healthcare professionals about community resources available to enable the patient to have a knowledgeable transition to the community. This resource is given to patient and family while in acute rehab. The resource guide is available online at www.sci.pmr.vcu.edu/index.html.

If you have a resource of interest, please contact **Vera Thomas**, MSW 804-828-2541 or email vthomas@vcu.edu.

Vera Thomas, MSW

DR. STANLEY DUCHARME HEADS LIST OF EXPERTS AT VCU'S 12th ANNUAL SCI SYMPOSIUM MARCH 28 - 29 2004

The VCU Health System will host the Mid-Atlantic Region's 12th annual conference on SCI Management. Rescheduled due to Hurricane Isabel from the original September 2003 date, this year's meeting will be held March 28 - 29 2004 in Virginia Beach, Virginia. More than two hundred SCI professionals and consumers with dozens of exhibitors are expected to gather at this meeting.

Historically, the diversity and interdisciplinary nature of this symposium has made the conference a wonderful educational opportunity for all SCI consumers, rehabilitation professionals, and students.

This year's meeting will feature keynote presentations by *Stanley Ducharme, Ph.D.* Dr Ducharme is a clinical psychologist and internationally recognized expert

in the field of sexuality and SCI. As a consultant at Boston University Medical Center, Dr. Ducharme specializes in the treatment of sexual dysfunction, physical disability, addictions, and relationship issues. He has traveled worldwide to assist hospitals and rehabilitation centers develop programs for individuals with disabilities and is the author



Stanley Ducharme, PhD
Assistant Professor of Urology
Boston University
School of Medicine

of the Sexuality After Spinal Cord Injury".

Billy Perkins, CTRS is a frequently requested motivational speaker at rehabilitation conferences. He provides a unique perspective as both a rehabilitation clinician and an SCI consumer, injured nearly 20 years ago. During that time he has led an amazing life and his blend of humor, practicality and positive attitude make him a speaker not to miss.

As always, there are also a number of concurrent sessions offered during the meeting. Also, a series of pre-conference workshops will be offered on May 29th.

For more details please contact: Conference Manager at (804) 828-0861, or e-mail beagle@hsc.vcu.edu.

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The information collected from these interviews and focus groups will be used to develop a comprehensive survey, which will be then be sent to everyone who is listed in Virginia's newly updated SCI registry. The results of the survey will be distributed to agencies serving people with SCI throughout the state, and will be used to enable them to develop and provide better programs and services, as well as to determine policies.

For this needs assessment project to be successful, we need to obtain information from as many Virginians with SCI as possible. To do this, we will be asking all persons with SCI living in Virginia to update their registry information and complete a mail survey. Cards will be mailed to all persons currently on the registry to ask for their assistance. If you receive a card in the mail asking you to update your registry information, please complete and return it. These cards will also be available at various sites serving persons with SCI, most likely in the fall.

We are excited about the project and the opportunity it provides to gain a more comprehensive understanding of the issues and concerns faced by persons with SCI and their family members. If you are interested in finding out more about this project, you can contact Phyllis Ellenbogen, Project Coordinator, at (804) 828-7962 or e-mail her at pellenbogen@vcu.edu. *Phyllis Ellenbogen*



The mission of The National Spinal Cord Injury Association (NSCIA) is to enable people with spinal cord injury and disease (SCI/D) to achieve their highest level of independence, health, and personal fulfillment by providing resources, services, and peer support.

The Old Dominion Chapter of NSCIA has been working with this mission in mind in the Richmond area since 1948. The ODC/NSCIA provides services to individuals, family members, friends and professionals working in spinal cord injury and disability-related fields. They are in the process of revitalizing their chapter and hold monthly meetings, publish a quarterly newsletter, and would love to have new people come and take part. For more information, contact Shawn Floyd @ 270-1793 or whlbound@comcast.net.

The National Spinal Cord Injury Association
Old Dominion Chapter
P.O. Box 8326
Richmond VA 23226

Spotlight on...

Shawn Floyd. Person with a Spinal Cord Injury. Advocate. Athlete. Mentor. Teacher. Researcher. Devoted Fiancé. Valued Employee.

Person with SCI. Shawn was in his 2nd year of college at Radford University when he sustained a T6 ASIA A SCI as a result of a car accident in November, 1998. After finishing rehabilitation, he returned to college at VCU and completed his Bachelors degree in criminal justice.

Advocate. Articulate and passionate, Shawn is devoting considerable energy revitalizing the Old Dominion Chapter of the National SCI Association. He will soon be completing his term as secretary and hopes to run for president of the chapter. His plans include establishing an official office, partnering with rehab facilities to institute a SCI Mentor program, and initiating fundraising events.

Athlete. A committed wheelchair basketball player for the last two years, Shawn can be seen on courts throughout Virginia and the mid Atlantic with the Charlottesville Cardinals, and heard complaining about the resulting aches and pains on the 1st floor of North Hospital where he works.

Mentor. For over 3 years, Shawn has served as a

peer mentor for individuals with new injuries that are completing their rehabilitation at VCUHS or Health-South.

Teacher. Shawn is one of the trainers for the Computer basics and Job Search Skills training classes. Initially hired only to teach a given curriculum, he has taken responsibility for ensuring that the class teaches practical skills and addresses issues around considering employment and interviewing with a disability.

Researcher. Well, sort of – it is a skill in development. Shawn serves as coordinator for the previously mentioned training class, a research project under VCU's SCI Model System. Though he's been heard to say that he'll leave the evaluation and research part to someone else, Shawn does assist with data collection for the Model System.

Devoted Fiancé. Having finally asked his girlfriend of 2 years to marry him, Shawn now spends part of his time making wedding plans.

Valued Employee. Definitely. Convincing Shawn to switch from occasional consultant to VCU employee in March of this year has been a very wise move. Shawn's energy, intelligence and practical down-to-earth manner provide balance and richness to the SCI Model System.

Michelle Meade, PhD

GLAD YOU ASKED!

QUESTION: My spouse is making progress in rehabilitation, but I am worried. I've been too embarrassed to approach the doctor on the subject of physical intimacy. Can you tell me what we might expect in terms of resuming our love life after hospital discharge?

ANSWER: Sexuality is an expression of a person's maleness or femaleness best expressed through their physical, emotional and social behavior. It affects our sense of well being, self-image and self-esteem. Sexual function plays an important role in the lives of individuals with spinal cord injury (SCI) and can have a tremendous impact on their quality of life.

Masters and Johnson best described the human sexual re-

sponse and proposed it as having four phases. These include the excitement phase, followed by plateau, leading to orgasm and ending with resolution. The excitement phase includes increase blood flow to the male and female genitalia leading to erections in males and vaginal lubrication in females. Nervous system control of sexual function includes both psychogenic (imagery, visual, olfactory and auditory stimuli) and reflexogenic (tactile stimuli). The plateau phase follows and is accompanied by a pattern of increased heart rate, blood pressure and breathing.

Orgasm includes male ejaculation and female pelvic floor contractions and is accompanied by a release of tensions built up during the excitement and plateau phases. Females can have immediate repeat orgasms whereas males will be unable to achieve orgasm again for at least 15

to 20 minutes.

Physical sexual impairments following SCI include erection and ejaculatory dysfunction in males and decreased vaginal lubrication in females. Most women reported that they continued to be sexually active after SCI, however with decreased frequency as opposed to prior to injury. Whereas sexual intercourse was reported as the "favorite sexual activity" prior to SCI, both men and women reported that activities such as hugging, kissing, touching and oral sex played bigger roles in sexual activity following SCI. Reported dissatisfaction with intercourse following SCI includes decreased enjoyment, opportunity and desire. Sexual dysfunction following SCI can be secondary, not only to the physical impairments, but also to decreased sexual drive (due to fatigue or

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STATEWIDE COMPUTER AND WORK READINESS PROGRAM

This program is geared specifically toward individuals with SCI interested in developing basic computer skills and (re)entering the workplace.

Instruction in the program includes:

- ▶ Basic computer skills
- ▶ Accessing Windows
- ▶ Introduction to the Internet
- ▶ Assistive Technology
- ▶ Dealing with fears and other issues
- ▶ Choosing a direction
- ▶ Evaluating Options
- ▶ Job Search Skills
- ▶ Resume and Cover Letters
- ▶ Interview Skills
- ▶ Dealing with Discrimination



Trainers Shawn Floyd and Gregory Morris

To be eligible, you must:

- ▶ Have a Spinal Cord Injury.
- ▶ Be at least 3 months post injury.
- ▶ Be between 18 and 60 years old.
- ▶ Be interested in exploring educational and employment opportunities.
- ▶ Be willing to participate in research by completing several brief surveys before and after this research and training program

*There is **no charge** for individuals to participate in this program. For registration or more information please contact :*

*Shawn Floyd
Research Specialist
Virginia Commonwealth University
(804) 828-1071
sffloyd@vcu.edu*

(Continued from page 6)

pain), inadequacy of self-esteem or self-image, or to a lack of knowledge surrounding sexual potential or behavior following disability. Additional associated factors may include difficulties with positioning during sex and occurrence of secondary SCI issues such as spasticity, bladder or bowel issues and blood pressure (such as autonomic dysreflexia).

Although erection capabilities are present in most males following SCI, they are frequently unsatisfactory in rigidity of duration and may lead to less than satisfactory functional ability for intercourse. Additional factors associated with erectile dysfunction include secondary medical disorders such as diabetes, hypertension, vascular disease or depression along with smoking, chronic use of alcohol and certain medication side effects.

Several effective options to enhance male erectile function include, most notably, the use of oral medications, vacuum pump and constriction ring devices or penile injection with medications that induce blood inflow. Individuals are encouraged to discuss these options with their physicians.

Self-report studies have noted that both males and females are much less likely to have orgasms following SCI (less than 50%). Women reported that orgasms took more time and effort to achieve than before SCI. In women, there is no loss of fertility (or ability to become pregnant), once menstruation has resumed (usually 3-12 months after SCI). Female contraception, then, remains an important issue and should be discussed with physicians knowledgeable about SCI. Male fertility following SCI can be substantially diminished (especially with the more complete injuries). This is due to diminished ejaculatory ability and poor sperm motility (movement). Through the use of assisted devices (such as penile vibrators, electro-ejaculation and home insemination kits) and assistive technology (such as intrauterine insemination and more recent advancements), fatherhood is very possible.

It is clear that SCI adversely affect sexual function and desire. An individual's success with sexuality and sexual function following SCI has been linked to many factors, however three key factors are:

- ▶ knowledge
- ▶ preparation
- ▶ communication.

The individual must be educated about the realities of potential sexual dysfunction and available options to enhance sexual abilities. Sexual interaction needs to be accompanied by appropriate preparation and open communication with the significant other in order to allow for the best potential for success.

William McKinley, MD

ATTENTION: Persons with Traumatic Spinal Cord Injury

SHARE YOUR IDEAS!

HELP DETERMINE FUTURE PROGRAMS & SERVICES

EARN \$50



You can do all of these by attending a 2 hour focus group or individual interview.

If you are a member of **any** of the following groups and have had a traumatic SCI, we are interested in hearing your opinions and concerns and those of your family members:

- ▶ women
- ▶ between the ages of 8 and 18 years old
- ▶ Black/African American, Hispanic/Latino(a)
- ▶ another racial minority group



To find out more, please contact:

Phyllis Ellenbogen at (804) 828-7962 or pellenbogen@vcu.edu

Interviews and focus groups are conducted as part of a comprehensive Needs Assessment of Virginians with SCI being conducted by researchers at Virginia Commonwealth University.

Research Byte...

The New England Regional Spinal Cord Injury Center is conducting a study on the relationship between pain and education and/or employment.

They are currently looking for participants to participate in a 45 minute telephone interview. To qualify, eligible participants must have sustained an SCI more than 2 years ago and be enrolled in the National Institute on Disability and Rehabilitation Research (NIDRR) funded Model Systems project (either at VCU or another center). Participants will receive \$25 for participating.

If you have questions about the study or are interested in receiving more information, please contact:

Mark Vedrani at:

1-800-796-1814

or

Jane Wierbicky at:

1-866-607-1804

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