
MOVE AGAIN PROGRAM: INFORMATION SCAN

EXERCISE and SPINAL CORD INJURY:

- ACTIVITIES AND RESOURCES IN WA**
- KEY INTERNATIONAL CENTRES,
RESEARCHERS, AND RESOURCES**

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1. PURPOSE AND METHOD

1.1 PURPOSE

The purpose of the information scan is to provide MAP investigators and associates with

- an overview of research and community based activities in metropolitan WA that are relevant to the topic “Exercise and Spinal Cord Injury”
- a brief description and contact details for current leading international organizations and ‘best practice’ relevant to the topic “Exercise and Spinal Cord Injury”.

This report is one of four foundation documents produced as a result of the Move Again Program’s (MAP’s) background research. The other three documents are:

- Move Again Program: Literature Search: Part I: Exercise and Spinal Cord Injury
- Move Again Program: Literature Search: Part II: Barriers to Exercise for People with SCI
- Move Again Program: Survey Development

The purpose of these documents to provide background information for MAP investigators and associates who collectively represent a wide range of academic and clinical backgrounds and whose experience with the SCI population is highly variable - from full time clinical involvement to virtually no direct experience.

1.2 METHOD

The scan was undertaken on a ‘rolling’ knowledge basis, starting with key WA and international workers who were known to the consultants, relevant community organisations, and members of the MAP team. The first round of stakeholders included those in government and non-government sectors, and working in universities, hospitals, and community agencies e.g. disability agencies, sport/recreation organisations, community centres, and commercial sector providers.

Relevant information was elicited through semi-structured interviews (face to face, and telephone), and emailed requests. A pool of questions (Appendix I) was used as a basis for tailoring interviews and other requests to each stakeholder. An electronic form was developed to seek and record information from MAP investigators and associates (Appendix II). Stakeholders who were contacted directly are listed in Appendix III.

The results do not constitute an exhaustive list of contacts but, for WA, they indicate a broad and what is believed to be a fairly comprehensive picture of the current activity in relation to “exercise and SCI”. For MAP investigators who wish to pursue specific lines of enquiry, this report provides baseline information from which they can further explore topics of interest and identify additional relevant stakeholders. The international results, and those from other Australian states, provide information on key organizations and centres, prominent researchers, and resources and equipment. Again, these do not form a complete inventory but provide leads to further examine ‘best practice’ outside WA.

2. SCI ORGANISATIONS/NETWORKS

2.1 AUSTRALIAN AND NEW ZEALAND

The Australian and New Zealand Spinal Cord Injury Network (ANZSCIN)

Established in 2007 to advance research and clinical trials into spinal cord injury and disease. Supported by the NSW Government, this Network draws together leading researchers, clinicians and key stakeholders from Australia and New Zealand. Currently supported by NSW State Government. Pulling all stakeholders together to foster collaboration & clinical trials. Recently launched and CEO appointed.

<http://www.anzscin.org/>

Spinal Cord Injury Australia (SCIA)

Spinal Cord Injuries Australia began 40 years ago as the Australian Quadriplegic Association. It continues today providing consumer based support and rehabilitation services to people with physical disabilities.

<http://www.scia.org.au/>

Spinal Cure Australia (formerly Australasian Spinal Research Trust)

Spinal Cure Australia pioneered the first Neurotrauma program in WA which funded neurological research through road safety initiatives. The concept has been developed and is now used in Victoria and Sydney. Website has useful links to Australian neurotrauma research.

<http://www.spinalcure.org.au/a/104.html>

Australian and New Zealand Spinal Cord Society (ANZSCOS)

No relevant information was located online. No website?

Spinal Cord Society of Australia

In 1999, the Spinal Cord Society of Australia determined that the best way to make progress towards finding a cure for SCI was to direct funding towards the establishment of local research laboratories here in Australia. They sponsor research projects at the University of Western Australia (Dr Giles Plant, Director of Red's Spinal Cord Research Laboratory, Senior Lecturer and NHMRC RD Wright Fellow), St Vincent's Hospital Medical Research Institute, and the Australian Stem Cell Centre. They accomplish this through public fundraising as well as lobbying government and supporting scientists to apply for government research grants. They also

- Invest in research projects which seek a cure for SCI
- Implement a research plan to advance clinical trials as soon as possible.
- Advance these clinical trials with proper ethical considerations and realistic expectations of improved spinal cord function.
- Co-ordinate a forum for spinal cure research
- Provide public education regarding the progress towards finding a cure for SCI.

<http://www.spinalcordsociety.org/2007/howeare/aboutus.php>

2.2 INTERNATIONAL

The International Campaign for Cures of Spinal Cord Injury Paralysis (ICCP)

A body of affiliate not for profit organizations, working to fund research into cures for paralysis caused by spinal cord injury. The ICCP coalition mission is "to expedite the discovery of cures for Spinal Cord Injury Paralysis". Membership:

- Christopher Reeve Foundation
- French Institute for Spinal Cord Research (Institute Pour la Recherche sur la Moelle Epinière)
- Japan Spinal Cord Foundation
- The Miami Project to Cure Paralysis
- Paralyzed Veterans of America
- Rick Hansen Man in Motion Foundation
- Spinal Cure Australia (formerly known as Australasian Spinal Research Trust)
- Neil Sachse Foundation (formerly Spinal Treatment Australia)
- Spinal Research (International Spinal Research Trust)

<http://www.campaignforcure.org/iccp/> Provides links to all of the above organizations.

The North American Clinical Trials Network (NACTN)

www.christopherreeve.org

The Inventory and Evaluation of Clinical Research Networks (IECRN) Project

Is part of the NIH Roadmap for medical research which seeks to improve health and to speed translation of these discoveries into practice. In particular, the IECRN is related to Reengineering the Clinical Research Enterprise, a Roadmap component which seeks to enhance the efficiency and productivity of clinical research by promoting clinical research networks that can rapidly conduct high quality studies capable of addressing multiple research questions. The IECRN project began in September 2004 and is ongoing.

<https://www.clinicalresearchnetworks.org/default.asp>

Christopher Reeve Paralysis Foundation

The Christopher Reeve Paralysis Foundation (CRPF) funds research that develops treatments and cures for paralysis caused by spinal cord injury and other central nervous system disorders.

<http://www.scia.org.au/links>

The Spinal Cord Injury Rehabilitation Evidence (SCIRE)

Developed from a research collaboration between Vancouver and London (Ontario) and involved their respective health centres (GF Strong Rehab Centre, St. Joseph's Health Care), research institutions (International Collaboration on Repair Discoveries, Lawson Health Research Institute) and universities (University of BC, University of Western Ontario).

A synthesis of the research evidence underlying rehabilitation interventions to improve the health of people living with SCI. Covers a comprehensive set of topics relevant to SCI rehabilitation and community re-integration. This project is intended to translate existing knowledge to health professionals to inform them of best practice. This research synthesis will also enable relevant decision-making in public policy and practice settings applicable to SCI rehabilitation. In addition, transparent evidence-based reviews can guide the research community and funding organizations to strategically focus their time and resources on the gaps in knowledge and identify research priorities. People with SCI and their families may also find the information useful to understanding their health care. 800 pages of evidence.

www.icord.org/scire/home.php

International Collaboration On Repair Discoveries (ICORD)

An interdisciplinary research centre for the development of effective strategies to promote functional recovery after spinal cord injury. This unique initiative brings together spinal cord injury researchers from the Sciences, Medicine, Surgery, Rehabilitation, Engineering, Education, and community-based Humanities research. ICORD is working to facilitate the discovery and implementation of relevant solutions to improve functional recovery, mobility, community integration and quality of life for people with spinal cord injury. <http://www.scia.org.au/links>

The International Society for Stem Cell Research (ISSCR)

An independent, nonprofit organization formed in 2002 to foster the exchange of information on stem cell research.

<http://www.isscr.org/about/index.htm>

International Spinal Cord Society (ISCoS)

Started by Guttman. Aims include; to serve as an international impartial, non-political and non-profit making association whose purpose is to study all problems relating to traumatic and non-traumatic lesions of the spinal cord. This includes causes, prevention, basic and clinical research, medical and surgical management, clinical practice, education, rehabilitation and social reintegration. This society will function in close collaboration with other national and international bodies, thereby encouraging the most efficient use of available resources.

Provide a scientific exchange among its members and others by collecting and disseminating information through publications, correspondence, exhibits, regional and international seminars, symposia, conferences and otherwise

<http://www.iscos.org.uk/>

Affiliated groups: (see links from ISCoS homepage)

- American Paraplegia Society (APS)
- American Spinal Injury Association (ASIA)
- Asian Spinal Cord Network (ASCoN)
- Association Francophone Internationale des Groupes d'Animation de la Paraplégie (AFIGAP)
- Australian and New Zealand Spinal Cord Society (ANZSCoS)
- Chinese Association of Rehabilitation for the Disabled Society of spinal Cord Injuries (CARDP-SOSCI)
- Deutschsprachige Medizinische Gesellschaft für Paraplegie (DMGP)
- Dutch-Flemish Society of Paraplegia (NVDG)
- Japan Medical Society of Spinal Cord Lesions (JASCoL)
- Latin American Society of Paraplegia (SLAP)
- Nordic Spinal Cord Society (NoSCoS)
- Società Medica Italiana di Paraplegia (SoMIPar)
- Southern African Spinal Cord Association (SASCA)
- Spanish Society of Paraplegia (SEP)
- Spinal Cord Society - Indian Chapter
- Turkish Society of Spinal Cord Diseases (TrSCD)

<http://www.iscos.org.uk/societies.html>

PARADOC - the documentation Centre on Spinal Cord Lesions

Ongoing database project created by the joint initiatives of ISCoS, its Education Committee, and the Swiss Paraplegics Foundation (SPF). It is based in the library of the Swiss Paraplegic Centre in Nottwil, Switzerland.

The aim of Paradoc is to collect publications and references concerning education and training on

the subject of spinal cord lesions. Designed for patients and their families as well as doctors, allied professionals, hospitals, rehabilitation centres and community based libraries.

www.paradoc.org

China Spinal Cord Injury Network (SCI)

See <http://keck.rutgers.edu/center/center.html>

3. WESTERN AUSTRALIA

3.1 CARE OF PEOPLE WITH SCI

In Western Australia at present, SCI patients are usually admitted to the Wellington St Campus of RPH, but may be referred from other hospitals in Perth. Following acute-phase treatment, patients are transferred to the Shenton Park Campus to undergo rehabilitation in the Spinal Unit. Patients are assigned a Case Manager, usually a Physiotherapist, Occupational Therapist or Social Worker, who works with the team, including medical and other staff, the patient and family and carers, to ensure the best transition through the clinical pathway to discharge. Each patient attends a 'Prognostic' meeting, where a general plan of action is set out, as well as an indication of most likely outcomes of rehabilitation. Therapy staff work with patients in the wards and in the Physiotherapy gymnasium and hydrotherapy pool, with an emphasis on developing mobility. Occupational therapy is geared to activities of daily living, so that patients can learn new skills in adapting to their new circumstances. Both centres have morning and afternoon sessions, with patients allocated according to their specific priorities.

The length of hospital stay varies considerably, from a few weeks to six months or more in severe cases. Hospital staff also work closely with Paraplegic-Quadriplegic Association of WA staff in providing on-going care via a home-care nursing service, as well as other services.

The hospital has the most comprehensive database of SCI in W.A., with approximately 1500 entries. The patient records have been taken for many years, and the quality varies from earlier entries made by ward clerks, to more recent entries following the ASIA scale.

3.2 KEY COMMUNITY ORGANISATIONS

Paraplegic-Quadriplegic Association of WA

Has been in operation for over 50 years. It provides advocacy, medical, housing, employment, recreation opportunities, holiday accommodation and home-care services for people with SCI and their families and carers. It operates the Quadriplegic Centre, a residential facility for people with high-level quadriplegia requiring constant care, and also has several short-term residences for patients unable to move immediately from the nearby RPH (SPC) to their own accommodation. It also runs the Selby Recreation Centre, which conducts a broad range of activities to meet the needs of members. The Association has a membership list of 400, to which it sends a newsletter, but this number includes carers and supporters as well as people with SCI.

Selby Recreation Service Co-ordinator Ph: 9381 0173.

The West Australian Disabled Sports Association (WADSA)

WADSA was formed in 1982 to serve individual clubs representing various specialist disability groups. Since that time it has grown to be the peak body for disabled sport in WA, and has 32 member clubs and organizations, in addition to conducting a wide range of sport, physical activity and recreation activities for individuals and member associations. It acts as an advocate for people with disabilities, their families and carers to government and non-government agencies. It has a strong focus on providing suitably modified/adapted equipment for people with limited mobility and who might require high levels of assistance. It also works with 22 State Sports Associations to

make their sport more inclusive to people with disabilities. There is no specific club representative of SCI but people with SCI may be members of various clubs, e.g. the Wheelchair Sports Association which is a member. While WADSA is well able to accommodate many needs of people with SCI, the proportion of active participants with SCI is estimated at less than 3% (personal communication, Dereck Mahady). Dereck Mahady, Executive Director <http://www.wadsa.org.au/>

Ability Solutions Inc

Ability Solutions is a West Australian, not-for-profit, registered charitable organisation that aims to improve the participation of people with disabilities – including those with SCI - in community life. It does this by developing implementing and evaluating mainstream inclusive practices in sport, recreation and physical activity and delivering or facilitating others to deliver appropriate services. It offers the expertise and capacity to co-ordinate and/or undertake high quality activities in six key areas

- Disability awareness, training and education localised and customised for disability organisations, individuals and groups including professionals, community workers, volunteers and carers.
- Policy & planning in sport, recreation & physical activity for people with disabilities
- Development production and marketing of adaptive equipment for people with disabilities
- Planning and implementation of projects in inclusive practice in community, school and special settings. The primary target groups are those where there is currently a high level of unmet need and include; people with mental illness, incarcerated persons with a disability, aged persons, and children with high care needs.
- Research, analysis and evaluation in the area of sport, recreation and physical activity for people with disabilities.
- Income generation through well established business activity.

Dereck Mahady.

<http://www.abilitysolutions.org.au/>

The Wheelchair Sports WA Association (Inc.) (WSWAA)

WSWAA is responsible for the management of wheelchair sports activities in Western Australia. Athletes compete in State, National and International competition in 10 sports. The Association also runs events, training, and competitions for Wheelchair Sports members, to assist athletes be the best they can be, as well as fitness and recreation activities for members who do not wish to play sport. The association has a fitness program centred at the Herb Graham Centre.

Sports including handcycling, rugby, basketball and athletics are organised for people who use a wheelchair – including those with SCI. The sports can be social or competitive to an international level. Athletes are recruited from the SCI community directly from Ward 11 RPH, or later. The organisation is available to all those with SCI, but is not utilised by all. There is an accessible gym attached which is integrated with a gym that is used by the wider community. The Association has over 600 members comprising people with a variety of disabilities and their families. It has a strong focus on competitive sport whereby competitors are not distinguished by whether they have SCI but by classification category of ISOD. The proportion of people with SCI is not known.

Gary Lees, General Manager

<http://www.wheelchairsportswa.org.au/>

Recreation and Sport Network (RSN)

RSN provides information and support to people with a disability who want to become involved in community recreation and sport – including a very small number with SCI Their mission is to improve quality of life for people with a disability, including those with SCI, through participation in recreation and sport. It also provides training to people involved in recreation and sport to give them strategies on how to value and include people with a disability. RSN has a detailed webpage

that includes many activities available in different communities. <http://www.rec.net.au/>

The Centre for Cerebral Palsy WA

Although not including people with SCI, the Centre has recently developed workshop material for staff of recreation centres. The material covers many aspects of physical disability. The next phase of the project is to run trial workshops to refine the material and make recommendations re future development/training. Janine Spilby. <http://www.tccp.com.au/content.php?page=1>

3.3 REHABILITATION AND FITNESS CENTRES

Hollywood Private Hospital Functional Rehabilitation Clinic

Is a privately owned and staffed enterprise that operates under the Perth Orthopaedic Institute. It is staffed by trained Exercise Physiology and Physiotherapy staff, and is focussed on rehabilitation following orthopaedic surgery, mainly of the hip and knee. It has no current activity/research function in SCI, but would consider being part of a broader rehabilitation network.

The UWA Health and Rehabilitation Program, School of Sports Science, Exercise and Health

Provides evidence based programs directed and supervised by a team of specialty accredited clinical exercise physiologists. Program staff are members of the Australian Association of Exercise and Sports Science and are accredited in the relevant specialty areas. People that attend the program benefit from a targeted individualised exercise program to manage their non-acute health conditions and/or to rehabilitate musculo-skeletal injuries. Clients present across the following areas: Musculo-skeletal Disorders, Cardiac Risk Factors (non acute), Osteoporosis, Diabetes, Osteoarthritis, Hypertension, Joint and soft tissue injuries, Hyperlipidaemia, Neck and back pain, Obesity, Pre/post operative rehabilitation, Compensable injuries.

The Program offers the following facilities and services for its clients:

Clinical assessment facilities, Clinically relevant exercise training programs, Programs supervised, Appropriate monitoring of programs e.g. heart rate, blood glucose, musculoskeletal loading (as appropriate), Variety of cardiovascular training modalities. Kerry Smith 64882474

Notre Dame Australia

With the recent official opening of its Health Sciences Research and Education building which houses the Institute for Health and Rehabilitation Research, the University of Notre Dame Australia now has a purpose-built facility, which includes a range of up-to-date exercise equipment, an indoor exercise pool, exercise testing facilities and examination rooms. The Institute will be utilised by UNDA staff and students for teaching, clinical and research projects, some of which will facilitate investigations and applications of physical activity, locomotion and exercise within the SCI community. Peter Hamer, Head of School of Physiotherapy, University of Notre Dame, Australia.

Edith Cowan University – Vario Institute

The Joondalup Rehabilitation, Health & Exercise Clinic at Edith Cowan University provides management of musculoskeletal rehabilitation services. The facilities include private consultation rooms, massage cubicles and exercise beds, and counter-balanced resistance equipment that allows range of motion control and precise incremental loading, has been acquired specifically for rehabilitation purposes. Services Include: hydrotherapy (conducted at selected venues that are easily accessible for greater patient participation), physiotherapy, exercise programs, health education, strength and conditioning, pilates, therapeutic massage. Initial sessions focus on individual case management with the aim of progressing to group supervision and ultimately,

independent control. Staff indicate that currently there are no SCI clients in regular attendance. Dr Darryl Turner Manager, d.turner@ecu.edu.au Ph: 6304 5868
www.varioinstitute.com/

3.4 COMMUNITY RECREATION CENTRES

Following discussions with peak bodies including WADSA, RSN, and WSWAA, the following private and local government health and fitness centres were identified as venues most likely to include SCI clients. However, staff could not discriminate if those clients using wheelchairs had SCI or other conditions (eg spina bifida).

- Arena Joondalup Life Program
- Edith Cowan University – Vario Institute
- UWA Health and Fitness Centre
- Curtin University
- Leisure Park Health and Fitness Balga
- Herb Graham Centre Mirrabooka
- Melville Leisure Centres
- Cyril Jackson Leisure Centre
- Craigie Leisure Centre
- Fuller Fitness Subiaco
- Park Recreation Centre
- Trysport Bassendeen

Relevant staff at each of these Centres were asked questions about the involvement of people with SCI in their services eg

- The number of people with SCI currently participating in exercise programs in their centre
- Any special arrangements put in place for people with disabilities eg support staff
- Use of modified/adapted equipment
- Whether staff had received any special training in disability
- The success/sustainability of the process

The results of these enquiries have been combined for discussion under the headings Participation, Special Arrangements, Staff Training, Cost Structure, Provision of Support, Use of Modified/adapted Equipment, and Success and Sustainability. It is important to note however, that there is a **very high staff turnover in this industry** and that programs often change depending on the initiatives of individual fitness professionals.

Participation:

Very few people with SCI appear to be currently utilising exercise programs available in community centres. Most of the centres contacted reported that between one and six clients regularly attended activity programs. The Herb Graham Centre reported the upper number of six SCI clients. This Centre runs a program for the Wheelchair Sports WA Association, and four of the six were regular sportspersons. In other cases staff could not distinguish SCI clients with other disability types who had mobility problems. No Centre reported a procedure for noting disabled clients, although those with specific programs (Joondalup Arena Life and Curtin University) required a disclosure statement whereby clients indicate the nature of their disability and related restrictions.

Special arrangements:

There was a wide variety of responses to this question. Private gyms tended to rely on personal trainers and carers to assist individuals. Fuller Fitness had developed a good reputation with the SCI group through personal involvement of the owner in Wheelchair Rugby programs. Several

Centres had developed working relationships with TAFE Cert III and IV Health and Fitness students. Students had completed units in 'Special Populations', and were then assigned to work with an individual to work as their personal trainer, with the assistance of the individual's nominated carer. Each TAFE student is required to undertake a two-hour session once per week for two terms (20 weeks) in the program. This model was working particularly well at Arena Joondalup (in association with Joondalup TAFE), where there are currently 40-60 clients involved SCI??, and the number of enquiries suggesting the need to go to a third session each week. A similar program is beginning at Curtin University, with Thornlie TAFE students engaged as personal trainers. University and other community fitness centres tend to work on a 'no-one excluded' policy, and recruit interested and trained students as personal trainers as required. A lift has been installed at the UWA Recreation Centre to assist people with mobility issues.

Staff training:

In community health and fitness centres this remains a major issue. Very few fitness and aquatic staff have received comprehensive disability training. There are several schemes available for such training. Pre-service training on disability issues is available in TAFE and university courses in Sports Science and Physical Education, where there are major streams in Exercise Rehabilitation. In some cases it is an option, but in others such as teaching, employers are demanding a minimum level of training in 'special needs'. Professional development courses available include the Disability Education Program and Sports CONNECT, conducted for the Australian Sports Commission by Recreation and Sport Network. These programs have a range of modules that can be tailored to suit individual/group needs. WADSA also conducts training, based on an initial assessment of clients needs, and then delivered and followed up by WADSA staff. Neither of these training approaches specifically covers SCI, but could if requested. These courses are not recognised under the Australian Qualifications Framework, but are usually taken into account by employers.

Lack of trained staff in community recreation facilities is exacerbated by the very high turnover of health and fitness staff - six months in the job is typical. The WA Local Government Association (WALGA), recognising the need to make their Health and Fitness Centres more welcoming and inclusive, launched a State-wide initiative called 'Captive'. This project was funded by the Disability Services Commission and the WA Department of Sport and Recreation, and was lead by a consortium of community service providers and the funding bodies. An environmental scan and literature review identified the service gaps and needs of local communities, and people with disabilities, their families and carers. This included a small but not precisely quantified proportion with SCI. As with much research into inclusion, the barriers encountered and the degree of support required are a key issue and only broad subgroups e.g. 'physical disability' are distinguished. An information kit for local government staff was then developed and is currently being trialled, and staff training workshops conducted. One of the project partners (The Centre for Cerebral Palsy) has also developed a training package for staff in fitness and aquatic specifically for people with physical disabilities. Full descriptions of this project can be found at dsr.wa.gov.au

Cost Structures:

Most Centres operate on a user-pays basis. For personal trainers this can range from \$25-50 per hour. Attending twice per week makes this a costly option for some clients. One program (Life Arena) has a concession price of \$5.50 per session. This is possible because of the use of TAFE students as assistants.

The provision of support:

This is a major issue identified in the 'Captive' project. What can a person with SCI reasonably expect to be provided by/at a community health and fitness centre? The general consensus was that individuals are responsible for their personal supports (carers, transfers, transport, medication etc.) and local facility staff are responsible for providing an accessible and welcoming environment with trained staff (counter staff, personal trainers, gym and aquatic staff).

Use of modified/adapted equipment:

Several centres reported the use of special/adapted equipment. In several, removable benches allowed the client to remain in his/her wheelchair to undertake the exercise, while others had acquired specialised equipment, eg arm ergometers, water wheel ergometers, etc. This was not widespread. Pool access varied across centres, the more recently built ones providing a good level of access/egress to the water, via ramps or hoists.

Success and sustainability:

Given the small number of SCI individuals currently undertaking regular exercise programs in Health and Fitness Centres in WA, many Centres have suggested that the lack of demand is disappointing given their efforts to make facilities more accessible. However, it more likely reflects a number of other personal and social barriers experienced by people with SCI. What is clearly needed is a system that links SCI patients with activities available in the community, and appropriate support mechanisms which would make available a range of choices, from exercising in a closed 'special' centre, to small group and individual activities with support from trained staff, to open participation in normal community programs, with carer support as needed.

3.5 OTHER

Technology Assisting Disability WA Inc. (TADWA)

Is a not-for-profit organisation dedicated to improving the quality of life for people with all disabilities, the frail aged, and those caring for them, through the application of technology and the skills of volunteers. TADWA operates through the activities of a pool of volunteers with a broad range of design, engineering, paramedical, craft, electronic, mechanical, computer and administrative skills. The volunteers devote their time and skills to develop, construct and modify devices. Currently has 100 projects in hand. The focus is not on sport and recreation but on activities of daily living.

<http://www.tadwa.org.au>

The Independent Living Centre of Western Australia

Is a non-government, not-for-profit, community based equipment information and advisory resource service which: Enables people to find out about, see and trial a range of equipment, assistive technology and training resources for people living and working with disabilities, injuries and age-related difficulties;

Hires specialist equipment that may assist individuals and organisations with short-term needs or for trial purposes; and offers an enquiry line, hire service and country program. The focus is not on sport and recreation but on activities of daily living.

<http://www.ilc.com.au/>

Ability Solutions Inc

Ability Solutions is a West Australian, not-for-profit, registered charitable organisation that aims to improve the participation of people with disabilities – including those with SCI - in community life. It and is very active in the development, production and marketing of adaptive equipment for people with disabilities. In particular it customises equipment in order to enable and encourage people with disabilities to become more involved in physical activity. For example, it has designed and implemented specific modifications to wheelchairs to enable participation in beach fishing, golf, lawn bowls and other activities; developed equipment to enable people to be out of their wheelchairs eg sit ski for waterskiing, abseiling sling, handcycle.

www.abilitysolutions.org.au

Trysport Multisport Coaching Services

Offer performance oriented services including tailored training programs, Max Heart Rate Testing, Correct bike setup, and other services. Has 4-5 people with SCI in regular attendance- mainly competitive handcyclists. Andrew Budge <http://www.trysport.com.au>

Cindy Evans. Consultant and recent Project Officer for the Disability Access and Inclusion Plan for the Shires of Collie Bridgetown-Greenbushes, Capel, Dardanup, Donnybrook-Balingup, Harvey, Nannup and Manjimup. Has worked with people with SCI in fitness context.

Darren Lomman, Young Australian of the Year 2007, Engineering UWA B Eng. Has designed and modified motorbikes, hovercrafts, and boats to make them useable by those with disability Promotes general physical activity. Has run projects for SCI
<http://www.dreamfit.com.au/>

3.6 RESEARCH/PLANNED RESEARCH**The Neurotrauma Research Program (UWA)**

Supports cutting edge scientific and clinical research aimed at improving long-term functional recovery from injury to the central nervous system. For a description of current projects. <http://www.waimr.uwa.edu.au/nrp/focus.html> including Professor Stephan Schug, Dr Michelle Byrnes and others: 'holistic multidisciplinary approach to the treatment of pain for individuals following spinal cord injury utilizing a biopsychosocial model'.

University of Western Australia Centres*Centre for Neuromuscular and Neurological Disorders*

The Centre was established as a joint venture between the Australian Neuromuscular Research Institute and UWA. Its mission is to provide an opportunity for multi-disciplinary approaches to research and education within the areas of diagnosis, understanding, treatment, prevention and cure of neurological and neuromuscular disorders and to provide facilities, funding and project support.

<http://www.cnnu.uwa.edu.au/index.cfm?objectid=15A37BC6-96BA-5DAE-BE15A098673E5CDD&CFID=10186868&CFTOKEN=f7565dd83be268e7-84B63A9E-96BA-5DAE-B08EE261FF9BA860&jsessionid=3c307cde1e8162d3d393>

Injury Research Centre, School of Population Health, Faculty of Medicine, Dentistry and Health Sciences

The IRC evolved from the Road Accident Prevention Research Unit that was established in 1989. In July 2001, the RAPRU extended its expertise in the study of road traffic-related injury to all areas of unintentional and intentional injury and was renamed the Injury Research Centre. In 2002 the IRC was redesignated as a World Health Organization (WHO) Collaborating Centre for the Prevention of Road Traffic Accidents for a further four years. The IRC receives financial support from the WA Dept of Health, Australia and the Road Safety Council - Office of Road Safety, Dept of Premier and Cabinet. The Centre's principle goals and objectives are to: apply a public health approach to the identification, prevention, and control of injuries; reduce the occurrence, severity, and consequences of injuries through evidence-based practice; build a research infrastructure that supports integrated basic, strategic, and priority-driven research as a platform for the development and implementation of cost-effective strategies for injury prevention that address state, national, and international priorities.

<http://www.irc.uwa.edu.au/>

Centre for Musculoskeletal Studies

Postgraduate physiotherapy research and clinical training in manual therapy and sports physical therapy is provided by the Centre for Musculoskeletal Studies, based in the Faculty of Medicine at UWA. Supervised Master of Medical Science and Doctoral research programs are also offered with a focus on neuromuscular and musculoskeletal research topics. From 2005 a Doctor of Physiotherapy degree will be offered. Graduate Certificate & Graduate Diploma in Sports Manual Therapy, and Master of Manual Therapy clinical programs are offered, employing a mix of flexible course delivery and intensive clinical skills training. Clinical associates attached to the Centre collaborate with research projects and support the teaching programs on offer. Interaction exists with departments across the Medical and Science Faculties and the metropolitan teaching hospitals.

Centre for Medical Research

Is a collaborative centre between UWA and the Western Australian Institute for Medical Research Inc (WAIMR). Established in 1998, the founding partners of WAIMR were The University of Western Australia (UWA) and the research foundations at Royal Perth Hospital (RPH) and Sir Charles Gairdner Hospital (SCGH). WAIMR is a multi-campus Institute with research laboratories at both RPH and SCGH. WAIMR has a strong research focus on the genetic-based causes of adult diseases. It examines the process at all levels, from the genetics of the disease through each step in the process to the final stages of clinical trials in patients. In 2002 a total of 30 new medical research projects were funded by the WAIMR. An initial \$1.7 million was allocated for these endeavours in the first year with a further \$2.3 million in 2003 and 2004. Several research projects funded related to nerve regeneration.

Dr Andrea Loftus UWA Psychology

Assisted movement (direct muscle stimulation), Dual protocol therapies.

Assoc Professor Danny Green, PhD, School of Sport Science, Exercise Health, UWA. brevis@cyllene.uwa.edu.au Has interest in microcirculation in SCI.

Dr Ed Skull, Bioengineer, RPH. Inventor of one of the original FES bikes 20 years ago. Possibly still has an interest in SCI.

Curtin University

Provides education and training for clinical and community practice in Physiotherapy, Occupational Therapy, Nursing. Also the Centre for Research on Ageing. Many student/staff projects, theses etc involving SCI. Garry Allison, Trudi Fischer

Edith Cowan University

Provides education and training for clinical and community practice in Exercise and Sports Science (AAESS accredited), Occupational Therapy, Nursing. No current involvement with SCI.

Neurotrauma Research Program, University of Western Australia

The program supports scientific and clinical research aimed at improving long-term functional recovery from injury to the central nervous system. Its research focus is described at www.waimr.uwa.edu.au/nrp/focus.html with descriptions of current projects and key researchers in the field.

MAP INVESTIGATORS/ASSOCIATES**Prof Sarah Dunlop (School of Animal Biology, WAIMR, UWA)**

Role: Team Leader. Track record in holding & directing multidisciplinary Program Grants (2 NHMRC, 1 JDRF/NH&MRC) and will continue to develop the MAP initiative, in parallel with ASCIN (Australasian Spinal Cord Injury Network).

Australian and New Zealand Spinal Cord Injury Network - Board Member

Chief Investigator on Victorian Neurotrauma Initiative Program Grant application “Promoting neural recovery following SCI through exercise: Translation of basic research into clinical programs”.

Basic biomedical research, nerve cell responses to injury, exercise-dependent plasticity.

Prof Frank Mastaglia (Centre Neuromuscular & Neurological Disorders, UWA, QEIIHC)

Role: Advisory role on neural rehabilitation and clinical research.

Mr John Ker (Spinal Unit, Royal Perth Hospital, Shenton Park Campus)

Role: Advisory role on Survey, ethical and clinical aspects of research projects and service delivery; Advocacy for spinal cord injured individuals

Prof Bob Grove (School of Human Movement & Exercise Science, UWA)

Role: Development of the Survey Questionnaires and coordinating publishing of survey findings

A/Prof John Buchanan (Physiotherapy Service, Royal Perth Hospital, Shenton Park Campus)

Role: Advisory role on physiotherapy service delivery; Liaison with Royal Perth Hospital (infrastructure, staff)

“Current project description will be submitted by RPH clinical staff (Redwood/Weston)”

Prof Peter Hamer (School of Physiotherapy, UNDA)

Role: Advisory role on design of exercise protocols; Coordination of NDUA physiotherapy student involvement; Member of MAP Interim Steering Committee.

Keen interest in provision of exercise and physical activity through research based programming facilitated through the Institute for Health and Rehabilitation Research, UNDA

Potential Projects - Vascular Function Response to Physical Activity in people with spinal cord injury – in collaboration with Green (UWA) and Thijssen (Netherlands).

Dr Barby Singer (Centre for Musculoskeletal Studies, School of Surgery and Pathology, UWA)

Role: Advisory role on functional electrical stimulation and design of research projects; Blind/external clinical assessor, as required, for research projects

Dr David Lloyd (School of Human Movement & Exercise Science, UWA)

Role: Advisory role on design of exercise protocols; Coordination of client assessments involving technologies

A/Prof Garry Allison (Neuroscience and Trauma Physiotherapy Royal Perth Hospital, Physiotherapy Department & Curtin University School of Physiotherapy)

Role: physiotherapy and physical therapy in SCI, limb function, quantitative functional assessment
Existing Projects

- The development of a Functional Hand Scale for individuals with Tetraplegia – AuSpinal.

- The role of virtual exercises (mirror and mimicking actions) in Neuropathic pain in individuals with SCI.
- Victorian Neurotrauma Initiative - a series of experiments and interventions programs for SCI. (EOI only)

Past Projects

- Development of an electronic system for quantifying inter and intra therapists assessments of hand function in tetraplegia. (Multi-centre trial)
- Movement patterns of individuals with SCI in transferring. EMG profiling
- Using Bio-impedance to assess body composition – can one use a wheelchair instead of lying down?

Dr Romola Bucks (School of Psychology, UWA)

Role: cognitive function after neural injury; qualitative assessment

A/Prof Gary Thickbroom (Centre Neuromuscular & Neurological Disorders, UWA, QEIIIMC)

Role: Advisory role on neural plasticity and assessment utilising transcranial magnetic stimulation and related technologies

Dr Brendan Lay (School of Human Movement & Exercise Science, UWA)

Role: Advisory role on design of exercise protocols and client assessments

Tracey Redwood, Physiotherapist Shenton Park. Not research per se yet, but support MAP

Renee Weston, Physiotherapist Shenton Park, Not research per se yet, but support MAP

Trudi Fischer, Physiotherapist & Lecturer, Curtin. Research

The use of virtual exercises in the management of lower limb pain in individuals with spinal cord injury.

Louise Daw, Coordinator, Neurotrauma Research Program & MAP

Michelle Meade, Physiotherapist (Stroke & Head Injury), Coordinator MAP and Research Project Officer. Existing Projects: MAP: Imminent upper limb (UL) study (to replace discontinued study) planned to investigate admission and discharge differences in function in tetraplegics admitted to Ward XI, RPH-Shenton Park. Plan to assess patients with current accepted UL outcome measures and try to establish a WA-developed measure (AuSpinal) as the gold standard measure for UL function in these individuals. Also plan to assess patients at 12 months to review any improvements or worsening in function to create baseline knowledge of function and to gain a greater understanding of why there are changes and the mechanisms behind any injuries. Potential Projects: MAP: Locomotion training study, whole body vibration study.

4. NEW SOUTH WALES

University of Sydney.

FES and treadmill in SCI & TBI. A/Prof Glen Davis, & Dr Che Fornusek,

<http://www2.fhs.usyd.edu.au/ESS/rrc/davis.htm>

Disabled sports physiology, field physiological and performance assessment, electrotherapy for performance and as ergogenic aids. Current projects:

- **The Shake-a-Leg FES Research Project**

Cardiorespiratory Responses to Arm versus Arm + Electrical Stimulation-Induced Leg Cycling Training in People with Paraplegia

- **FES Project**

There are three phases. First, it will quantify the cardiorespiratory and neuromuscular effects of computer controlled functional electrical stimulation cycling over a range of velocities in recent spinal cord-injured patients. Second, the project will train these individuals using a new Australian FES-cycle versus a traditional exercise bicycle to assess the effectiveness of FES exercise for enhancing cardiorespiratory fitness, muscle size and strength. Finally, it will seek to define the optimal stimulus for cardiorespiratory and muscle training to improve general health in spinal cord-injured patients.

- **Multi-Tems Pty Ltd**

an Australian medical instrument company with a proven history of developing and marketing bioengineering technologies for therapeutic use within the physically disabled community, has recently developed a new FES exercise cycle which overcomes all of the limitations of the US-manufactured device at a substantially lower cost (\$A15,000). This FES exercise cycle, in addition to utilising a unique stimulus wave-form to activate the paralysed muscles, employs an exercise paradigm and force application which is unlike any other currently in use world-wide.

- **Arm Cranking Exercise for People with Spinal Cord Injuries**

This project is investigating the cardiorespiratory and haemodynamic responses to arm exercise in people with paraplegia during orthostatic stress. In particular, we are interested in the neural control of heart rate, arterial blood pressure and peripheral blood flow when central blood volume is reduced (via lower body negative pressure) or increased (via augmented venous return during electrical stimulation leg muscle contractions).

Dr Jacqui Raymond

- **Walk Back to the Future**

The Rehabilitation Research Centre coordinates a multi-disciplinary research project to investigate the therapeutic and scientific outcomes of Functional Electrical Stimulation for standing and walking in spinal cord-injured individuals. Entitled "Walk Back to the Future", this three-year research project is administered at the Faculty of Health Sciences, but features the significant participation of a wide range of clinicians, researchers and biomedical engineers at The University of Sydney, Royal North Shore Hospital, Royal Rehabilitation Centre, Prince Henry Hospital, the Neural Engineering Clinic (Maine, U.S.A.) and the University of Alberta (Alberta, Canada).

Dr Ashley Craig Professor; Rehabilitation Studies Unit, Northern Clinical School, Faculty of Medicine, The University of Sydney. Ph: 0417 290 521

- **The Burn Rubber Burn Project**

is a 12-month Greater Metropolitan Clinical Taskforce funded project to be carried out at the Prince of Wales Spinal Injury Unit in partnership with the State Spinal Cord Injury Service. The project aims to describe how to deliver a safe exercise gymnasium program for people with a spinal cord injury to maximise cardiovascular fitness and to establish partnerships with gymnasiums who are able to assist people with established SCI access suitable equipment and supervision. The project will monitor the effect of a 6-12 month training program for people with SCI C5 and below, living in the community and medically stable. The MAA provided funding of \$132,000 to the

Prince of Wales to expand the program to include a network of accessible and affordable community based gymnasiums offering the Burn Rubber Burn classes to people with a SCI.

Simon Robinson Di-Francesco on (02) 9382 5623 Simone.Robinson@sesiahs.health.nsw.gov.au

<http://www.health.nsw.gov.au/gmct/spinal/projects.html>

The Spinal Injuries Research Centre

<http://www.powmri.edu.au/sirc.htm>

Established at the Prince of Wales Medical Research Institute in late 1999 and officially opened in 2001 by the Premier of NSW after receiving a \$1million grant from the NSW Government. Many projects including the study of Autonomic Hyperreflexia, Sympathetic Nerve Pathways below the lesion, Neural control post injury, spinal cord cysts (syrinx), muscle force, reflexes and electrical stimulation.

Current projects include:

- Spinal cord injury and restoration of muscle force:

Using electrically stimulation over muscles they plan to continue with their work on Indirect activation of the spinal cord below the injury to map out reflexes involved in walking. It is hoped that this will eventually lead to restoration of a natural form of walking with electrical stimulation of the damaged spinal cord. Other work is examining the novel respiratory reflexes which may be used to monitor precisely changes motor and sensory function in the spinal cord at the thoracic level. Professor Simon Gandevia, A/Professor Peter Nickolls and Professor David Burke and Dr Dave Collins

- Respiratory complications in spinal cord injury:

Our current studies aim to improve cough in people with high level SCI using techniques of functional electrical stimulation (FES) applied to the paralysed abdominal muscles. Dr Jane Butler

- Sensorimotor control and integration in spinal cord injury:

We want to investigate how the properties of the smallest functional units of muscles (single motor units) change when the command signals from the brain are compromised and try to find a way to establish the progression of these changes. We are also looking at how signals from sensory receptors in skin and muscle are affected by the reduced limb use, and how their interaction with motor nerves in the spinal cord changes at levels below the site of injury. Dr Penelope McNulty

Rehabilitation Studies Unit, University of Sydney (RSU)

The RSU has many research projects in progress (including eight NHMRC funded projects) that can be divided into four themes:

- traumatic brain injury,
- spinal cord injury,
- musculoskeletal injury and
- evidence-based practice.

Dr Lisa Harvey, University of Sydney. Physiotherapist and PhD. Upper limb function. Effects of passive movement. Clinical trial experience. Development of exercise prescription package - see

<http://www.physiotherapyexercises.com/>

Garvan Institute of Medical Research (St Vincent's Hospital, University of NSW)

Our ultimate goal is to understand how we can harness the brain's own stem cells and/or modulate nerve cell's connections (i.e. how we can harness neural plasticity) to help treat Parkinson's disease, spinal cord injury and Alzheimer's disease, all of which result from loss of nerve cells and their connections from specific regions of the nervous system. We study how abnormal signalling at nerve cell junctions contributes to these movement and memory disorders and we work to understand why the nervous system's own repair systems, i.e. the formation of new nerve cells, is ineffective in these conditions. We hope to find novel stem cell treatments that will profoundly impact people with brain diseases. Bryce Vissell

<http://www.garvan.org.au/research/research-groups/neurodegenerative-disease.html/>

The Royal Rehabilitation Centre Sydney Moorong

Dr James Middleton: Medical Director of the Moorong Spinal Unit, Royal Rehabilitation Centre in Sydney and a Senior Lecturer in the Rehabilitation Studies Unit at the University of Sydney. His research interests include outcome measurement, morbidity and mortality, orthotics and functional electrical stimulation. Current president of ANZSCoS.

http://www.royalrehab.com.au/annual_report/RRCS_Annual_Report.pdf.

5. QUEENSLAND

Centre of National Research on Disability and Rehabilitation Medicine (CONROD)

Established in 1997 through a partnership between the Motor Accident Insurance Commission (MAIC), The University of Queensland (UQ), the Queensland Institute of Medical Research (QIMR) and the support of the Queensland Government. The current five year agreement took effect on 1 November 2005 between UQ and MAIC. MAIC funding, totalling \$9.25 million across five years, supports the five core research programmes. The University provides \$1.5 million across the five years, as well as meeting infrastructure needs. In addition, Queensland health is providing \$816,667 towards the Queensland Trauma Registry. The Centre's core research complements the MAIC objective of generating research outcomes in the area of acute treatment and rehabilitation of people injured in motor vehicle accidents or other analogous events. This focus links CONROD to other MAIC funded research initiatives relating to injury prevention and disability management, located at the University of Queensland, Queensland University of Technology and Griffith University. This combined research then incorporates all aspects of injury control from prevention through treatment, rehabilitation and disability management. Projects include:

Identifying and quantifying environmental barriers after injury or disabling conditions using the CHIEF-SF. This project investigates the role of environmental factors as barriers in the lives of persons living in Qld who have experienced such an injury or condition and who have requested assistance from LifeTec in the previous 18 months. The specific results provide important information about barriers experienced by people with SCI as well as the response of LifeTec to those barriers. It represents a novel research collaboration with a non-governmental organization such as the Spinal Injuries Association and provides a model for future collaborations. Dr Cheryl Swanson

<http://www.uq.edu.au/conrod/>

Clinical Centre of Research Excellence in Spinal Pain, Injury and Health (CCRE)

This multidisciplinary Centre at The University of Queensland creates new opportunities for research on effective and cost-effective clinical interventions and education in this area. The CCRE commenced operation in 2007, with a grant of \$2.0m over five years, from the National Health and Medical Research Council. Will be an Australian centre of back and neck pain research and treatment featuring two community-based clinical research sites where trials of innovative new treatments for spinal pain will be conducted. The Centre's multidisciplinary group of chief investigators will collaborate with a network of Australia's leading spine scientists and provide training. Director, Professor Paul Hodges 07 3365 4567.

Social and Behavioural Science. Vocational and Community Rehabilitation. The University of Queensland

Research: Review of the Spinal Cord Injuries Response - The purpose of this study is to review and evaluate the appropriateness, impact, effectiveness and efficiency of the Spinal Cord Injuries Response. Additionally, the findings may contribute to the development of initiatives to support other groups of people being discharged from hospital. Funding: Disability Services Queensland
Dr Pat Dorsett, Dr Heidi Muenchberger, A/Prof. Elizabeth Kendall

www.uq.edu.au/sbs

The Queensland Brain Institute

At the University of Queensland. Works to discover the cellular and molecular mechanisms which underlie the ability of the adult brain to generate new nerve cells and form new functional connections. Adult stem cells & replacing lost motor neurons.

QBI is headed by Professor Perry F. Bartlett, ARC Federation Fellow, UQ Foundation Chair in Molecular Neuroscience and Fellow of The Australian Academy of Science. In 2004 the team discovered a molecule blocking regrowth of damaged nerve processes – of significant relevance to SCI recovery processes.

www.qbi.uq.edu.au

Princess Alexandra Hospital

Australia's first human clinical trial – transplantation of olfactory nasal cells into SCI patients. From <http://www.spinalcure.org.au/a/50.html> Phil Waite
pwaite@unsw.edu.au

Walk On SCI Recovery Project

Is an initiative that brings the Project Walk Spinal Cord Injury Recovery Program to Australia, with the first facility to be based in Brisbane. The Walk On intensive exercise recovery program, offers a path to maximising functional recovery through a structured program based upon the Project Walk www.projectwalk.org application of the Dardzinski methodology, which has been offered in the United States since 1999. Project Walk reports that the techniques used increase central nervous system activity, muscle mass and movement, and decrease pain, depression, skin tissue breakdown and other health problems associated with spinal cord injury. With funding support from Spinal Cure Australia and venue partner Sporting Wheelies and Disabled Association of Queensland, several exercise physiologists have been trained at the US-based Project Walk Recovery Centre to achieve their Level 1 Certification in the recovery methodology. These Recovery Specialists will then return to Australia and continue to offer the program to clients under the guidance of Project Walk and one of their Lead Recovery Specialists. Program costs \$55 per hour.

David Prast dprast@scia.org.au; Sean Tweedy

<http://www.scia.org.au/walkon>

The Queensland Spinal Cord Injuries Service

Located in Brisbane, this Service has developed a unique continuum for the acute care, rehabilitation and ongoing management of individuals with spinal cord injuries, representing a best practice model in this field.

The Queensland Spinal Injuries Unit provides acute management and primary rehabilitation services to people from Queensland and Northern New South Wales. The Transitional Rehabilitation Program (TRP) provides ongoing rehabilitation in the community and allows earlier discharge from the Spinal Injuries Unit. The Spinal Outreach Team (SPOT) provides allied health and nursing consultancy and early intervention service for people with spinal cord injuries, their families and other health professionals all over Queensland. SPOT has recently conducted research

into the changes experienced by people with long duration spinal cord injury.

spot@health.qld.gov.au

The Adapted Physical Activity Program (APAP)

A service provided through the School of Human Movement Studies, University of Queensland. The main aim of the APAP is to assist people with disabilities who are not physically active on a regular basis to find ways to increase their physical activity and thereby improve their health and functioning. The Program can also assist people who are already active to make sure their activity is safe, appropriate and effective. APAP specialises in interventions for people with neuromusculoskeletal impairments of both traumatic and non-traumatic origin, including brain injury, spinal cord injury, amputations, cerebral palsy, stroke, spina bifida, epilepsy and multiple sclerosis. While the vast majority of clients are referred by rehabilitation agencies, people with disabilities interested in becoming physically active may self-refer. The APAP uses evidence-based behaviour change strategies and problem solving techniques in 6-8 face-to-face sessions and telephone support delivered over a 12-16 week period. Clients determine the type of activity they wish to engage in eg prescribed gym program, home exercise programs, facilitation of involvement with community-based sport and recreation organisations (either segregated or integrated settings), structuring increases in incidental exercise, and educating clients about the positive benefits of, and opportunities for, regular participation in physical activity. People interested in the APAP have two options: 1) By students enrolled in Exercise Science in the School of Human Movement Studies and is provided free of charge, under the supervision of Dr Sean Tweedy. 2) Professional service provided by Exercise Physiologists accredited with the Australian Association for Exercise and Sports Science (AAESS) - costs \$80.00 per face-to-face session with many clients eligible for rebates from various sources. Specific projects currently being undertaken on SCI. Kelly Clanchy on 3365-6764 or Dr Sean Tweedy on 3365-6638.

Sporting Wheelies and Disabled Association of Queensland

The Sporting Wheelies and Disabled Sport and Recreation Association of Queensland, Inc. is the peak body for the promotion of sport, recreation and fitness opportunities for people with a physical disability or vision impairment throughout Queensland. Has significant SCI membership. <http://www.sportingwheelies.org.au/>

6. SOUTH AUSTRALIA

Spinal Injury Unit

A cooperative research study between the Orthopaedic, Amputee and Spinal Injury Rehabilitation Service, the Sleep Studies Unit at RAH and the Repatriation General Hospital at Daw Park, showed that up to 30 percent of tetraplegic people are affected by sleep apnoea. A paper on cognitive effects associated with obstructive sleep apnoea in tetraplegia resulting from this study has been accepted for publication. The Spinal Injury Unit is also studying the effects of functional electrical stimulation (FES) in healthy volunteers with chronic stable paraplegia, and the potential benefits of such stimulation applied to individuals with acute spinal cord injury. In addition, the Motor Accident Commission has funded a study to look at the effects of FES on bone metabolism, clinical measures and rehabilitation outcomes.

<http://www.rah.sa.gov.au/research/rsspinal.php>

Hampstead Rehabilitation Centre

Hampstead Rehabilitation Centre is a campus of Royal Adelaide Hospital. It is a 150-bed facility that provides clinical rehabilitation services for people suffering from traumatic brain injury,

stroke, other neurological and medical disorders, spinal cord injury, orthopaedic conditions and amputations. It is part of the South Australian Spinal Cord Injury Service (SASCIS). This service which also covers the Northern Territory and Western New South Wales provides acute injury management, rehabilitation and follow-up for people who have suffered spinal cord injury or disease.

There is also a Centre for Physical Activity in Aging that has a comprehensively equipped gymnasium available to exercise rehabilitation and health promotion client. A well-equipped exercise laboratory facilitates the conduct of fitness testing within rehabilitation and research programs. Clients with disabilities and physical limitations are well accommodated through modification of existing equipment items and programs. Water based programs are conducted in the hydrotherapy pool. The Centre also conducts various “off campus” programs which utilise the facilities of different community groups/organisations. The therapy facility is also used as a training and support network for South Australian Paralympic athletes. SASCIS staff are actively involved in a range of research programs aimed at improving quality of life and community integration. A comprehensive team of spinal cord injury nurses, physiotherapists, occupational therapists, remedial physical educators, social workers, clinical psychologist and peer advocates.

Dr Ruth Marshall, Medical Director; Dr. Adrian Winsor, Deputy Director, SASCIS.

<http://www.rah.sa.gov.au/hampsted/hampsted.php>

Dr Raymond Cripps

Associate Lecturer in the Research Centre for Injury Studies, in the School of Medicine at Flinders University. Involved in developing the Australian Spinal Cord Injury Register, which he manages as part of his role in the AIHW National Injury Surveillance Unit. His research interests include spinal cord injury and injury among horse riders.

Dr Nigel Jones

NRF Professor of Neurosurgery at the University of Adelaide. His research interests are neurotrauma, particularly neuronal and axonal changes after closed head injury and the development and progression of syringomyelia. Past President of the Spine Society of Australia.

7. VICTORIA

The Victorian Neurotrauma Initiative (VNI)

A \$63 million health research fund established in 2005 in Victoria with five years funding provided by the State’s Transport Accident Commission in partnership with the Victorian Government’s Department of Innovation, Industry and Regional Development. The VNI maintains a close working relationship with the local neuroscience sector via collaboration with **Neurosciences Victoria Ltd (NSV)**. The VNI supports research into Traumatic Brain Injury (TBI), Spinal Cord Injury (SCI) and Peripheral Nerve Injury (PNI) conducted by Victorian scientists in collaboration with their national and international colleagues.

The objectives of the VNI are:

- to reduce the impact of neurotrauma and improve the quality of life of those affected.
- to expand the scope of innovative neurotrauma research through multidisciplinary, national and internationally-linked collaboration.
- to focus Victorian, Australian and international research and attention on the consequences of neurotrauma.

To date, twenty-two projects have been approved to receive VNI funding, to an aggregate value of \$15.6 million. Spinal Cord Injury research projects:

- Novel Sodium Channel Blockers

- Corticospinal Regeneration
- Sleep Health in Tetraplegia
- New Treatments for Brain and Spinal Cord Injuries
- Macrophage Cytotoxicity after SCI
- Spinal Cord Recovery in the Opossum
- EphA4 Peptide Inhibitors for Neurotrauma Treatment
- Bone Marrow Grafts for Spinal Cord Repair
- Matrix Technology for Spinal Cord Repair
- Singing in Spinal Cord Injury
- Functional Electrical Stimulation for Hand Function in Quadriplegia

<http://www.vni.com.au/research/cid/1/parent/0/t/research>

- **The Global Evidence Mapping Initiative in Traumatic Brain Injury and Spinal Cord Injury**

This project is a collaboration between the University of Melbourne and Monash University, the National Institute of Clinical Studies, Royal Melbourne Hospital, Southern Health, the Australasian Cochrane Centre and National ICT Australia. The Global Evidence Mapping (GEM) Initiative aims to make available evidence about ‘best-practice’ approaches and knowledge ‘gaps’ by systematically identifying, updating, appraising and delivering existing research evidence in the fields of traumatic brain injury and spinal cord injury. It is engaging experts in evidence-based medicine and knowledge transfer nationally and internationally. The evidence maps will provide VNI with optimal guidance for where and how to direct future research efforts by prioritising important unanswered questions and avoiding duplication of existing research. The evidence maps will also allow VNI to feedback evidence-based clinical and rehabilitation strategies to healthcare providers, as well as the TAC policy and claims divisions. This has the potential to help healthcare providers to develop ‘best-practice’ models of client service provision. The outcomes of this project will also be of substantial benefit to the wider neurotrauma community, both locally and internationally.

Associate Professor Russell Gruen

- **Enhancing the research capacity of the Victorian Spinal Cord Service**

The Victorian Spinal Cord Service (VSCS) is based at Austin Health and provides acute, rehabilitation and community outreach services for people with a Spinal Cord Injury (SCI). Currently all VSCS staff are employed within clinical services roles. This initiative aims to enhance the research output of the Victorian Spinal Cord Service (VSCS). This initiative will fund the employment of a full-time Research Development Co-ordinator and a part-time Database Manager, over a two year period. The Research Development Co-ordinator will be responsible for the development and management of research projects undertaken by the VSCS. The Research Development Co-ordinator will also play a key role in building SCI research collaborations and providing mentorship opportunities for clinical staff based at the VSCS. The Database Manager will be responsible for the development and maintenance of a SCI database. This database will contain the details of Victorian individuals with SCI and will be used to assist in the identification of potential research participants.

Chief Investigator: A/Prof Douglas Brown

Lead Organisation: Austin Health

The Centre of Clinical Research Excellence in Neuroscience

University of Melbourne, Is a multi-disciplinary clinical research model focusing on producing innovative patient-centred research, training and education into stroke, epilepsy and other neurological disorders. Research disciplines range from neurology and medicine through physiotherapy, occupational therapy, speech therapy and nursing, to neurophysiology, psychology, neuroimaging, neuroepidemiology and public health. Funded by the National Health and Medical

Research Council (NHMRC), the Centre was established in 2003 and builds upon the achievements of the Centre of Clinical Excellence in Hospital Based Research – Stroke and Epilepsy. The Centre is based at the Austin Health Repatriation campus in Heidelberg, Victoria and administered by the Department of Medicine Austin Health/Northern Health, The University of Melbourne. It is headed by a multi-disciplinary team of four Chief Investigators:

Professor Geoff Donnan, Leader of the Centre, Director of the National Stroke Research Institute

Professor Sam Berkovic AM, Director of the Epilepsy Research Centre

Professor Mary Galea, Director of the Rehabilitation Sciences Research Centre - Exercise and FES (eg rowing machines) for SCI. Physiotherapy background and basic research into SCI.

Professor Judy Parker AM, former Head of the School of Nursing, at the University of Melbourne.

School of Physiotherapy: Rehabilitation Sciences Research Centre Research Programs

University of Melbourne. Overall Theme: Movement Control Mechanisms in Health and Disease. Research at the Centre is concerned predominantly with the elucidation of the mechanisms underlying control of movement in healthy individuals and those with movement problems arising from disease or injury. Some projects also involve the investigation of intervention programs to reduce disability and improve participation in society. Spinal Cord Injury Projects Mary Galea

- Feasibility of a low cost and easy to use rowing ergometer for paraplegic individuals using surface stimulation of paralysed muscles: A pilot study
- The effect of vibration training on macro-architecture of bone and blood flow in chronic spinal cord injured individuals

Mapping Wellbeing after spinal cord injury

Research project represented a collaboration between Monash University, ParaQuad Victoria and the Robert Rose Foundation, and was supported by the Austin Hospital and Caulfield General Medical Centre.

http://www.paraquad.asn.au/index.php?mact=News.cntnt01_detail_0&cntnt01articleid=21&cntnt01returnid=25 Christine Migliorini on (03) 9594 1254. Email: INFO@PARAQUAD.ASN.AU

Monash Institute

Embryonic & adult stem cell. From <http://www.spinalcure.org.au/a/50.html>

HyperMED Australia

This company incorporates the trading identities Spinal Rehabilitation Group Pty Ltd and Melbourne Hyperbaric Pty Ltd. It's website describes the various treatment and management approaches to chronic spinal disorders that it has used, including hyperbaric oxygenation and use of a Lokomat robotic walking machine.

www.spinalrehab.com.au

8. INTERNATIONAL CENTRES AND RESEARCHERS

8.1 UNITED STATES OF AMERICA

Spinal Cord Injury Hospitals & Rehabilitation Centers Listed by State

Lists key centres in USA.

<http://www.sci-info-pages.com/rehabs.html>

Key US research funding agencies: see for current and past research

National Institute on Disability and Rehabilitation Research

<http://www.ed.gov/about/offices/list/osers/nidrr/index.html?src=mr>

National Institutes of Health <http://www.nih.gov/>

National Science Foundation <http://www.nsf.gov/>

Centers for Disease Control & Prevention <http://www.cdc.gov/>

VA Office of Research & Development <http://www.research.va.gov/default.cfm>

US Department of Veterans Affairs

<http://www.research.va.gov/programs/>

Rehabilitation Research and Development Centres of Excellence - some directly address SCI.
eg

Miami, FL: The Center for Functional Recovery in Chronic Spinal Cord Injury investigates spasticity, pain management, recovery of motor and sensory function, and other areas of critical importance to veterans with spinal cord injury (SCI). The Miami center works to strengthen the network of VA SCI investigators and the community of clinician-scientists dedicated to helping patients with spinal cord injury and their families.

Bronx, NY: Spinal Cord damage Research centre, Department of Veterans Affairs Rehabilitation, Research and Development Center of Excellence, Veterans Affairs medical Centre, Bauman William, Spungen Ann

Model SCI Care Systems

The Model Spinal Cord Injury System program, sponsored by the National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitative Services, US Dept of Education, provides assistance to establish innovative projects for the delivery, demonstration, and evaluation of comprehensive medical, vocational, and other rehabilitation services to meet the needs of individuals with spinal cord injury. Model System Centers across the United States work together to demonstrate improved care, maintain a national database, participate in independent and collaborative research and provide continuing education relating to spinal cord injury.

14 Model Spinal Cord Injury Systems (links)

National Spinal Cord Injury Statistical Center (links)

<http://www.spinalcord.uab.edu/show.asp?durki=21392>

UMHS Model Spinal Cord Injury Care System. University of Michigan Health System (UMHS), Physical Health and Rehabilitation, Ann Arbor, MI

UMHS Model Spinal Cord Injury Care System is one of 16 comprehensive programs in the United States that combines advanced clinical care, research and education of SCI specialists under a grant from the National Institute on Disability and Rehabilitation Research. The UMHS program is the

only one of its kind in the Midwest. Together, the 16 SCI centers aim to improve the care of the more than 200,000 people living with a spinal cord injury, and the 11,000 more who are injured each year. http://www.med.umich.edu/pmr/model_sci/ or e-mail model_sci@umich.edu.

Gater, Tate, Scelza, Zemper, E.

University of Pittsburgh Model Center on Spinal Cord Injury

The research projects evaluate the impact of selected innovations in technology on service delivery and on outcomes such as function, independence, and employment. One project examines an innovative technology in the form of an exercise system (GAMECycle) to increase cardiovascular fitness in a population with SCI. The GAMECycle is an interface between a personal computer and an arm ergometer allowing for computer play while exercising.

www.upmc-sci.org

Michael L. Boninger, MD.

The Model Systems Knowledge Translation Center (MSKTC)

Summarizes research, identifies health information needs and develops systems for sharing information for the NIDRR model systems programs in traumatic brain injury, spinal cord injury and burn injury.

<http://www.msctdisseminationcenter.org/>

The Rehabilitation Research and Training Centers (RRTCs) in Spinal Cord Injury

Sponsored by the National Institute on Disability and Rehabilitation Research (NIDRR). The primary goals of these Centers are:

- to conduct research targeted toward the production of new knowledge which will improve rehabilitation methodology and service delivery systems, alleviate or stabilize disabling conditions, and promote maximum social and economic independence.
- to institute related teaching and training programs to disseminate and promote the utilization of research findings.

Includes RRTC on Secondary Prevention Through Exercise: A Participatory Approach for People with SCI. eg

- Research project consisting of a novel exercise program for individuals with SCI. The basic format of each program is defined by both researchers and consumers with SCI, while still allowing flexibility for the individual needs of the participants with SCI. Will provide information to help facilitate participation in, and long term adherence to, routine physical activity. Setting is either in the individual's own home or at the National Rehabilitation Hospital (NRH)'s exercise facilities in Washington, DC.
- Research project: Exercise and Secondary Conditions: A National Survey of Individuals with Spinal Cord Injury. Uses a 2 year national survey of people with spinal cord injury, combined with in-depth interviews, to generate new knowledge about SCI and physical activity. This knowledge will allow health care professionals to target their exercise training recommendations and follow-up to those with SCI who are least likely to exercise, and to those who are most likely to benefit from exercise.

<http://www.spinalcord.uab.edu/show.asp?durki=21807>

Suzanne L. Groah, MD, MSPH; Director of SCI Research, National Rehabilitation Hospital, Washington, DC. Suzanne.L.Groah@Medstar.net

The Miami Project to Cure Paralysis

The world's largest comprehensive spinal cord injury (SCI) research center; dedicated to finding more effective treatments and, ultimately, a cure for paralysis; A Center of Excellence housed at the Lois Pope LIFE Center at the University of Miami Miller School of Medicine.

The Miami Project has assembled a broad spectrum of researchers, clinicians, and therapists whose expertise relate directly to the problem of SCI and whose full-time focus is SCI research. Has local

research links with the South Florida SCI Model System, the Miami VA Rehabilitation Research Center of Excellence in Functional Recovery and SCI, and the University of Miami Center on Aging.

Neuromotor Rehabilitation Research Laboratory, Department of Neurological Surgery, University of Miami School of Medicine, 1095 Northwest 14th Terrace, Miami, R-48, FL 33136, USA.

Jacobs PL, Nash MS, Gater, Field-Fote E **Professor Edelle Field-Fote**, Miami Project to Cure Paralysis. Massed practice for upper limb function, treadmill training for SCI

<http://www.themiamiproject.org/>

<http://www.themiamiproject.org/x21.xml>

Rehabilitation Engineering Research Center on Recreational Technologies and Exercise Physiology Benefiting Persons with Disabilities (RERC RecTech)

University of Illinois, Chicago. This program researches access to recreational opportunities and physical endurance of people with disabilities, targeting four primary areas: (1) increased access to fitness and recreation environments; (2) interventions to increase physical activity and recreation participation; (3) adherence strategies to reduce physical activity relapse and dropout rates; and (4) randomised clinical trials to evaluate improvements in health and function. Research and development projects include: (1) a comprehensive needs assessment that involves ongoing assessment of consumer needs as they pertain to existing and emerging recreational and fitness technologies; (2) research on the use of information technology and a newly designed environmental accessibility instrument for facilitating access to recreational and fitness environments and promoting improved health and function; (3) research on the use of "tele-exercise" technology for promoting participation and for monitoring intensity and physiological/psychological outcomes of home-based exercise programs; (4) development of broadly applicable aftermarket accessory kits for adapting existing cardiovascular exercise equipment for use by people with disabilities and determining the efficacy of the new adaptations in improving fitness; (5) development of technology to allow users adaptive control of exercise machines; and (6) development of an online RecTech solutions database of currently available recreational and fitness technologies to make available solutions more accessible to consumers. Two training projects promote capacity building for future recreation, fitness, exercise physiology, engineering, and rehabilitation professionals, and two additional training projects support professional development.

www.rerrectech.org

James H. Rimmer

NeuroRecovery Network (NRN)

A grant program involving only a handful of select hospitals and rehabilitation centers across the nation. The goal of the NRN is to improve the overall health and wellbeing of people living with paralysis as well as promote functional recovery. The program seeks to support the application of science and research into intensive locomotor training, which is an activity-based rehabilitation treatment. Long-term goals include: maximizing the availability and quality of rehabilitative care for patients with spinal cord injuries and other neurological disorders; developing a comprehensive database to track the success of activity-based therapeutic interventions; identifying the optimal locomotor training regimens for specific patient populations; and maintaining an administrative network that can supply logistical, technical, and personnel-based support for rehabilitation programs. The program is funded through a cooperative agreement between the Christopher Reeve Foundation and the Centers for Disease Control and Prevention. The Foundation selected the **Shepherd Center, a leading rehabilitation hospital**, to participate in its NRN. The specializes in the treatment of people with spinal cord injuries, acquired brain injuries, multiple sclerosis, chronic pain and other neurological conditions. <http://www.shepherd.org/>

NextSteps Chicago Spinal Cord Injury Rehabilitation Center

O'Connor Foundation dba as NextSteps Chicago is the first non-profit exercise facility devoted to the rehabilitation and overall wellness of SCI victims. NextSteps' mission is to provide the Chicago SCI community with affordable, dynamic, and progressive spinal cord injury rehabilitation while utilizing technologically advanced equipment and personalized functional exercise therapy and training methods. It provides treatment for chronic and acute SCI clients with the latest protocols in activity based motion therapies that help SCI clients regain function and sensation even after years of paralysis. Recipient of the Christopher Reeves Paralysis Foundation Quality of Life Grant

National Spinal Cord Injury Statistical Center (NSCISC), Birmingham Alabama.

Research by Michael DeVivo includes epidemiology and long-term outcomes of persons with spinal cord injury, including life expectancy and causes of death, lifetime costs of care, return to work, frequencies and risk factors for secondary medical complications, and psychosocial outcomes. Michael DeVivo

W.M. Keck Center for Collaborative Neuroscience

Rutgers the State University of New Jersey

Hosts the CareCure Community

<http://keck.rutgers.edu/center/center.html>

Medical University of South Carolina, Department of Rehabilitation Sciences,

77 President St., Charleston, SC 29425, USA.

Krause James - A 25-year longitudinal study of SCI

Kennedy Krieger Institute, USA

John McDonald

University of California – Los Angeles

Dobkin, Bruce. Neurologist, researcher, locomotor therapy, clinical trial completed and published. SCI and stroke.

bdobkin@ucla.edu

<http://neurorehab.neurology.ucla.edu/index.html>

Harkema_ Susan. Treadmill for both complete and incomplete SCI

<http://www.harkema.ucla.edu/index.html>

Edgerton, Reggie. Human and basic work. Treadmill. Whole body vibration

<http://www.physci.ucla.edu/index.php>

<http://www.physci.ucla.edu/physcifacultyindiv.php?FacultyKey=82>

Gomez-pinilla, Fernando Activity-based plasticity in SCI

<http://www.physci.ucla.edu/physcifacultyindiv.php?FacultyKey=886>

John McDonald, John. Neurologist & researcher. The Kennedy Krieger Institute.

<http://www.spinalcordrecovery.org/>

Rehabilitation Institute of Chicago

Robotic assistance for movement re-training in SCI. Walking (Lokomat, HAL), Upper arm (Armeo, T-WREX, ARM Guide Laboratory).

<http://www.rehabchicago.org/ztestz/arm/index.aspx>

Body Composition Unit, Columbia University-St. Luke's/Roosevelt Hospital Center, New York, New York

Wang Jack

College of Health and Human Sciences, Department of Exercise and Sport Science, Oregon

State University

Manns PJ, McCubbin JA,

Project Walk

<http://www.projectwalk.org/> Project Walk is a non-profit organization that aims to provide an improved quality of life for people with spinal cord injuries through intense exercise-based recovery programs, education, support and encouragement.. New research is posted under "Current Research Articles" and past articles are available in the Research Archives section. Originated near San Diego with a full cost recovery exercise facility using specially trained physiotherapists. Has begun a campaign of opening of centers nationwide eg see California, and more recently Texas (<http://www.projectwalk.org/texas/index.htm>), which is slated to open in the 4th Quarter of 2008 with a 10,000 sq ft center that will be the most advanced exercise-based spinal cord injury recovery center in the Southwest. It will facilitate all aspects necessary for recovery including gait training, assisted gait training, assisted treadmill training, FES, vibration training with the use of the Power Plate®, closed chain workout platforms, active nervous system recruitment, active muscle recruitment, The Dardzinski Method™ and the Five Phase of Recovery, acupuncture, and deep tissue muscle work. The Center will work closely with local hospitals and researchers to provide continued long term care after the client leaves the hospital. Project Walk's goal is to work together with the community to provide a life long exercise program equipping its clients with the best possible healthcare and recovery outcomes. The Center will be staffed with Certified Spinal Cord Injury Recovery Specialists.

8.2 CANADA

The Spinal Cord Injury Treatment Centre (Northern Alberta) Society (SCITCS)

A non-profit organization run by a volunteer board and sustained by a dedicated group of volunteers. It provides support to persons with a spinal cord injury through three main facilities:

- The SCITCS FES Exercise Clinic, in The Steadward Centre at the University of Alberta, Edmonton.
- The Neurological Unit at the Glenrose Provincial Rehabilitation Hospital Edmonton.
- The SCITCS FES Research Laboratory located in the Research Transition Facility 1098A University of Alberta

jursulak@interbaun.com info@scitcs.org pwresearchtraining@sbcglobal.net

Department of Kinesiology, Centre for Health Promotion and Rehabilitation, McMaster University, Hamilton, ON, Canada

Latimer A, Martin Ginis, Ditor

The Community University Research Alliance to Promote Physical Activity in People Living with SCI (CURA) - McMaster University

Researchers at McMaster University have been awarded \$1-million to investigate how best to increase physical activity among people with spinal cord injuries (SCI), so they can improve their physical and psychological well-being and, ultimately, their quality of life.

“We have two main goals for this project: to provide people with knowledge and skills to start a physical activity program and to find the most effective way to disseminate this information to the SCI community,”

The five-year project will marry the expertise of university researchers with the front-line experience of community workers, services groups, organizations and consumers.

The funding comes from the Social Sciences and Humanities Research Council (SSHRC). An additional \$1.3-million in supporting funds will come from partnering institutions, including McMaster University and community groups.

<http://www.mcmaster.ca/opr/html/opr/media/main/NewsReleases/2007/Spinalcordresearch.html>

McGill University

Montreal, Quebec, Canada H3G 1Y5

Hugues Barbeau

The Active Living Alliance for Canadians with a Disability (ALACD)

Promotes, supports and enables Canadians with disabilities to lead active, healthy lives. We provide nationally coordinated leadership, support, encouragement, promotion and information that facilitates healthy, active living opportunities for Canadians of all abilities across all settings and environments. Our network has grown to more than 500,000 contacts. Strong lobby group for government support for programs and research including SCI.

Professor Keith Hayes

Neuroscience Program, The University of Western Ontario, London, Ontario Canada

http://www.umass.edu/sphhs/kinesiology/news_events/Alumni_News.html

8.3 NEW ZEALAND

University of Otago Rehabilitation and Disability Research Theme

This Theme represents the collaboration of researchers from across the University of Otago. It includes a steering group of external advisors and Research Theme leaders with the goal of becoming the premier rehabilitation and disability research organisation in New Zealand. The Theme's objectives are to promote health and wellness for people with injury and disability; enhance the quality of rehabilitative care; and optimise quality of life for people with injury and disabilities, including those musculoskeletal, neurological, and chronic health conditions that may lead to impairment and/or disability.

<http://www.rehabotago.net/management-group.php>

School of Sociology, Social Policy and Social Work, Massey University,

A longitudinal study of the life histories of people with spinal cord injury. Sarah Derrett. \$900,000 (2007-2011): Sarah is a co-investigator on this HRC-funded study led by Dr Martin Sullivan from Massey University, and with other co-investigators: Professor Charlotte Paul (Department of Preventive and Social Medicine, University of Otago), Associate Professor Peter Herbison (Department of Preventive and Social Medicine, University of Otago), Mr Peina Tamou (Burwood Academy of Independent Living), Ms Maureen Crawford (School of Sociology, Social Policy and Social Work, Massey University) and Mr Paul Glover (Auckland Spinal Rehabilitation Unit).

Ph (06) 350 5799 ext 2833

Burwood Spinal Unit, Christchurch, New Zealand.

The Burwood Spinal Unit consists of a 26 bed ward, a hostel with space for four patients and four self care units. The Burwood Spinal Unit is a recognised tertiary service with a patient catchment area, which encompasses the entire South Island and the North Island from Tauranga down. There are formalised links with the Auckland Spinal Unit, which serves the remainder of the North Island. Dr Rick Acland.

The Burwood Academy of Independent Living

Is a dynamic organisation committed to improving the life experience of people recovering from serious injury and illness. Based onsite at Burwood Hospital in Christchurch, the Academy is dedicated to building a vibrant culture of research and learning. We are working to establish strong links to consumer organisations, universities and rehabilitation professionals. The Academy is coordinating the Western Pacific Region component of World Health Organisation International Classification of Functioning (ICF) Spinal Core Set Project to identify the health, functioning, environmental and social factors that are relevant for people living with a spinal cord impairment. To learn about the ICF Framework visit:

<http://www3.who.int/icf/icftemplate.cfm?myurl=introduction.html%20&mytitle=Introduction>

8.4 UNITED KINGDOM

Spinal Injuries Association

The Spinal Injuries Association is the UK's leading organisation dedicated to the well-being of spinally injured people. It can offer advice and assistance on a range of topics from exercise, medical aids, holidays, care facilities and other current issues on paralysis. www.spinal.co.uk

Spinal Research (UK)

A pioneering charity that aims to find ways to repair spinal cord injury and to reverse the paralysis that results from it. Recognised as a leader in its field it funds groundbreaking projects at scientific and medical institutions around the world. www.spinal-research.org
http://www.spinal-research.org/display_page.asp?section=database&id=212

Comprehensive evaluation of the physiological and functional adaptations induced by locomotor training in incomplete spinal cord injured subjects - Mr David B. Allan. Prof B Conway. Dr Malcolm H. Granat. Mr Jonathan Hassler. Dr Kenneth J Hunt. University of Strathclyde
Categories : Clinical initiative. Treadmill training. End Date: 2008

As one of the groups that are taking part in Stage 2 of the Clinical Initiative, a scientist, clinician, physiotherapist and engineer are fine-tuning tests to monitor all aspects of spinal cord function as patients receive physiotherapy that involves assisted walking on a treadmill. This type of rehabilitation therapy is known to significantly improve mobility in patients with incomplete injuries, so it is an ideal situation in which to evaluate the sensitivity and usefulness of tests to determine changes in spinal cord function. Accurate, reliable methods to assess small changes in spinal cord function are needed before we start to test any potential treatments in humans. In Stage 2 of the Clinical Initiative, researchers are refining a battery of tests that will be used to determine spinal cord function during clinical trials of potential therapies.

In this study, these tests will be assessed in patients with incomplete spinal cord injuries as they undergo a locomotor training program that involves repeated physiotherapy in which they are trained (with assistance) to walk on a treadmill. This type of rehabilitation therapy is known to significantly improve mobility in patients with incomplete injuries, so it is an ideal situation in which to evaluate the sensitivity and usefulness of tests to determine changes in spinal cord function.

Exercise at Physability

Rehabilitation & exercise therapy for spinal cord injury, head injury, stroke, multiple sclerosis and other paralysing conditions

<http://www.physability-uk.com/index.htm>

The Inclusive Fitness Initiative (IFI)

This is an excellent English model, which has been in operation since 2001, receiving in total £6m from the Sport England Lottery Fund (Inclusive Fitness Initiative 2006). The IFI operates around five key principles

- Accessible facilities
- Inclusive fitness equipment
- Staff with appropriate training and skills
- Appropriate, inclusive marketing strategies
- The development of alternative inclusive sporting opportunities

The combination of these elements ensures that the IFI creates not only accessible facilities, but inclusive environments. The IFI now boasts a network of over 180 inclusive facilities across England. Every IFI Site has undergone an access audit to ensure that their Accessible changing room facilities most effectively meet the needs of people with disabilities. These access audits focus specifically on the fitness related services including changing and catering services etc.

The IFI has been working in partnership with fitness equipment manufacturers for more than five years to ensure that the equipment available on the market is as inclusive as current technology and development will permit. It has worked alongside the industry to create a unique list of accredited fitness equipment. They suggest a minimum equipment set would include

- Treadmill
- Upright and/or recumbent cycle
- Upper body ergometer
- Leg curl
- Leg extension/leg press
- Upper body multi-station and/or a range of accredited upper body resistance equipment
- Package of small equipment

In addition to access and equipment, IFI has also developed 'Gym Buddies', whose role is to

- accompany and/or work out alongside disabled user(s) within the fitness suite and provide additional support e.g. adjusting weight stacks/ start positions and programming consoles etc;
- motivate, encourage, mentor and befriend a disabled person and support them in achieving their fitness goals;
- help break down barriers to participation for disabled people i.e. access, communication, social and psychological.

All Gym Buddies receive basic disability equality training and a gym induction, and are not expected to lift and carry or transfer disabled users onto any of the fitness equipment, provide transport or assist disabled user to change or personal care, prescribe exercise, or to assist with or administer medication.

<http://www.inclusivefitness.org/>

University of Dundee, Alliance for Self Care Research, School of Nursing & Midwifery

11 Airlie Place, Dundee DD1 4HJ

Dr Thilo Kroll

t.kroll@dundee.ac.uk

8.5 OTHER

The European Multicentre Study about Spinal Cord Injury

Initiated by Swiss NCCR which formed a group on Neural Plasticity and Repair

<http://www.emsci.org/>

Spinal Cord Injury Center, Balgrist University Hospital, Forchstrasse 340, CH-8008 Zurich, Switzerland.

Professor Volker Dietz, Harkema S. Anton Wernig Treadmill, locomotor training in incomplete and complete SCI. Physiology measurements.

http://www.balgrist.ch/index.cfm/s_page/58190

dietz@balgrist.unizh.ch

Department of Physiology, Radboud University Nijmegen Medical Centre, the Netherlands

Dr Maria Hopman, Dr Dick Thijssen — vascular studies and adaptation to skeletal muscle deconditioning in response to spinal cord injury.

Also Drs Hjeltnes, Ellenkamp, Berkelmans, Heesterbeek, deGroot, Wecht

Department of Rehabilitation Medicine, Erasmus MC, University Medical Center, Rotterdam

Haisma, van der Woude

Unité PPEH EA 3062, faculté de médecine Jacques-Lisfranc, université Jean-Monnet, service de médecine physique et de réadaptation, hôpital Bellevue CHU, 42055 Saint-Étienne cedex 2, France.

Devillard

Radboud University Nijmegen Medical Centre, Nedlerlands

Dr Maria Hopman, Dr Dick Thijssen. Vascular studies and adaptation to skeletal muscle deconditioning in response to spinal cord injury

9. RESOURCES

This section lists some Australian resources (equipment, training) as well as key international websites sites and products.

9.1 AUSTRALIAN

Creating a Universal Access Weights Room: Cindy Evans

This report/manual was produced for the Shires of Collie Bridgetown-Greenbushes, Capel, Dardanup, Donnybrook-Balingup, Harvey, Nannup and Manjimup as part of the 2007/2008 United Shires DAIP project funded by WALGA and the Disability Services Commission of WA.

Contents include:

Challenges to creating universal access weight training areas

The four key areas of inclusive fitness – accessible facilities, inclusive fitness equipment, staff with appropriate skills, inclusive marketing.

Creating an inclusive weight training room

Equipment - Placement of equipment, layout/placement, fitness areas, selecting equipment, stretching areas, cardiovascular equipment

Adaptation ideas

Examples of universal access equipment

Equipment contacts.

Useful links.

Centre for Cerebral Palsy WA (TCCP)

TCCP has developed workshop material covering aspects of physical disability for the various areas of a recreation centre. Includes hand book material, presenter notes, Powerpoints and templates for:

- Orientation to disability , definition list and inclusion in recreation programs Approximately 2 hour module
- Swimming lessons, further info definition list and client and carers checklist template Approximately 2 hour module
- Sports skills groups, further info definition list and client and carers checklist template Approximately 1hour module
- Gym room and further information template, definition list Approximately 1 hour module
- Crèche Approximately 1/2 hour module
- Reception staff Approximately 12 hour module

The next phase of the project is to run trial workshops to refine the material and make recommendations re future development/training of the material

Voluntary exercise equipment

- University of New South Wales. Glen Davis Has a range of exercise equipment- mainly arm ergometers
- The Fitability Gym (Sydney) has an uppertone (UK) machine that can be used from a wheelchair. See http://209.85.175.104/search?q=cache:Q_itWAVSQn0J:www.paraquad.org.au/content/documents/paraquad_news/PQ%2520NEWS%2520MAY%252006.pdf+fitability+gym&hl=en&ct=clnk&cd=1&gl=au&client=firefox-a re fitability and world champs
- Burn Rubber Burn (Sydney) have some excellent recent equipment that can be used from the wheelchair

- Che Fornusek has new FES system. They have 2 ERGYSII trainers but rarely used now because for stationary training they now use custom design stimulators with the Reck Motomed (German) cycle ergometers. For FES recreational (and stationary) cycling they are intending to buy some Berkelbikes.

Walking

Locomat robotic walking machines (very expensive), Litegait (mobile frame with walking harness), Spacetrainer (they have one at Moorong and POW spinal units in Sydney). These don't have FES, but the PARASTEP walking system does.

FES equipment

No application of routine FES as part of either acute or chronic rehabilitation in Australia. Several groups have plans for using FES rehabilitation in chronic SCI:

- Spinal Cord Injuries Australia has Project Walk (from California) and it appears that some of the US branches have begun implementing FES exercise – it is likely that SCIA will also do so.
- Burn Rubber Burn in Sydney has plans to include FES cycling into its circuit based upper body exercise program for those with chronic injury.

FES cycling is probably the most widespread and commercially developed. The companies that sell FES cycles are:

Therapeutic Alliance Inc (USA) sell the ERGYSII. TAI has the longest history (20 years), but does not use a motorized cycle ergometer so this limits some of the applications.

WalkOnWheels (AUS) sells HASOMED (German) FES cycling systems.

BerkelBike (Holland) allows recreational and stationary FES training

K&T (Germany)

RTI (USA).

Database of 211 physiotherapy exercises.

See <http://www.physiotherapyexercises.com/>

Lisa Harvey, Joanne Glinsky, Adrian Byak, Julia Batty, Lyndall Katte and Jillian Eyles. Details the development of a database of 211 physiotherapy exercises appropriate for people with spinal cord injuries. The software created enables physiotherapists to write personalised exercise booklets for their clients with spinal cord injury.

Fitness Industry Training Package: Australia

<http://www.ntis.gov.au/Default.aspx?/trainingpackage/SRF04/unit/SRFFSP010A>

SRF04: Fitness Industry Training Package – from Service Industries Skills Council

Fitness Industry Training Package includes Generic Units and the following Fitness Specific Units:

- Allied health networks (2 units)
- Children and young adolescents (1 units)
- Circuit training class (1 units)
- Community fitness program (1 units)
- Endurance training program (1 units)
- Fitness (1 units)
- Fitness (16 units)
- Fitness Specialist (10 units)
- Group fitness activities (2 units)
- Individual fitness instruction (2 units)
- Older adults (1 units)
- Personal training (1 units)
- Specific populations (1 units)

Tai Chi (3 units)
Water based fitness activities (1 units)
Water based fitness activities (1 units)

Unit SRFSP002A: Develop and apply an awareness of specific populations to exercise delivery. This unit covers the skills and knowledge to provide appropriate advice to specific population clients on participation in fitness appraisals and fitness activities. It covers the pathology of the more common disease states and conditions encountered within the fitness industry and the limiting effects of the condition on exercise performance and functional capacity. Includes SCI.

Unit SRFSP010A: Plan and deliver exercise for low to moderate risk clients with neurological impairment

Description: This unit has been developed for the Fitness Industry Training Package and provides the fitness specialist with skills, knowledge and competencies required to plan and deliver exercise programs to clients with neurological impairments who present with no more than moderate risk of untoward event or exacerbation of impairment during exercise. Clients likely to be encountered in the exercise setting might include those with cerebral palsy (CP), stroke or other form of acquired brain injury (ABI), multiple sclerosis (MS), muscular dystrophy (MD), Parkinson's Disease (PD) and spinal cord injury (SCI). This unit deals with exercise instruction and delivery only for clients who are deemed low to moderate risk and have been cleared to exercise by their medical practitioners.

9.2 INTERNATIONAL

Clinical SCI trials

Includes exercise-based trials

<http://clinicaltrials.gov/search/term=Spinal+Cord+Injury>

The Spinal Cord Injury Resource Center

<http://www.spinalinjury.net/index.html>

http://www.spinalinjury.net/html/_finding_a_rehab.html

The National Database of Educational Resources on Spinal Cord Injury

Contains information about materials such as videotapes, audiotapes, and written materials on SCI topics such as employment, exercise, nutrition, rehabilitation and many others.

<http://www.msdisseminationcenter.org/>

This will soon be available through the Texas Model Spinal Cord Injury System website in Houston, Texas at www.texasmsdis.org.

National Centre on Physical Activity and Disability (NCPAD)

Funded by the US Centers for Disease Control and Prevention this website is hosted at University of Illinois, Chicago. It is an information service dedicated to promoting physical activity for people with a disability. It is funded by Centres for Disease Control and Prevention (CDC) and hosted by the Department of Disability and Human Development at the University of Illinois at Chicago.

A vast array of resources and information is listed.

<http://www.ncpad.org/index.php>

Examples include:

NCPAD: Focus on Secondary Condition Prevention:

www.ncpad.org/yourwrites/fact_sheet.php?sheet=604&PHPSESSID=80e0c6508660f271e9befab9eb965f3a - 14k - Cached - Similar pages

NCPAD: Special Considerations in Respect to Exercise and SCI

www.ncpad.org/exercise/fact_sheet.php?sheet=274&view=all&print=yes - 21k - Cached - Similar pages

NCPAD:Videos: Exercise Program for Individuals with Spinal Cord ...

SCI Exercise Video ... developed in conjunction with the Rehabilitation Institute of Chicago and the National Center on Physical Activity and Disability. ...

www.ncpad.org/videos/fact_sheet.php?sheet=271 - 13k - Cached - Similar pages

NCPAD: Best Exercises for Persons with SCI. Aerobic exercise to maintain cardiovascular

www.ncpad.org/disability/fact_sheet.php?sheet=62&view=all - 20k - Cached - Similar pages

NCPAD:Videos: Exercise Program for Individuals with Spinal Cord ...

SCI Exercise Video. Main Menu. Aerobics. Strength Training. Flexibility ... second exercise video produced by the National Center on Physical Activity and ...

www.ncpad.org/videos/fact_sheet.php?sheet=421 - 14k - Cached - Similar pages

NCPAD:Research: The Combined Effects of Controlled Breathing ...

The exercise program was designed for individuals with SCI and required the participants to train 60 minutes a day, three times per week, for 6 weeks. ...

www.ncpad.org/research/fact_sheet.php?sheet=441 - 14k - Cached - Similar pages

Spinal Cord Injury Information Network – University of Alabama at Birmingham.

Information on SCI topics such as Medical, Psychosocial, Equipment, Accessibility, Publications, Disability Organisation, Education & Training www.spinalcord.uab.edu

CareCure Community

An extremely popular and busy online discussion forum on spinal cord injury run by leading scientist and researcher Wise Young. The forums cover topics such as community and personal issues, research, health, family, life, politics and care giving. The site also has specific forums on Multiple Sclerosis, Transverse Myelitis, brain injury and stroke. <http://sci.rutgers.edu/>

RECTEC (USA)

This company's recent technological advances in 'exercise and SCI' include:

- a database of products for fitness, recreation, and sports
- Developing a Web application illustrating key elements of an accessible fitness centre, park, and pool by illustrating typical problems and how they can be solved.
- Exploring the development of autoconfiguration devices ie that adjust themselves to the requirements of the user
- Adapting technology to improve adherence by making exercise more engaging – eg VR technology to add variety or motivational support; exercise equipment that can be interfaced to control popular game platforms – GameCycle, EyeToy. Can allow those with SCI to participate in activities that may be difficult or impossible in the real world.
- Teleexercise program that includes monitoring (physiological), feedback and education eg Health Buddy home exercise system

For more detail see Rimmer J Schiller J Future directions in exercise and recreation technology for people with spinal cord injury and other disabilities: Perspectives from the Rehabilitation Engineering research Centre on Recreational Technologies and Exercise Physiology for People with Disabilities. Top Spinal Cord Inj Rehab 2006; 11 (4) 82-93

Spinal Core training

<http://spinalcoretraining.com/fitness.html>

A good site for fitness professionals to visit. A private company whose mission is: to diminish the gap that separates the SCI population from participating in an appropriately designed and

supervised exercise regimen with the hope that both quality of life and life expectancy can be increased. Spinalcoretraining.com is owned and operated by Andrew Milano, PA-S. Andrew is currently attending Drexel University's (Philadelphia) Hahnemann Physician Assistant Program and created this organization as a requirement for the completion of his Master of Health Sciences degree.

10. LIST OF APPENDICES

APPENDIX I	General questions used to elicit information
APPENDIX II	Information form: MAP investigators and associates
APPENDIX III	Stakeholders contacted by the consultants

APPENDIX I

General questions used to elicit information

Used in interviews and discussions.

1. Who is 'doing or researching' 'SCI and exercise' (in WA? Australia? International?) (key person, contact details)
2. Where? Rehab, government, NGO, community (address, contact details)
3. What are they doing?
4. Who is participating – para, quad, age etc
5. What equipment is in use?
6. What programs are they running?
7. Any evidence of benefit of exercise?
8. What are their future intentions, plans etc?
9. Who do they collaborate with? Interested in MAP collaboration?
10. What documentation do have about their activity eg reports, websites?

etc

APPENDIX II

Information form: For MAP investigators and associates

Move Again Project

Please email, fax or post your reply to Richard and Anne Lockwood, Research Officers, MAP by Wednesday 2nd May, 2008

- To complete this document please firstly ensure that it has been **SAVED TO YOUR 'DESKTOP' or to an appropriate folder**. Do not fill out the document directly from within your e-mail program eg. Outlook, as you may end up not being able to easily save the information you enter.
- Using Microsoft Word, the table areas will automatically expand as you type your responses.
- When completed, please **SAVE, then ATTACH and SEND** to lockwood@swiftdsl.com.au.
- Alternatively, you can **PRINT AND FAX** it to 9336-3277, or post it to:
R&A Lockwood Consultants, 43A Daly St, SOUTH FREMANTLE 6162.

1) Your contact details	
Name	
E-mail	
Institution	
Department	
Phone	
Fax	

2) Your research or program involvement with the spinal cord injured community in relation to the topic <i>Exercise for people with SCI</i> . Please enter project title and/or topic of study.	
Existing Projects	
Past Projects	
Potential Projects	

3) Awareness of other research or programs relating to Exercise for people with SCI.

Please enter a brief title/description of each activity and/or name of researcher

In WA	
Nationally	
Internationally	

4) Awareness of community related activities relating to Exercise for people with SCI.

Please enter a brief title/description of activity and/or name of relevant personnel

In WA	
Nationally	
Internationally	

5) Awareness of documents relating to Exercise for people with SCI

Internal eg. student papers, department reports, audits,	
Student Dissertations or Theses	
Facility based reports, audits, programmes	
Other documents	

6) Suggestions for expanding the MAP contact database ie names and contact details of others who may be in some way involved with research or programs related to *Exercise for people with SCI*

Name and contact details	
Name and contact details	
Name and contact details	
Name and contact details	
Name and contact details	
Name and contact details	

7) Your expertise and interests relating to *Exercise for people with SCI*

Expertise Area	
Expertise Area	
Expertise Area	
Interest Area	
Interest Area	
Interest Area	

Do you have any other relevant information? or comments you wish to make?	
--	--

THANK YOU

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R&A Lockwood Consultants, 43A Daly St., SOUTH FREMANTLE 6162

APPENDIX III

Stakeholders contacted directly by the consultants*

Spinal Unit, Royal Perth Rehabilitation Hospital (SPC), Medical Director	Ker, John
Royal Perth Hospital, Superintendent Physiotherapist	Buchanan, John
Spinal Unit, Royal Perth Rehabilitation Hospital,	Weston, Renee
Paraplegic-Quadriplegic Association WA, Chief Executive Officer	Glass, Nigel
Paraplegic-Quadriplegic Association WA, Recreation Department	Wallace, Fran
Hollywood Hospital Rehabilitation Centre	Ackland, Tim
Hollywood Hospital Rehabilitation Centre	Gilbey, Helen
The WA Disabled Sports Association, Executive Director	Mahady, Dereck
The WA Disabled Sports Association, Manager Community Development	Draper, Brooke
WheelChair Sports Association Western Australia, General Manager	Gary Lees
WheelChair Sports Association Western Australia, Executive Officer	Waldrodt, Bruce
WheelChair Sports Association Western Australia, President	Bowen, Esme
The Centre for Cerebral Palsy	Spilby, Janine
Rocky Bay	Tate, Michael
Recreation and Sport Network	Morse, Aaron
Technology Assisting Disability WA (TADWA)	Otago, John
Australian Sports Commission (Disability Sports Unit)	McDonald, Hamish
WA Disability Services Commission	Hutson, Mark
WA Disability Services Commission	Marriott, Jeremy
WA Department of Sport and Recreation	Elwood, Kim
Department of Environment and Conservation, Deputy Director	Jim Sharpe
Notre Dame Australia	Hamer, Peter
The University of Western Australia	Smith, Kerry
Vario Institute, Joondalup Rehabilitation Clinic	Turner, Darryl
UWA Sports Centre, The University of Western Australia	Meakin, Bruce
ECU Sports Centre	Reader, Hayley
Curtin Fitness Centre	Turnor, Sue
Herb Graham Recreation Centre	Roberts, Karen
Arena Joondalup- Life Program	Hannent, Peter
Melville	Doyle, Mick
Leisure Park Balga	Ellis, Luke
Park Centre	Allen, Peter
Fuller Fitness	Kindal, Neal
TAFE	Bower, Carol
Trysport (Handcycling training)	Budge, Andrew
Aspire fitness	Manager
Exercise for Life	Harris, Matt
Consultant	Deschamp, Phil
Wheel Sport Science leisure and recreation options	Evans, Cindy
ECU student	Bulloch, Leah
MAIC Research Fellow - Physical Activity and Disability, School of Human Movement Studies University of Queensland	Tweedy, Sean
Rehabilitation Research Centre, The University of Sydney	Davis, Glen
Rehabilitation Research Centre, The University of Sydney	Fornusek, Che
The University of Western Ontario, Parkwood Hospital	Hayes, Keith
School of Physical Education, University of Otago	Miyahara, Motohide

* includes five people with spinal cord injury.