

SCIAccess

Insights and Information for People with Spinal Cord Injuries

Spreading Our Wings: The Michigan SCI System (MSCIS) Enters a New Era

By: Denise G. Tate, Ph.D., ABBP, FACRM

Summer/Fall 2017

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This newsletter marks the beginnings of an exciting new era of spinal cord injury (SCI) research and education in our Department of Physical Medicine and Rehabilitation (PM&R). We have joined forces



Dr. Denise Tate

with scientists from across the state, nation and world who share our laser-focused research goal-achieving better health outcomes for people with SCI. Over the past several years, efforts have been made to improve the health and quality of life of our patients with SCI by our research and clinical care teams. While results have been very good, we still have more opportunities for improvement as our health care environment and research funding changes. A number of exciting steps mark these new beginnings.

The Michigan SCI System

In developing a new infrastructure and leadership role, we are expanding our research collaborations with new partners across the state. One of our strategic objectives is to build a statewide system for research on SCI that can lead to new innovations and discoveries. We are moving forward with our affiliation with the Grand Rapids-based, Mary Free



Dr. John Butzer

Bed (MFB) Rehabilitation Hospital and Dr. John Butzer, Director of the Butzer Center for Research and Innovation. We also continue our partnership with the Ann Arbor Center for Independent Living (AACIL), which dates

back to 1986. The first meeting with our partners occurred in February of 2017 with more than 40 collaborators present representing researchers, clinicians, consumers and state agency administrators. A second meeting took place in June in Grand Rapids.

New Research Funding

I am pleased to announce that our department's SCI research team has received funding from the U.S. Department of Defense (DoD) Office of the Congressionally Directed Medical Research Programs, the Craig H. Nielsen (CHN) Foundation, and the Michigan Fraternal Order of the Eagles for new studies on a variety of SCI topics. We continue to move forward with our focus on neurogenic bowel and bladder research and two newly funded projects will address this topic. Following our first study funded by the DoD on bowel and bladder complications, one new study will examine how civilians and veterans with SCI make decisions about managing their bowel and bladder and related outcomes. Through this study, patients' narratives will contribute to our understanding of clinical practice guidelines for neurogenic bowel and bladder management by adding their perspectives. Personal values and preferences take on great importance in making treatment decisions. We are very grateful to our project collaborators: Dr. Lisa DiPonio, Chief of Physical Medicine and Rehabilitation at the VA Ann Arbor Health Care System and Michael Harris, Michigan Paralyzed Veterans of America.

Funded by the SCI Research and Clinical Trial program of the CHN Foundation, another new project will test a wireless technology to help evaluate bowel problems. Dr. Gianna Rodriguez, Clinical Associate Professor who treats many SCI patients at U-M while working in the Michigan Medicine Bowel Control Program, will lead this project in collaboration with U-M's Division of Gastroenterology.



THE MICHIGAN DIFFERENCE

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Springing Forward: SCI Collaborators Spark Fresh Project Ideas and Plans

By: Sunny Roller, SCI Access Editor and Tom Hoatlin, Co-Chair MSCIS Advisory Council, SCI Access Co-Editor

On Feb. 22, 2017, Denise Tate, Ph.D. organized and led the first meeting of the new MSCIS. The main goal of this meeting was to establish an SCI network of research collaborators in Michigan. This will include consumer representatives and clinicians who are concerned with the wellbeing and quality of life of persons with SCI. Those who attended included consumers and professionals from the MSCIS Advisory Board, the Ann Arbor Center for Independent Living (AACIL), Mary Free Bed Rehabilitation Hospital, the Michigan Medicine Department of Physical Medicine and Rehabilitation, and Department of Family Medicine.

The specific purposes of this meeting were to:

- Identify critical areas of research for persons with SCI living in Michigan and implications for policies based on this research
- Brainstorm potential joint research proposals, publications and ideas to submit to new governmental and private funders
- Expand the network of collaborators locally, statewide, nationally and internationally.

A Personal Reflection from Tom Hoatlin

At the meeting, all discussions had quality of life for people with SCI as the most important outcome. Nothing new there, but what was noteworthy is that we were invited to the table and asked what was most important to us. The four areas were:

- Treatment and methods of recovery including clinical, drug and device trials to improve function
- Interventions to make Activities of Daily Living (ADLs) easier for people with SCI
- Wellness, fitness and exercise after SCI and
- Sexuality and intimacy.



Mr. Hoatlin co-chaired this meeting and is a person with SCI.



Spreading Our Wings...Continued from page 1

The team will investigate the use of a new technology, the Wireless Motility Capsule (WMC) to evaluate the pathophysiology of neurogenic bowel dysfunction in SCI. The WMC has been used to assist with improving the accuracy of measuring gastrointestinal motility and pressures. It is an ingestible capsule that utilizes sensory technology to evaluate gut transit times with great accuracy. The WMC is an innovative device that will make it easier for patients to complete GI testing and for physicians to diagnose problems. The WMC is ideal for use among people with SCI who have GI issues since it is a less complicated procedure for people who have mobility impairment and access challenges.

The second of four studies that are being funded by CNH Foundation asks, "how does exercise improve life and what are the secrets for maintaining a long-term SCI workout program?" This investigation compares the effectiveness of two barrier-free health programs. For this, U-M's Drs. Michelle Meade and Mark Peterson will be working closely with Dr. John Butzer, study PI, and his research team at MFB Rehabilitation Hospital. Our research faculty also continues to explore ideas for further research collaboration with Dr. Allan Kozlowski, Director of Outcomes Research at MFB, on mapping life trajectories for persons with SCI.

The third CNH study will evaluate if an easy to use quality of life measure for people with SCI is responded to similarly by people in different areas of the world. This research led by Dr. Tate and her team involves two sites in the United States (U-M and Craig Hospital in Colorado) along with sites in Brazil, Australia, and The Netherlands. The idea is that this measure can be used around the world to examine the effects of treatments for SCI and their impact on people's lives.

Quality of caregiving is a key issue to people with SCI. The fourth study will develop a new measure of the relationship between people with SCI and their caregivers. It explores caregiving from the perspective of people with SCI. Marty Forchheimer, our Senior Research Associate, and the study's principal investigator will lead it, along

with Dr. Tate, Dr. Meade, Director of the U-M Rehabilitation Engineering Research Center, and Dr. Carlozzi, Director of the Center for Clinical Outcomes Development and Application (CODA)."



Carolyn Grawi, (second from the right) Director of the Ann Arbor Center for Independent Living, is fully engaged as a SCIMS collaborator.

Fifth, Dr. Carlozzi will evaluate how sleep quality affects day-to-day symptoms of fatigue, pain, thinking, physical activity and social participation. The study will have participants utilize wrist-worn sleep and activity monitors, do text messaging and take surveys. Project results should help researchers discover useful ways to improve both sleep and functioning for people with SCI. Dr. Carlozzi is partnering with researchers from the University of Washington on this study titled "The Impact of Sleep Quality on Symptoms, Cognition, and Functioning in SCI".

We continue to be funded by the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR) as a SCI Model Systems Data Collection Center. This funding allows us to continue to follow our patients who have been part of our UM-SCIMS program since 1986. With some funding from the Michigan Fraternal Order of the Eagles we will be examining other disorders in those aging with SCI as well as developing a common data collection system to best share SCI knowledge on treatment and clinical trials

with other sites around the world.

Our MSCIS is also committed to educating young professionals to become excellent SCI researchers. Funded by NIDILRR since 1994 we have trained more than 115 fellows

over the years. We continue to collaborate with both the Institute of Gerontology at Wayne State University and with Michigan State University's Rehabilitation Counseling doctoral program to recruit and train post-doctoral fellows in rehabilitation research. Our current fellows, Edward Rohn PhD and Ryan McGraff PhD, are both conducting SCI research in collaboration with their community partners. While Dr. Rohn continues to manage our DoD studies on bowel and bladder and decision making, Dr. McGraff recently presented his work on SCI mortality at the 34th James Rae Research Day in Ann Arbor.

As we conduct these new studies and further expand the MSCIS we look forward to sharing the research results with you, our readers, in person, on our website and in forthcoming issues of *SCI Access*.

**For your comments
about this newsletter please
contact Diane Nicholls
at the MSCIS office.
Her email address is:
dnicholl@med.umich.edu**

Not Your Grandpa's YMCA!

The New Mary Free Bed YMCA is a National Leader in Universal Design

By: Tom Hoatlin

On a recent field trip for a Mary Free Bed (MFB) and Michigan Spinal Cord Injury System (MSCIS) collaborative meeting in Grand Rapids, our group was treated to a private tour of the new MFB YMCA located at 5500 Burton Street SE, Grand Rapids, just a short drive from the downtown hospital campus.

As a health and sports minded paraplegic, I was blown away by the lengths that the architects went to make the facility a national model of universal design. The building is designed with everyone in mind. The first "welcome sign" to me was right when I entered the building. A wide entrance to a massive ramp that everyone uses to access the main service area on the lower level greeted me. Though there were stairs, located on either side of the ramp, they clearly served as a secondary option for accessing services. This visual feature invited me to be a part of the MFB YMCA experience right from the get-go!

The 36-acre complex is home to a wide range of fully accessible spaces and amenities. From a sea of neatly lined up and appropriately spaced cardio equipment to free weights, strength and training equipment and youth and adaptive fitness equipment, this \$30 million facility is not your Grandpa's YMCA! I watched people of all abilities walk, run and roll around the half mile outdoor paved trail. While outside I saw accessible sports fields, a green house, learning farm and tennis courts. Back inside, I was impressed with the family fun pool, the lap training pool and sauna. One challenge people with disabilities have in traditional gyms is changing and showering in locker rooms. Not only is there a fully accessible family locker room with roll-in showers, but there is also a full size raised mat to be used for dressing.

This exemplary facility gives so many more community members an opportunity to take part in engaging activities that promise to enhance their well-being. Actually, you could even bring your Grandpa to the MFB YMCA because you would both be able to get in and access the same programs and services.

For more information on the Mary Free Bed YMCA and adaptive sports programs visit their website at: www.grymca.org/mary-free-bed-ymca or call: 616-285-9077.

We Enthusiastically Join Michigan Medicine to Benefit People with SCI

By: John F. Butzer, M.D., Director of Research, Mary Free Bed Rehabilitation Hospital

We at Mary Free Bed (MFB) are very pleased to be collaborating with the strong research team at the University of Michigan. Our work has become intensely fortified as we now focus together on our mutual goal: to benefit the lives of

annual sports clinics. MFB sponsors the Hand-cycle and Wheelchair divisions of the Fifth Third River Bank Run and hosts several annual special events such as the Junior Wheelchair Sports Camp and Bikes for the Rest of Us. Along with this physi-



Mary Free Bed's Research Team Front row: Sam Ho , Jackie Wo dolowski , Abby Moore , Rebecca Cistaro , Lauren Lenca , Roberta Virva Back row: Joe Gavan, Ariel Lugo, Al Koslowski, John F. Butzer

people with SCI. The combined research teams at MFB and Michigan Medicine's Department of PM&R are committed to improving physical function and quality of life for persons with SCI. We believe that good research requires teams of talented scientists, clinicians, and people with SCI who agree to actively participate in that research. Such dedication then, will attract more research funding that will ultimately lead us to vital new knowledge about living well with a spinal cord injury.

As mentioned on page three, we are currently collaborating on a study, funded by the Craig H. Neilsen Foundation, to increase physical activity and health related quality of life for people with SCI. This study is based at the MFB YMCA in Grand Rapids, which is a new fully accessible facility with adaptive equipment suitable for people with SCI. The Wheelchair & Adaptive Sports Program sponsors 14 sports teams and hosts seven

cal activity study, we are also immersed in critical research on women's health.

In addition to research, we are jointly advocating at the local, state and national levels for new public policies that will ultimately improve the quality and fullness of life for people with SCI.

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MFB is a private, non-profit, teaching hospital located in Grand Rapids, Michigan. MFB operates 119 acute rehabilitation beds and an additional 48 skilled nursing beds for subacute rehabilitation. Comprehensive outpatient care including therapy, home health, and physicians serve persons in West and other areas of Michigan. For over 100 years, MFB has advocated for people with disabilities and particularly for participation in sports.

Interview:

Fin Biering-Sørensen, M.D. Praises the Value of Internationally Shared SCI Datasets

By: Denise G. Tate, Ph.D., ABBP, FACRM

Dr. Fin Biering-Sørensen visited MSCIS to discuss how to get our electronic medical records (EMR) containing clinical data for SCI patients compatible with the system he is using in his hospital in Denmark. He shared his perspectives on the value of an integrated SCI data system which uses the International SCI Standards and Data Sets. For more information go to www.iscos.or.uk (international SCI data sets).



Drs. Gianna Rodriguez (left) and Fin Biering-Sørensen after the meeting.

SCI Access: Why should we support the SCI International Datasets and the Common Data Initiative in SCI?

Biering-Sørensen: There is great value in being able to compare results obtained across centers. The standardization will make it easier in the future to perform multi-center clinical trials. It is also a good way to educate new researchers as they learn about the most helpful and relevant patient information to collect. This new knowledge in turn promises to influence researchers' selection of the most pertinent SCI study topics in the future. An international data set can further provide structured standardized data that has the potential to improve the clinical care of persons with SCI.

SCI Access: What are the next steps that need to be taken by hospitals and rehab centers in the US in support of this initiative?

Biering-Sørensen: The most important will be to implement the international SCI core and basic data sets in clinical practice. This will make it possible to collect prospective data in the clinical setting, opening up opportunities for more centers to engage in ongoing clinical research.

SCI Access: What can you tell us about your experience with this data system in Denmark?

Biering-Sørensen: We now have included the international standards for neurological classification of SCI, the international SCI core and most of the basic data set elements in

our EMR. Our new doctors have immediate access to this template, which is an important part of their introduction to what information is most pertinent to record when first treating a patient with SCI. Long-term, we hope to be able to take advantage of previously stated uses. Our therapists have also started using several outcome measures that have been recommended in professional reviews of available SCI instruments. The SCI Lower Urinary Tract, Bowel, and Quality of Life Basic Data Sets will be completed by the nurses at the time of patient discharge after initial rehabilitation. Occupational therapists will similarly use The International SCI Upper Extremity Basic Data Set in their follow-up of individuals with tetraplegia.

SCI Access: Are there any plans to provide persons with SCI greater access to their own data through this system?

Biering-Sørensen: In Denmark, all patients have access to their own data through the internet. This is required by law, although the five Danish hospital regions have different EMR systems. The information stored must be available for individuals with SCI who hopefully will become very active partners in many future SCI research projects.

MSCIS Moving Forward Fast: Mary Free Bed Hosts Second MSCIS Meeting in Grand Rapids

By: Denise G. Tate, Ph.D., ABBP, FACRM

A team made up of SCI researchers, clinicians and peers led by Dr. Denise Tate from the MSCIS program met in Grand Rapids with Dr. John Butzer, Director of Research for MFB Hospital in June 2017. The meeting was a sequel to our first meeting in Ann Arbor to discuss specific research collaborations between the two institutions. It also included representation from our community partners, Tom Hoatlin, SCI Consultant to the MSCIS program and Carolyn Grawi, Executive Director of the Ann Arbor CIL. Representatives from the Disability Advocates CIL of Kent County were also present.

Dr. Butzer opened the meeting highlighting the importance of collaborations in research for and about persons with disabilities, especially those with SCI. He also highlighted the role of our organizations in addressing the rehabilitation needs of those

with a disability and the significance of developing common ways to share information that can benefit research and clinical care.

Dr. Tate mentioned the next steps agreed to by collaborators during the first meeting in February. These included:

- Creating common policies and procedures thus providing an infrastructure for collaborators from all sites (data sharing policies; recruitment; IRB, financial administration, common methods of data collection; agreement on products and deliverables)
- Establishing a core group of leaders at each site responsible for overseeing developments and providing input into decision making
- Building common protocols for data collection and entry
- Developing a work agreement covering these activities

- Encouraging researchers to meet and identify sources of funding for joint applications.

Researchers from both institutions presented descriptions of their work related to SCI and other areas of disability research. These included: mild traumatic brain injury (J. Donders); stroke rehabilitation outcomes (A. Kozłowski); physical activity (R. Virva); physical activity intervention (R. McGrath); bone mineral density in SCI (S. Ho); neurogenic bowel and bladder and decision making after SCI (E. Rohn); caregiving in SCI (M. Forchheimer) and technology for SCI inpatients (D. Hilker).

Individual investigators at both sites were encouraged to develop future projects together. Both institutions will soon unveil a pilot research program with funding for up to four joint pilot projects with at least one designated for SCI.

Marva LaVetra Ways:

A Shining Star, a Source of Inspiration Extraordinaire

By: Denise G. Tate and Tom Hoatlin

We were so sorry to hear about the passing of our long-time friend and colleague, Marva Ways. Marva LaVetra Ways was born in 1949 and passed away on July 29, 2017. She was 67 years old and lived with her spinal cord injury for over 40 years. Marva served as a member of our U-M Spinal Cord Injury Model System team for more than 20 years, most recently, as a participant on the program advisory council of the newly established MSCIS. Conscientious as a council member, she was a consistent source of strength—full of ideas and always thinking of our patients first.

As a psychologist at University Hospital in Ann Arbor, Dr. Denise Tate counseled newly injured persons with SCI in coping with their losses, usually caused by a tragic accident or serious disease. To assist with this work, she often called upon Marva, especially when the patient was a young African American woman who felt depressed and lost. Denise recalls, “She was always



Marva LaVetra Ways

prompt to help, no matter the circumstance. Marva served as a source of encouragement not only to many newly injured patients, their families and the professionals serving them, but to all of us as individuals.”

In 2015, Marva agreed to take part in a national educational video for persons with SCI about bowel management and complications. Needless to say, she was a star from beginning to end. She tackled this difficult subject by sharing her own experiences, making recommendations and suggesting

shortcuts—all with the perfect amount of humor. Marva helped make the video not only informative, but warmly entertaining at the same time. To watch this video at the Model System Knowledge Translation Center (MSKTC) website go to: http://www.msktc.org/sci/Hot-Topics/Bowel_Function/managing-Bowel_Function

Marva Ways radiated. The moment she entered a room, people were drawn to her charismatic charm, unlimited energy and secure sense of integrity. With Marva’s passing, we lost a great advocate for a large community of people who are experiencing the struggle caused by disability. We also lost a shining role model, a gifted mentor, and an especially wonderful human being. Marva was a colleague and a loyal friend who was so very beautiful both physically and spiritually. We will miss her dearly.

We join in extending to the members of her bereaved family our heartfelt sympathy.

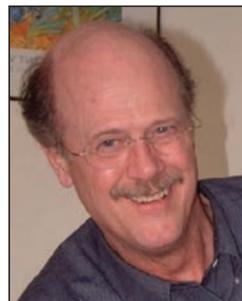
Eric A. Appleberry DDS, MS:

Committed to Serving Others, Always Moving Forward

By: Connie Pines, RN

Sadly, another of our longtime U-M SCIMS alumni passed away January 18, 2017, Dr. Eric A. Appleberry. Eric loved his wife, his children, his vegetable garden, his dental profession and helping others. In 1959, Eric attended Ohio State University where he pursued his future wife Pat and his Doctor of Dental Surgery degree. He and Pat married in 1964 and were soon joined by daughters Jennifer and Nicole.

Eric and Pat moved to Ann Arbor in 1972 where he earned his specialty degree in Periodontics at The University of Michigan School of Dentistry. He taught at the University and then transitioned into a full-time private practice. At home he enjoyed family dinners, caring for his 75-gallon saltwater tropical fish tank, folk guitar and taking long runs down dirt roads through the rural landscape.



Dr. Eric A. Appleberry

on what he could do, not what he couldn’t. Friends adapted his John Deere tractor with hand controls for the enormous garden which he tended. An avid photographer, he continued to document family gatherings and nature’s beauty. Eric’s wholehearted commitment to serving others took many forms over the years after his injury made it impossible to continue his dental practice. He reviewed articles for the Journal of Peri-

Eric always chose to move forward through challenges with a positive outlook. Even after a 1998 accident which left him paralyzed from the chest down, he concentrated

odontology and served on the U-M Medical School’s Institutional Review Board.

Although he received a number of awards throughout his career, he felt particularly honored when the periodontal program’s graduating class of 2011 selected him for their Faculty Appreciation Award. He worked with organizations advocating for people with disabilities in order to give hope and practical advice to others newly facing life with paraplegia, he wrote a variety of articles for the *SCI Access* newsletter.

He believed that those who have died live on in the hearts of people whose lives they touched.

Eric will be missed by family, dear friends and many others who were warmed and inspired by his compassion, generosity, and indomitable spirit.

Making Life Better: New Study Should Lead to Improved Neurogenic Bowel Treatment

By: *Martin Forchheimer, MPP, Senior Research Associate*

Many people with SCI have problems with constipation, difficult bowel movements,



Dr. Gianna Roderiguez

bowel accidents, abdominal pain and bloating. These intimate issues can be quite embarrassing and seriously disrupt life on a daily basis—especially a person's work and social activities.

Unfortunately, researchers and clinicians still know little about the most useful treatments for bowel problems with SCI. It is difficult to diagnose and treat bowel-related problems because our understanding of what actually occurs in the gastrointestinal (GI) tract after SCI is limited. There is no test that evaluates the whole GI tract, from the stomach through the colon.

Recently, the Craig H. Neilsen Foundation awarded a research grant to Dr. Gianna Rodriguez for a study entitled, "The Wireless Motility Capsule (WMC) for Neurogenic Bowel in Spinal Cord Injury". This project started on August 1st and will last for two years. Dr. Rodriguez will conduct the study with assistance from faculty and staff from both the U-M Department of PM&R and the Division of Gastroenterology.

The WMC is a small device that people swallow. Then it flows through the GI tract. As it does, it sends information to a digital recorder. The Capsule will allow us to measure movement through the GI tract. Other tests will be done to evaluate the function of the anus and the rectum. Combined, these tests should let us determine where delays are occurring in the digestive tract, improving our ability to provide effective treatment.

We will recruit 62 people with SCI who have bowel-related problems from U-M's

SCI clinics and the Michigan SCI Research Registry for this study. After consenting, participants will come in for a basic examination and complete some brief questionnaires. They will then swallow the WMC. Data from the device will be sent to a recorder for 7 to 9 days as it flows through their digestive tracts. Upon conclusion of their study, participants will return the recorder and problem log to the GI and/or PMR-SCI clinic.

Results from this study will continue to improve our understanding of abnormalities that occur in the stomach, intestines and colon and how these relate to each other. It will better help physicians and persons with SCI in selecting the right medicines and bowel programs to prevent and treat constipation, bowel accidents and other GI-related problems.

We expect to start recruiting study participants early in 2018.

Positive and Motivating: SCI Support Groups Rev Up Activities

By: *Tom Hoatlin*

Peer support is the cornerstone of a healthy adjustment to a catastrophic change like a spinal cord injury. It reduces isolation and improves one's quality of life. Groups can also be the catalyst to making new friends, learning a new skill, beginning a new hobby or adaptive sport or hearing an experienced speaker. This may not sound like any support group you have been to or thought about. That's because sitting around a room listening to people take turns talking about their challenges has given way to positive and motivating educational, activity-based and peer facilitated gatherings. We are lucky to have many different types of SCI support and activity groups all over Southeastern Michigan and throughout the state.

- **SCI Support Group Med Rehab at Briarwood,**
Fourth Tuesday of the month 12:00-1:00 pm, 355 Briarwood Circle, Ann Arbor, Contact-Sarah Kulek 734-998-8096

- **SCI Meet UP Group Cromaine Library,**
Last Thursday of the month 5:00-7:00 pm, 3688 Hartland Rd, Hartland, MI, (Time and location change based on sports and activities) Contact-Krystina Miller 989-400-1152
- **SCI Round Table Rehab Institute of Michigan,**
First and Third Wednesday of the month 12-1:00 pm, 261 Mack Ave, Detroit, Contact-Kerri Macudzinski 313-745-1055
- **SCI Support Group Rehab Institute of Michigan Novi,**
Every Wednesday 11:30 am-12:30 pm, 42005 W. 12 Mile Road, Novi, Contact Stephen Vangel, PhD, 248-305-7575
- **SCI Friends and Family Support Group, Special Tree Rehabilitation,**
Every fourth Wednesday from 1:00-2:00 pm., 10909 Hannan Rd, Romulus, Contact-Todd Hammons 734-893-1000

- **Ann Arbor Center for Independent Living**
General (all disabilities welcome) Support Group, Every Wednesday 10:00-11:00 am, 3941 Research Park Drive, Ann Arbor, Contact- Carolyn Grawi 734-971-0277

**FOR INFORMATION ON
SUPPORT GROUPS
IN YOUR AREA**

contact the

**Disability Network
of Michigan**

WWW.DNMICHIGAN.ORG

for the

**Independent Living Center's
information and referral specialist
serving your county.**



SCI Access

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The Michigan SCI System publishes SCI Access. This newsletter is designed to provide information on research, treatment, and social issues related to rehabilitative care, spinal cord injury and disability.

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Thanks for Talking to Us! Our Data Center Continues Interviewing and Collecting Valuable Information About You

By: Gina Jay, Ph.D.

We are thrilled to be named a SCIMS Data Center for the next five years, allowing us to continue to follow our 699 active participants. May we take this opportunity to thank everyone who has so generously taken the time to talk to us when we call! With your help, we complete approximately 130 follow-up interviews every year. The information you provide is instrumental in influencing SCI treatment, education and policy decisions, and is invaluable in helping us understand how people adapt to living with a spinal cord injury.

Over the past 30 years, we have enrolled 1159 individuals with traumatic spinal cord injuries in this national database, and

conducted 3877 follow-up interviews with them. In the 1980s and 1990s we con-



Connie Pines (left) and Teresa Mc Cartney look forward to connecting with you. There is a \$20.00 honorarium for sharing your valuable life experiences.

ducted follow-up interviews annually. More recently, we moved to a follow-up schedule of one year, five years, and every five years after that, post-injury.

Thanks to you, this year we have already completed several 30-year follow-up interviews, and look forward to many more in the years to come. By 2021, we will start our 35-year follow-ups. While we continue to conduct most of our interviews by phone, we are excited to offer our participants a secure self-administered online survey option as well, allowing them to complete the survey at a time and place that is most convenient for them.

Do stay tuned. You'll be hearing from us. Let's keep talking!

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