SPINAL CORD INJURY SCOPE OF SERVICES
UNIVERSITY OF ROCHESTER MEDICAL CENTER/STRONG MEMORIAL HOSPITAL

The scope of services described in the following document is intended to assist in identifying the needs of the community and defining the services and programs offered to meet those needs.

Service Comprehensiveness: The Continuum of Care

I. Emergency Medical Services

II. Intensive and Acute Medical/Surgical Care/Neuro ICU

III. Rehabilitation Management:

a. Medical/physiological sequelae
b. Functional
c. Psychosocial
d. Education and training
e. Case management
f. Resource management
g. Transition planning across the lifespan
h. Follow up
i. Health promotion and Wellness
j. Community Integration
k. Primary and secondary prevention
l. Home safety plans

IV. Follow-Up Services

V. Community Advocacy and Education

In accordance with our Mission,

University of Rochester Medical Center is fully equipped to provide comprehensive medical and follow-up care for persons with spinal cord injury. With regard to services, Strong Memorial Hospital is the major referral hospital for this region and is also the major teaching hospital for the University of Rochester School of Medicine and Dentistry. Strong Memorial Hospital defines its catchment area as Monroe and the surrounding 13 counties; the approximate population is 1,400,000 people. It is believed that University of Rochester Medical Center receives that vast majority of spinal cord injuries occurring within the defined catchment area, and for a number of years the Rehabilitation Unit of Strong Memorial Hospital has received late referrals from neighboring metropolitan areas including Niagara Falls, Buffalo, Jamestown, Syracuse, Utica and Watertown.

The rehabilitation team, along with Strong Memorial Hospital, endeavors to maintain and attain the competencies and provide the resources required to treat the following conditions associated with spinal cord injury, disease and dysfunction.

Spinal cord injury often refers primarily to trauma, but it also includes patients with multiple sclerosis, tumor (either primary or metastatic), herniated intervertebral disc with significant neurologic deficit, spontaneous vascular accidents, and spinal cord compression secondary to osteomyelitis or degenerative changes. Because of the full continuum of services available within this comprehensive system, the many medical sequelae associated with spinal cord injury and disease can also be managed within the system.

I. Emergency Medical Services (EMS)

Strong Memorial Hospital is the designated Level I trauma center for the Rochester area.
Strong Memorial Hospital has developed a relationship with area EMS services that has historically lead to improved onsite care for patients with suspected spinal cord injury. It is also where the Office of Prehospital Care is located. The EMS Medical Director is a strong advocate of the spinal cord injury system of care. They are responsible for monitoring and improving the care related to SCI in this phase of the continuum. The following are several components of quality that have helped demonstrate the close relationship the hospital maintains with community EMS providers:

- Problem identification and follow-up – The office of prehospital care is notified by all area hospitals or others if patient care is inappropriate, including taking patients with SCI to non-trauma centers or failing to do spinal immobilization. This provides an excellent opportunity for community education.
- Protocol development/revision in conjunction with REMAC (Regional Emergency Medical Advisory Committee), which is a group of physicians and EMS providers that is responsible per NYS statute for protocols and other EMS issues for our region. The Office of Prehospital Care makes recommendations to REMAC and is responsible for publishing the regional protocols and answering questions about the State protocols. Both NYS and local protocols call for bringing a patient to a trauma center if there is a possible spinal cord injury. Strong Memorial Hospital is the designated trauma center for the Rochester area. Exceptions would be cardiac arrests or unmanageable airways, in which a patient would be brought to the nearest hospital for stabilization and then transferred later to Strong Memorial Hospital.
- Education - as problems are identified, one on one education or group presentations are done. Also since there is a new state program that allows re-certification through CMEs and QA, the office of prehospital care includes presentations on SCI. They also are including information on spinal cord injury in other lecture topics such as near drowning, sports injuries, etc. The Office of Prehospital Care is also involved in pediatric EMS education and now includes SCIWORA (Spinal cord injury without radiologic abnormalities) in their lectures, as well as info related to a new NYS EMS advisory on AAI (Atlantoaxial Instability) in Down's Syndrome patients. The community education office of local EMS providers has also emphasized the effects of osteoporosis in the elderly and the higher incidence of vertebral fractures from even minor mechanisms of injury, such as a fall from a standing position that would not have the same impact on younger folks. The office of prehospital care also has a minor role in the education of the ED residents, but it is usually directed more toward ACLS, PALS and general aspects of EMS. There is also the opportunity for informal education for the established physicians on REMAC to discuss protocols and other improvements in care and technology.

As the regional trauma center, with a trauma bay, Strong Memorial Hospital Emergency attending physicians and the Trauma Team are well versed in most issues of acute emergency management of new traumatic SCI. Physical Medicine & Rehabilitation is occasionally consulted in the ED for recommendations and early interventions.

II. Intensive Care and Acute Trauma/Neuro-ICU and Medical Care

Acute care of patients with new traumatic SCI may occur by several mechanisms. Depending on the initial injury, the patient may be admitted through the trauma, orthopedic, Neurosurgery, or other service. The patient will usually be admitted to the trauma unit. While the patient is on the trauma/orthopedic/Neurosurgery service, that service assumes responsibility for the total care management for that patient. While on the trauma care, rehabilitation starts with referrals to physical and occupational therapies and an initial Physiatric consult. The consult service begins the rehabilitation process. The PM&R consult service is initially comprised of a physiatrist and resident, who will evaluate the patient, make recommendations, and follow the patient until transferred to the rehab unit. The physiatrists and the consult team (SW, Neuropsychologist and residents) will evaluate the patient and recommend treatments relating to skin, bowel and bladder care, autonomic function (i.e. hypotension, hypertension, etc.). The entire team will round on the patients once weekly and monitor patients' medical status and guide SCI care, begin family teaching, address discharge issues and related problems. Physical and Occupational therapy is provided at the bedside. Any member of the rehab team is available to provide education to staff on other units regarding SCI care.
The same pathway exists for non-traumatic SCI patients at SMH, except the admitting service may not be orthopedics/trauma/Neurosurgery. PM&R has established working relationships with all major services.

Pulmonologists will consult initially, and follow the patients on ventilators. Pulmonary service will make recommendations regarding weaning, including the most appropriate place to wean. They will assume care of the patients if transferred from then on. Tetraplegics at C4-8 level should be able to wean off the ventilators if other comorbid conditions do not exist. Every attempt should be made to wean them at SMH. For difficult to wean patients, or if patients and families choose to go elsewhere, the Physiatrist and pulmonologist will facilitate transfer and transition of patients to an appropriate ventilator care unit.

The Rehab unit at Strong does not accept patients requiring ventilators. This decision was made based on the small number of patients that are ventilator dependent in the region. We feel that we would not be able to maintain expertise for this patient population with an occasional patient on ventilator.

If a patient is unable to be weaned from the ventilator, the patient will need to be transferred to a rehab unit outside of Strong to provide Ventilatory and SCI rehab for the patient and provide family training.

As part of PM&R's commitment to providing a continuum of care, a pathway has been developed with the Highlands of Brighton (HAB) to provide local ventilator rehab services in the Rochester community with SCI expertise and consultation provided by PM&R consult services. If the patient is eventually weaned, the pathway calls for a transition to acute rehab for intensive therapy and a community discharge.

The Social Worker from the acute rehab unit will also evaluate and guide the patient and family throughout their stay, along with the Social Worker from the referring floor, until the patient is transferred to a Rehab unit.

For any SCI patient not admitted to the acute rehab unit, PM&R staff will communicate with the SW from the SMH Unit to ensure that Rehab follow-up information is part of the transition plan .

When patients are transferred to out of town Rehab facilities, the PM&R consult service will identify itself as a discharge resource to the out of town admitting facility for the purpose of transitioning back to the community and lifetime follow up care. He/she will also facilitate smooth transition of patients back to the community with appropriate services in PM&R outpatient services.

The SCI Connection is a peer program for patients with SCI. The PM&R consult service can access peer resources for the patient and family while on the trauma service.

The PM&R Consult Service considers the following when determining admission to the acute rehab unit:

Diagnosis, Prognosis, Morbidities, Co-Morbidities, Premorbid level of function, Mental status and Ability to tolerate the intensity of care and Support system.

Unless the patient expresses that he/she is unwilling to participate in the rehab process, the patient is accepted on the Rehab service.

III. Rehabilitation Management

When the patient is medically stable and able to participate in the intensive therapy program, he/she will be transferred to the Acute Rehabilitation Unit. The PM&R Consult team will prepare the patient and family, explain the rehab process, services provided and facilitate a tour as needed. Tour protocol (written) includes assisting the patient and family members in identifying and expressing expectations. The person providing the tour, along with the consult team is to provide realistic expectations of what services we provide and at what intensity. Staff can answer questions about average length of stay, average hours of therapy, expected outcomes, what family participation expectations and patient and family involvement in the rehabilitation process. The consult team will also alert the patient and family to our in-house orientation video available on the patient closed circuit television to supplement the information provided. PM&R assumes responsibility for the care of the patient while on the Rehab Unit.

a. Medical/Physiological Sequelae

PM&R will manage the following conditions. In addition, specialists are available through consultation for all of the following conditions.

- Adjustment to Disability
- Autonomic Dysreflexia
- Bowel Function
- Bladder Function
- Demyelinating disorders
- Depression
- Dysphagia
- Fertility
- Infectious Conditions
- Musculoskeletal Complications
- Neurological Changes
- Nutrition
- Pain
- Psychological Function
- Respiration
- Sexual Function
- Skin Integrity
- Spasticity
- Vision
- Other medical complications such as heterotrophic ossification, Deep Vein Thrombosis, Pulmonary Embolism, Pneumonias, GI and GU problems

Strong Memorial Hospital has the capability to provide for services by many specialty care providers. These services are directly linked with SMH and are available by consultation:

- Pulmonologist for pulmonary care and ventilatory management.
- Urologist for bladder, urinary tract, male fertility management
- Speech therapy for dysphagia

- Neuro-immunology for Auto-immune disorders, immune suppression and Demyelinating disorders
- Orthopedics, Orthotics and prosthetics for Musculoskeletal Complications
- Neurology and Neurosurgery for Neurological Changes
- Acute pain service and Palliative Care Services for pain and comfort
- Nutritional therapy and food services for nutrition
- Plastic surgery, specialty bed service for skin integrity
- Ophthalmology for visual concerns
- Infectious Disease, ENT, Surgery, Dermatology,
  General Medicine, Cardiology, Endocrine and Psychiatry as needed.

Upon admission to the rehab unit, the team begins to assess the patient's level of impairment and determine how their injury has affected their level of activity and participation. These areas of assessment are key to developing a plan of care that envelope all aspects of a person's life affected by spinal cord injury.

It is with great care that the team discovers the expectations and needs of the spinal cord injured patients and their family. Family meetings are established to provide consistent information and resources are identified that would assist a patient to successfully return to the community. Information is provided and contacts are established with community resources that might provide after care or services. By facilitating this contact, the rehab staff have improved the likelihood of utilization of services and reduced the anxiety often encountered immediately post discharge.

In 2007, input from the community identified pediatric rehabilitation, including spinal cord injury as an area for strategic enhancement. The chair of PM&R devoted substantial resources to staff training, development of competencies, unit renovations and widespread communication of these achievements.

b. Functional Needs:

Activities of daily living are assessed by all members of the Rehab team and incorporated into the plan of care. When indicated, our patients have the opportunity to use the independent living skills apartment with a caregiver/family member in preparation for discharge.

Mobility impairments are addressed and the Rehab team endeavors to provide a family centered approach to maximizing a person's independence in mobility by providing instruction and training in the areas of generalized strengthening, balance, bed mobility, wheelchair mobility, transfers, home/community ambulating and stairs. We also have a car in the gym to assist with car transfers for the patient and family.

Assistive technology and durable medical equipment needs are evaluated most often by the Occupational and Physical therapists. Staff will assist in assessing needs and resources of consumers and family members to facilitate the best match of technology and personal need. Through a combination of adaptive equipment and physical conditioning and skills training, it is our goal to maximize a person's ability and independence at home, at work and in the community. This may include recommendations for equipment such as motorized wheelchairs, head control, sip-n-puff and specialized electronics, computer based environment systems, office/home automation equipment or referral to driving/equipment/computer specialists in the area.

Seating needs are assessed. Based on patient's anticipated functional goals, seating systems are trialed while on the rehab unit. There are ongoing relationships with DME vendors. Vendors work directly with patients along with therapists on the Rehab unit and often bring equipment for the patients to trial. The physician along with the therapist provides a justification letter and performs all follow-ups with the vendor to help facilitate timely receiving of the equipment and to facilitate required adjustments to the equipment.

Environmental modifications are explored with members of the rehab team. Patient's families may be asked to assist therapists by taking digital or video photos to better understand the patient's home environment. A home pass may be used for patients to practice skills in the home and to identify barriers and problem solve with possible solutions. In rare situations, the therapist may do a home evaluation. There is a list of contractors available if patients request a referral. The list is compiled by therapist and is based on positive feedback by former patients. It is not intended to be all-inclusive.

Orthotics and Prosthesis are generally prescribed by the Orthopaedic, trauma, neurosurgery service or by Physical Medicine and Rehabilitation. Certified orthotists and prosthetists are on staff at SMH and are available for both in patients and outpatients. They are also available immediately for any types of necessary adjustments.

Cognition is evaluated beginning with the consult service. All team members evaluate cognition informally. A Neuropsychologist (specializing in behavior consequences of brain injury) conducts interviews and examinations when there are symptoms or indications of brain injury or where the mechanism of spinal cord injury may indicate potential for cognitive deficits. Test results are discussed with patients and their families where questions are answered. Recommendations based on the test results are incorporated into therapeutic treatment and discharge plans. Speech therapy and Occupational Therapy may provide therapy services for cognitive deficits.

Communication: All team members evaluate communication informally. Speech therapy may provide therapy for communication impairments. Comprehensive evaluation and treatment of communication is provided by the speech pathologist. This includes assessment of patients who require a tracheostomy. Evaluation for use of a speaking valve is performed when appropriate. Augmentative communication can also be implemented on an individual basis. In cases where the person has also experienced brain injury, a comprehensive evaluation of speech, language, and cognitive linguistic skills is completed and a treatment plan is developed. A referral for audiological consultation is available upon request.

Community Integration: All team members assist in preparing persons served and their families for a return to the community. Therapeutic passes are made available to practice community skills and to help facilitate a safe return into the community, maximizing independence with a person's work, self-care, and leisure roles. Leisure and recreation assessment and introduction to adaptations takes place. Community members with disabilities have provided information to patients and staff to introduce their experiences with recreation. Patients are provided with information about Sportsnet, a local group dedicated to providing opportunities for inclusive sports and recreation for disabled and able bodied participants. Patients and families are encouraged to use the available lounge with recreational supplies and equipment.

Drive rehabilitation is offered through Rochester Rehabilitation Center in a program called Drive-On. Patients are provided with information regarding driving programs. Persons are routinely informed about the need to have their driving ability assessed after a disabling event. Information regarding area driver evaluation and rehabilitation programs is available and routinely given to patients and family members. The rehabilitation team maintains a close relationship with driver rehabilitation venues in the community through in-services and solicited consumer feedback.

Medication teaching is done by the nursing and medical staff. The physicians prescribe all medications and RN staff administers the medications. The nursing staff provides medication teaching to both the patient and family as appropriate. Medication teaching sheets are provided for each medication. A self-medication record will be given to the patient with the medication names, dosages, dates and times. Medications are provided for apartment and home passes. Medication Reconciliation with home medication regimen and within the continuum is high priority in Strong Memorial Hospital patient care. Medication Reconciliation is completed electronically and verified with a sample audit process. At discharge a list of all medications, including last doses of administration is provided.

Vocational assessment begins during rehabilitation. The most common resource recommended by the social worker is the New York State office of Adult Career and Continuing Education Services-Vocational Rehabilitation (ACCES-VR). The Social worker can assist with the referral process as needed and facilitate issues regarding accessibility and funding. Most often, vocational rehab takes place after discharge home. Patients and family members are educated on what services are available in the area to help them get back to work or school. Therapies on an outpatient basis most often begin treatment intervention to develop or rebuild skills needed for their occupation.

Depending on a patient's functional status, he/she may require assistance for self care and mobility. In the Rochester community, there has been a slow but steady increase in the number of personal care assistants. More often, family members assume responsibility for providing care at home. Certified nursing agencies may also provide assistance. All members of the rehab team carry out training for family members. Family members are invited to participate in all nursing and therapy sessions. If a patient plans to employ personal care assistants, the Center for Disability Rights helps the patient to arrange for the service. Patients receive ongoing education to direct their own care. If there is a special skill that the patient would like caregivers to learn, staff from Rehab may provide that training. For patients receiving care by family or by an outside agency, patients are given resources in their patient manual to contact the rehab department with questions. PM&R staff will work with family members, Community Nursing agency's home health aides or nursing staff on SCI specific issues, on an individual or group basis.

c. Psychosocial

Psychological and emotional adaptation by patients and their families is very important to the rehabilitation process. Where indicated, consultation, individualized psychotherapy sessions, or other specialized treatment programs may be initiated to address emotional and psychological coping strategies, substance abuse concerns or other common challenges associated with coping. Specific referral to Psychiatry Consultation-Liaison Service, Marriage and Family Clinic, or Chemical Dependence program is typically carried out in conjunction with the social worker or physician.

SCI Connections, a peer support network supported by the local Rochester Spinal Association is offered routinely to patients and their families. Peer volunteers are trained in providing experience related information and personal coping strategies and general support to patients and families and can provide valuable information to the team regarding a person's or families needs. SCI Connection volunteers may work individually with a patient, if the patient consents to a peer visitor, or may be integrated into the Rehab unit's activities. The Christopher Reeves "Request a Mentor" program is also an option for patients

A person's sexuality, intimacy and relationship needs can be addressed in a variety of venues including nursing interaction, direct physician assessment, family counseling sessions or group support opportunities. Sexual and intimacy concerns can also be addressed in the outpatient setting. Depending on the nature of the expressed concern, further management may be done by the medical or nursing staff, urologist, or psychiatry services.

d. Education and Training

Throughout the spinal cord injury system of care continuum there are opportunities to evaluate the level of education and training required by both the persons served and their support system. Family members and others are invited to participate in learning about care and resources. This is a core component in all levels of care. In general, patient education is provided on an individualized basis. All patients and families receive the Patient Journey Book that can be customized with individual teaching information. Plans are underway to have this material available on-line. There are many videos available for patients to watch to supplement their learning needs. Patients have access to computers if their preferred learning style is identified as such. With

funding from the Neilsen foundation, SCI information booklets were produced for patients and families to take home.

e. Aging

The issues of aging in SCI are addressed in a multi-disciplinary fashion. Based on changing demographics in our SCI population, with increasing age at incidence of SCI, we have identified two different features of aging.

- The older person who has sustained a new SCI
- The person with an SCI who is aging

For the elderly person who has sustained an SCI, treatment plans are implemented based on the previous and existing function and expected functional outcomes for that individual. Care is taken to identify existing resources. Some patients will choose to be discharged to home with home care services and intensive family education is provided. Other patients may choose to be discharged to a Skilled Nursing Facility (SNF), either as a temporary or permanent placement option.

Several lines of communication have been established with area SNF rehab facilities to insure a smooth transition from acute rehab to SNF rehab. Dialogue has been initiated with several SNF's to examine the most efficient care path for older patients to optimize recovery, including the possibility of SNF rehab with support from acute staff followed by an acute rehab stay prior to discharge home. MedTel (outcomes follow up system) follow-up data suggests the majority of patients (89%) discharged from acute rehab to SNF rehab are home within 3 months of acute rehab discharge.

For persons aging with a SCI, issues regarding aging are addressed in the SCI clinic, both in an anticipatory method as well as addressing problems that may already be present.

- Current function is evaluated and recommendations are suggested for methods that may preserve function, or improve function.
- Referral to therapy to evaluate mobility and assess ability to transfer safely. Equipment modifications along with education and needed Physical Therapy and/or Occupational Therapy may be advised.
- Respiratory function is assessed, including recommendations for Pneumococcal and annual influenza vaccination status.
- Skin assessment is done with education regarding potential changes in skin turgor and elasticity.
- Bladder and Bowel management options are discussed and advised. Renal evaluation is performed.
- Ability to remain living independently in the community is assessed and when needed other options are explored.
- Effects on caregivers are addressed. Care is taken to identify quality of life issues and methods to maintain independence.

f. Case Management

The rehabilitation team uses a physician team leader model for case management services while on the inpatient unit. The physician directs the care and because of the closeness of the unit and the opportunities for close communication, the physician can direct care, monitor progress toward goals and facilitate changes in the program as necessary. In conjunction with the team, patient and family, the physician helps develop a successful transition plan.

The role of Social work is to serve as liaison with health and social service agencies, which may provide case management services. The social worker also serves as a resource consultant and collaborates with members of the health care team around matters related to patient care and discharge planning.

g. Resource Management

Persons in the spinal cord injury system are made aware of resources through a variety of venues. Through ongoing assessment, the need for resource management can be identified and addressed. Examples of resources that are frequently recommended are SCI clinic, Community Health Nurse (CHN) support, Rochester Spinal Association (RSA), Center for Disability Rights (CDR), Sportsnet. Also available in the community are resources that can support a person's choice to participate in self-directed care. Staff can make that referral and follow-up with support and advocacy. Lifespan is a community organization that can work individually to educate and assist individuals with long term care planning.

h. Transition Planning

Transition planning starts with a team discussion during team meeting. With input from the family and patient, the physician directs the transition. The social worker and care coordinator facilitate the smooth transition to the next level of care. This includes identifying barriers to discharge and problem solving with the team to overcome these barriers. The care coordinator's role is also as facilitator between team members to coordinate discharge needs including choosing a home care agency to assure the transition plan is carried through in the home setting. The Care Coordinator schedules patients in SCI follow-up clinic to assure all transition plans have been successfully implemented and will assess for any gaps in service or additional referrals that may be necessary. The social worker coordinates discharge-planning activities for patients who are determined to be at psychosocial risk, in collaboration with the Community Health Nurse and other members of the health care team. The Recreation Therapist also plays a role in transitioning the patient back to the community and identifying resources available including supporting the peer network that can extend into the community if necessary.

i. Primary Prevention

Example: Education in the proper use of van lifts and vehicle tie downs, prescription and fitting of wheelchair restraints to prevent additional SCI to name a few.

The spinal cord injury system offers several opportunities to address the primary prevention of spinal cord injuries, both for those with spinal cord injury/disease or for those at risk of incurring an injury. For those persons in the system, assessment of need frequently identifies areas that may require referral to one of our specialty or referral to a community provider (driver rehabilitation).

A staff member has been appointed by the county legislature to sit on the county traffic safety board to direct county resources targeted for injury prevention. Other educational efforts aimed at both the general public and persons with SCI include participation in conferences, health fairs and community events.

j. Secondary Prevention

Examples are Prevention of pressure sores, complications due to syringomyelia, bowel/bladder dysfunction, autonomic dysreflexia etc.

The prevention of secondary complications is an ongoing and comprehensive educational effort that permeates the spinal cord injury system. Education begins with the identification of injury and continues throughout the continuum and is independent of the point in the continuum a patient enters the system. For patients with sudden onset of injury a comprehensive educational program is provided in the rehab unit. For those with delayed admission or whose admission is for an exacerbation of symptoms, an assessment of current knowledge

and gaps in knowledge are addressed. Follow-up clinic is an excellent opportunity to assess retention and understanding of information that had been previously addressed.

IV. Follow-Up Services

Patients discharged from the acute rehab unit are provided with a portable profile folder detailing their current status and transition plans. This summarizes the hospital stay in patient friendly language, provides a medication list, follow-up instructions, and personalized information from the rehab team. Patients have also been provided with a list of patient resources after inpatient rehabilitation and follow up appointments. An appointment is made for the patient to see their primary care provider within the two weeks. In addition, contact information is listed for SCI related and general health issues, including the rehab unit, the physiatrist and the care coordinator. Any of these providers can access the spinal cord injury resources needed to address the patient's needs. The spinal cord injury clinic is one component of the continuum for patients in the community with spinal cord injury or disease. Upon discharge from the acute rehab unit, the patient is scheduled to be seen in the SCI clinic within 4-6 weeks. At the SCI clinic, the physiatrist and resident evaluate the patients. Referrals are often made to Physical Therapy, Occupational therapy, Urology, Orthopedics, and Neurosurgery. Follow up after SMH inpatient Rehab is usually 6 weeks, 3 months, 6 months and yearly. Patients can be seen for problems at times other than the SCI clinic in any of the attending physicians' outpatient clinics. Patients are directed to call the PM&R offices for help for problem solving.

Many factors determine the follow-up care that a patient with SCI receives after discharge. For someone returning home, there are several community nursing organizations that may be involved. While hospitalized, patients are offered a choice of agency; geographic location or insurance carrier may determine the choice. Home care services may include nursing, home health aide, physical therapy, occupational therapy, and social work. Some patients with Medicaid are eligible for consumer directed care services. This program is administered by the Center for Disability Rights (CDR). While an inpatient, CDR is contacted to evaluate the patient for the program, explain the process and coordinate. Staff from PM&R may be instrumental in helping to train caregivers as needed.

If a patient requires skilled nursing services, then PT and OT services may be provided at home through the home care agency. Written information is provided at discharge to assist the home care therapists. This process provides the opportunity for the patient to transition to the home setting with therapy services in their home environment and allows for appropriate problem solving. Home care therapy staff is encouraged to consult with acute rehab therapy staff or the SCI agency liaison (department administrator) for SCI specific issues that arise. Home care therapy services are usually temporary. Many patients will then start Strong Hospital outpatient therapy services.

Outpatient Physical and Occupational Therapies are provided at our Clinton Crossings facility. When discharged from the acute rehab unit, in patient therapy staff will provide written information to the outpatient therapists regarding progress, function and goals. Goals are set with the patient, family and therapist. Depending on goals and patient, therapy may take place 1, 2, or 3 times weekly. Outpatient therapists are able to access the physiatrist and acute rehab staff for patient related issues, via written reports as well as informally in the clinic. Discharge criteria from outpatient therapy services are guided by completion of goals.
As part of the continuum, Speech Therapy and Neuropsychological services can also be provided if indicated.

The average number of patients discharged to the community each year from the spinal cord injury system of care is between 60 and 80. This has proven to be a very manageable number considering the extensive informal network available. An active peer program, a local support group chapter of United Spinal Association (RSA), several independent fund raising activities and staff involvement with all of these groups has lead to a community atmosphere of cooperation and frequent opportunities for informal contact.

The SCI clinic is a key component in the continuum for persons who come into the Rochester area with a spinal cord injury or who complete their acute rehabilitation elsewhere, to become established in the network. Staff in the department of PM&R make themselves available to meet and work with patients during the hospital stay and then continue to interface post discharge. Therapists who staff the outpatient spinal cord injury care program have established their expertise while rotating through the inpatient unit. Rehab therapists and the nursing discharge coordinator are often in contact with home care agencies to consult with nurses and therapists regarding spinal cord injury specific issues. Regular communication is encouraged between outpatient and inpatient staff, physicians, referring physicians and other care providers. It is in spinal cord injury clinic and outpatient PT and OT that more in-depth activity and participation issues can be identified and referrals made or resources identified. It is in this venue that vocational, sexual, psychosocial and other issues can be identified and managed.

Other clinics that are available through the spinal cord injury center that address quality of life for patients include:

Spasticity Management

The Department of Physical Medicine and Rehabilitation uses many treatment options in the treatment of spasticity including Intrathecal Baclofen, Botox injections, oral medications and physical therapy. Intrathecal Baclofen clinics are held at SMH and other treatment options are offered during outpatient clinics.

Spinal Cord Injury Male Fertility Program

Patients requesting Spinal Cord Injury Male Fertility Services are referred to the University of Rochester Department of Urology. They have been very successful in meeting patient and family needs.

V. Community Advocacy and Education

In order to support the community re-integration efforts of staff and clients being discharged from the inpatient rehabilitation unit, staff have developed and maintained liaisons with a variety of community groups that have contact with or might influence the successful reintegration of a client from the rehabilitation unit. Through these liaisons, the rehabilitation staff has been identified as experts in the field of community reintegration for clients with spinal cord injury or disease or other significant disability. This designation is maintained and reinforced by staff, particularly the accessibility and exposure of the medical director, nurse manager and social worker. They make regular contact with agencies, community programs, disability interest groups and legislators to remain informed and to help educate regarding issues specific to clients with spinal cord disabilities. Reintegration is a driving force behind most of the activities that take place on the rehabilitation unit and throughout the Spinal Cord Injury Center. The emphasis placed on the community contacts is regarded as a priority for improving a client's return to the community. Areas of the community that have been targeted as having a major influence on successful reintegration include those agencies that directly support health, employment, transportation, home care, accessibility and consumer rights.

Regional Center for Independent Living (RCIL)

The independent living movement in the Rochester area has a long and dynamic history of meeting the needs of the disabled community. Established in 1967, the Regional Center for Independent Living has had a mission of

service to the community. The relationship RCIL has traditionally had with the Spinal Cord Injury Center has been one of communication and support. The RCIL has an impressive history of being sensitive to current issues in the community and mobilizing their efforts to address the needs as appropriate.

Center for Disability Rights (CDR)
Center for Disability Rights is a vocal and active disability rights group whose energies have been targeted at a variety of community issues. The group's most recognized efforts were in publishing a descriptive paper addressing issues surrounding attendant care. The paper detailed the current state of attendant care services in the community and provided insight and guidelines into reengineering the provision of services. The proposal is for a system that includes self-directed care with an emphasis on personal choice and responsibility. The Spinal Cord Injury Center staff and former clients have participated in the preparation and distribution of the document, including providing data and commentary as well as providing limited text and editing support.
RCIL and CDR have recently moved into shared building space. The Department of PM&R continues to actively support both organizations.

PREVENTION
SCI prevention occurs at both the national and local level. Emeritus professor Dr. Poduri is a member of ASIA and sits on the Prevention Committee. Locally, a staff member from The Spinal Cord Injury Center has been appointed to the Monroe County Traffic Safety Board to ensure that programming throughout Monroe County includes injury prevention. http://www2.monroecounty.gov/safety-trafficsafety.php

Education and SCI Advocacy

Throughout the spinal cord injury system of care continuum there are opportunities to evaluate the level of education and training required by both the persons served and their support system. Family members and others are invited to participate in learning about care and resources. This is a core component in all levels of care.

Examples of how competencies are maintained include staff in-services, CMEs, attending and presenting at national and international conferences, CRRN and MD accreditation as SCI specialists.

SMH staff have co-sponsored local events that have provided a wide variety of education for consumers, community health care providers and staff. For example:

- The SCI Health Fair is held annually for the benefit of persons in the community with SCI. This is a community event that is developed to provide up to date information to the Rochester community about SCI. Topics are chosen based on feedback and survey results of persons with SCI in the community.
- Bi-Monthly SCI support group has a topic or speaker of interest each month that may include topics such as sports, travel, disability advocates, medical professionals, sexuality, equipment etc.

CURE information

The PM&R department's continuous communication with persons in the community living with SCI has uncovered a strong network of persons interested in information and updates regarding progress in spinal cord injury research. Staff is very interested in providing safe and up to date information in a format that is accessible and easy to understand. The department has invited national researchers to Rochester to speak to both consumers and scientists regarding a variety of cure topics. Speakers have included:

Marc Buoniconti, Miami Project to Cure Paralysis

Wise Young, MD CareCure.org Rutgers University
Mark Noble, PhD, Director UR Stem Cell and Regenerative Medicine Institute
Aime Jackson, MD UAB, Model Spinal Cord Injury System of Care
Kenneth Parsons, MD Director Institute for Rehab and Research, Houston TX
Keith Tansey, MD, PhD Director of SCI research Shepard Center, Emory University
Thomas Bryce, MD Mount Sinai School of Medicine
William Donovan, MD Texas Regional SCI Center (retired)
Bradford Berk, MD, PhD University of Rochester Neurorestoration Institute

Continuous update
Last update 9/21