

AAHD

American Association on Health and Disability
110 N. Washington Street • Suite • 340-A Rockville, MD 20850

PUBLICATIONS, ORGANIZATIONS, AND PROGRAMS PERTAINING TO PEOPLE LIVING WITH PARALYSIS

EXERCISE

Title "Fitness Programs for Children with Cerebral Palsy", presented by Diane Damiano, Maria Fragala-Pinkham, Cindy Miles, Wayne Stuberger, and Deborah Thorpe, August, 2006

Source The Pediatrics Section of the American Physical Therapy Association (APTA), hosted by Munroe-Meyer Institute, University of Nebraska Medical Center

Format Course

Description This 2-day course was developed to disseminate information following the Research Summit on Fitness for Children with Cerebral Palsy (CP), sponsored by the APTA Section on Pediatrics in November 2004. The first day of this course focused on advancements by leading researchers in the area of fitness prescription for children with CP, and the second day was designed to present fitness programming options. Following completion of this workshop, it was the objective that participants would be able to discuss the need for programming to address fitness and secondary conditions in children with cerebral palsy; discuss current research related to the effects of aerobic exercise, flexibility interventions, strength training, and outcomes assessment in children with disabilities; integrate information from current research and model programs into the design and implementation of a fitness program for children with CP; and examine factors that act as facilitators or barriers to participation in fitness programs for children with disabilities, including accessibility and motivation.

Contact URL <http://www.pediatricapta.org/members/fitnesscourse.cfm>

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Title NextStepsNW

Source NextStepsNW

Format Non-profit organization

Description NextStepsNW is a specialized & intensive exercise recovery therapy and wellness center for people with paralysis from spinal cord injuries and neurological disorders such as multiple sclerosis and strokes. NextStepsNW strives to maximize health, wellness, and quality of life for individuals with paralysis through specialized exercise recovery therapy and wellness programs. The 3 major components in training are: 1) locomotor treadmill training-- through a weight supported treadmill, locomotor training is used to retrain the nervous system to walk, 2) electrical stimulation cycling-- with Electrical Stimulation bikes, surface electrodes deliver low-level electrical pulses to the muscles that stimulate leg movement which helps prevent atrophy in the legs and improves muscle strength and circulation, and 3) visualization of activation muscle training--the client works with the rehab therapist by visualizing each movement while the therapist presses trigger points for muscle activation during the exercise.

Contact URL <http://www.nextstepsnw.org/>

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Title Recovery Center

Source Brain & Spine Center of Brackenridge Hospital of the Seton Family of Hospitals

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Format Rehabilitation Center

Description In 2003, the Brain & Spine Center, working with the Lone Star Paralysis Foundation, started a research study to analyze the effects of sustained cardiovascular exercise for people with spinal cord injury (SCI). Findings helped launch the Brain & Spine Recovery Center, designed to help participants continue the cardiovascular exercise from the research studies and to add full capability for stretching, weight training, and cardiovascular exercise to all people with SCI. Staffed by physical and occupational therapists and certified trainers, the Center gives people with spinal cord injuries access to wellness and fitness equipment, and includes strength and weight training, cardiovascular workout and functional development programs. The fitness gym, open evenings and weekends, provides equipment specifically for people with SCI. The second phase of rehabilitation is an outpatient program offering experience in the following and more: uneven transfers, difficult terrain, floor to chair transfers, "wheelie" skills for stairs and curbs, assisted gait, standing readiness, and continuation of bowel and bladder retraining programs. The Advanced Recovery Program offers a very intense exercise and neuromuscular retraining program to increase function.

Contact URL

http://www.seton.net/about_seton/news/2006/09/13/people_with_spinal_cord_injuries_now_have_access_to_comprehensive_recovery_program

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MULTIPLE SCLEROSIS

Title "Healthy Living with MS"

Source National Multiple Sclerosis (MS) Society

Format On-line articles

Description According to the webpage of the National MS Society, "wellness is a dynamic state of physical, emotional, spiritual, and social well-being that can be achieved even in the presence of a chronic illness or disability." For people with MS,

wellness involves not only treatment of the disease, but also health promotion and prevention strategies. This webpage provides links to on-line articles on MS and exercise, food and diet, preventive care, alternative medicine, and specific health issues for men and women.

Contact URL

http://www.nationalmssociety.org/site/PageServer?pagename=HOM_LI
[VE healthy living with ms](#)

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Title The Multiple Sclerosis Association of America (MSAA)

Source The Multiple Sclerosis Association of America (MSAA)

Format Organization

Description MSAA is a national nonprofit organization dedicated to enriching the lives of people affected by multiple sclerosis by providing ongoing support and direct services to individuals with MS and the people close to them. MSAA also serves to promote greater understanding of the needs and challenges of people who face physical obstacles. In addition to its programs and services, such as consultations, support groups, equipment distribution, home modifications, MRI diagnostic funding, and public awareness campaigns, MSAA also provides information through its quarterly magazine and other literature.

Contact URL <http://www.msaa.com/programs/programs.html>

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Cherry Hill, NJ 08002

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Title Patient Services Directory

Source The Multiple Sclerosis Foundation (MSF)

Format On-line directory

Description The MSF provides these services concerning the physical, emotional, and social impact on people diagnosed with multiple sclerosis (MS): 1) National Toll-Free Helpline--free of charge, caseworkers and peer counselors provide unique information, referrals, and assistance in accessing services, 2) Internet Helpline--provides live interactive chat one-on-one with a caseworker or peer counselor, 3) Internet Forums--provide an opportunity to have questions answered by qualified healthcare professionals or by people facing the same challenges as the requester, 4) Homecare Assistance Grant Program--provides support for in-home services including personal care, homemaker companion services, physical, occupational, and speech therapy, transportation services and caregiver respite, 5) Assistive Technology/Equipment--provides support for services and devices that increase, maintain, or improve capabilities of individuals with disabilities, 6) Complementary & Alternative Medicine (CAM)--provides information and education about CAM, which is commonly used as an adjunct therapy for symptom management, pain relief, and improved well-being, 7) Cooling program--offers the cooling vest, along with brim hats, work collars, skull-pads, wristbands, cooling pillows, and neckties, 8) Support Groups--networks with a variety of independent support groups throughout the U.S., and 9) Lending Library--provides books, videos, and audiocassettes for loan, by mail across the United States.

Contact URL http://www.msfacts.org/programs_services.php

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(954)938-8708 (fax)
E-mail: admin@msfocus.org

Program Services Assistance, MS Helpline

Call toll-free (within USA): 888-MSFOCUS
or Fort Lauderdale area (954) 776-6805
(954) 351-0630
E-mail: support@msfocus.org

OBESITY

Title "Obesity growing as health concern for people with spinal cord injury",
December 23, 2004

Source University of Michigan

Format On-line Article

Description University of Michigan Health System (UMHS) researchers investigated how people with spinal cord injury (SCI) burn calories and how muscle mass and body weight affects this, to make better recommendations to people with SCI. People living with SCI tend to burn calories at a reduced rate; combined with limitations on physical activity, this contributes to obesity, as well as to associated health problems such as high cholesterol and coronary artery disease. Dr. David Gater, director of Spinal Cord Injury Medicine at UMHS and director of the Spinal Cord Injury Research Center at the VA in Ann Arbor headed a research team that looked at glucose tolerance, body composition and cardiovascular risk factors in people with spinal cord injury and tried to determine how this group burns calories during different types of activities, including rolling their wheelchairs and playing basketball. This information could be used to develop a table so people with SCI can determine how many calories they're going to burn doing each activity for a certain period of time.

Contact URL <http://www.med.umich.edu/opm/newspage/2004/hmsci.htm>

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Ann Arbor, MI 48109

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PUBLIC HEALTH PLAN

Title "A Public Health Action Plan For Paralysis And Similar Mobility Impairments, October 2005" by Jeanne Alongi, Public Health Consultant

Source Paralysis Task Force convened by the Christopher Reeve Paralysis Foundation and funded by the Centers for Disease Control and Prevention (CDC)

Format Public Health Action Plan

Description In 2004, the Paralysis Task Force met to develop a Public Health Action Plan for Paralysis, a draft of which was released for review by Task Force members. Some recommendations this Action Plan calls for include: the development of a national coalition and new resources committed to improving the quality of life for people living with paralysis; the development of universally accessible elements that enable those with paralysis to participate fully in activities of daily living and that facilitate health promotion such as physical activity and clinical preventive services; the development and distribution of culturally sensitive education information for individuals with paralysis and their caregivers, healthcare providers, and the general public; a review of research on health promotion for those living with paralysis and similar mobility impairments; an assessment of the public health needs of this population; the development of a prevention research agenda and a national surveillance plan that identifies key data elements including prevalence, morbidity and quality of life outcomes, and risk and protective factors; a regular schedule for collection, analysis, and interpretation of these data; and national coordination and information sharing of efforts affecting the quality of life of people living with paralysis.

Contact URL <http://www.spinalcord.org/news.php?dep=1&page=0&list=645>

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SECONDARY CONDITIONS

Title Secondary Conditions webpage of The University of Alabama at Birmingham Model SCI Care System

Source Funded by a grant from the National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education

Format Webpage

Description This webpage provides information on and links to the Secondary Conditions of Spinal Cord Injury Health Education Video Series, an 11-part video series intended to be useful for people with spinal cord injuries, as well as by health and rehabilitation centers for education and training activities. The videos include: Understanding Spinal Cord Impairments and Functional Goals, Life with SCI: A Group Discussion, Sexuality & Sexual Function, Bowel Management, Bladder Management, Pressure Sores: Skin Care Prevention and Treatment, Pain Management, Spastic Hypertonia, Respiratory Management, Cardiovascular Health, and Bone Health.

Contact URL <http://www.spinalcord.uab.edu/show.asp?durki=97417>

Contact Name
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SPINA BIFIDA

Title The Spina Bifida Association (SBA)

Source The Spina Bifida Association (SBA)

Format Association

Description SBA is a national voluntary health agency serving adults and children living with spina bifida through education, advocacy, research, and service. SBA has a

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nationwide presence through its network of chapters, defined a research agenda at a conference entitled "Evidence-Based Practice in Spina Bifida", encourages students with spina bifida through a series of scholarship programs, and provides people with information from resources and publications through its National Resource Center on Spina Bifida. Information is also provided by SBA's fact sheets on various topics including "Depression and Anxiety in Individuals with Spina Bifida," "Medical Considerations for Therapeutic Riding with Spina Bifida," "Obesity," and "Urologic Care and Management."

Contact URL

http://www.sbaa.org/site/c.liKWL7PLLrF/b.2642991/k.DE3F/About_SBA.htm

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SPINAL CORD INJURY

Title The Christopher and Dana Reeve Foundation

Source The Christopher and Dana Reeve Foundation

Format Foundation

Description The Christopher and Dana Reeve Foundation is dedicated to curing spinal cord injury by funding research and improving the quality of life for people living with paralysis through grants, information and advocacy. In 1982, the American Paralysis Association was formed by a group of people that refused to accept the existing idea that once the spinal cord was injured, it could not be repaired; they believed that scientists and researchers would discover a way to connect and regenerate the damaged nerves and cells resulting from paralysis. Christopher Reeve shared the Association's belief in a cure, and the organization became known as the Christopher and Dana Reeve Foundation.

Contact URL

[http://www.christopherreeve.org/site/c.geIMLPOpGjF/b.1029229/k.C912/
About Us.htm](http://www.christopherreeve.org/site/c.geIMLPOpGjF/b.1029229/k.C912/About%20Us.htm)

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SPORTS AND RECREATION

Title BlazeSports America

Source BlazeSports America

Format National organization

Description BlazeSports America provides sports training, competitions, summer camps and other sports and recreational opportunities for youth and adults who use wheelchairs, have a visual impairment, have an amputation, or who have a neurological disability such as cerebral palsy or spina bifida. Participant ages range, depending on the program, from 6 years through adulthood. As of January 2006, BlazeSports America operates in 50 communities and 25 states and the District of Columbia. The national program is funded through corporate sponsorships, grants and individual donations.

Contact URL www.blazesports.com

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Title National Disability Sports Alliance (NDSA)

Source National Disability Sports Alliance (NDSA)

Format National Coordinating Body

Description NDSA is the National Coordinating Body for competitive sports for individuals with cerebral palsy, traumatic brain injuries and survivors of stroke and also provides programming for other physically disabling conditions such as muscular dystrophy and multiple sclerosis. NDSA is responsible for administering and conducting national championships in ten approved sports in the United States, disseminating safety and sports medicine information, and selecting athletes to represent the United States in international competition. NDSA provides a variety of services and programs for its membership, including publications, educational programs, fund-raising activities, sports medicine programs, video resources and general information about sports related activities.

Contact URL <http://www.ndsaonline.org/purpose.htm>

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Title Sports & Recreation Program of the Paralyzed Veterans Association (PVA)

Source Paralyzed Veterans Association (PVA)

Format Program

Description The goal of the Sports & Recreation Program of the PVA is to improve the quality of life of paralyzed veterans and other people with disabilities by expanding opportunities in sports and recreation, especially activities which enhance health and fitness for a lifetime. Some of the activities the PVA promotes includes the National Veterans Wheelchair Games (NWPA), the PVA Bass Tour, the PVA National Trapshoot Circuit, the PVA/NWPA National Wheelchair Billiards Tournament Series,

and the PVA/AWBA Bowling Tournament Series. PVA supports the national governing bodies of many other disabled sports organizations, including: National Wheelchair Basketball Association, United States Quad Rugby Association, American Wheelchair Bowling Association, National Wheelchair Softball Association, and National Wheelchair Pool Players Association. The live PVA Sports Message Board is available for use on the PVA website and provides a forum for members to stay informed and connected, discuss upcoming events, and discuss any matters related to the Sports and Recreation Program.

Contact URL <http://www.pva.org/site/PageServer?pagename=homepage>

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STATISTICS

Title "Executive Summary: Developing an Action Plan to Improve the Quality and the Quantity of Data about Paralysis", September 2005

Source by Michael H. Fox, ScD, principal investigator; Jennifer L. Rowland, PhD, project director; Dee Vernberg, PhD, Katherine Grobe, PhD, Glen W. White, PhD, and Andrew Rosdahl, Department of Health Policy & Management, University of Kansas Medical Center & Research and Training Center on Independent Living, University of Kansas--Funding for this project has been provided by a grant from the Christopher Reeve Paralysis Foundation (CRPF) to the University of Kansas Medical Center

Format Report

Description In October, 2004, researchers from the University of Kansas started a one-year project to: 1) investigate how paralysis is being measured in this country, 2) examine the validity of prevalence and incidence estimates based on these approaches, and 3) identify successful measurement reporting systems. Because data specific to paralysis are not available through existing surveillance, recommendations include: 1) develop a uniform definition of paralysis that includes the many possible ways that paralysis can manifest itself, 2) develop paralysis survey questions on how people with paralysis are limited functionally, 3) provide incentives to encourage organizations representing people with conditions where paralysis exists to add items to an ongoing data collection system to collect more detailed information on the severity or nature of the condition, 4) improve future data collection by working more closely with states with data-driven public policy capacity, 5) further involve consumers in data use to turn improved surveillance information into practice. A national advisory group comprised mostly of people with paralysis should be convened to help interpret improved surveillance information to ensure that these data are used to benefit people diagnosed with conditions associated with paralysis.

Contact URL

<http://72.14.253.104/search?q=cache:9qlfJrGlpGAJ:www.rtcil.org/products/RTCIL%2520publications/Health%2520Issues/Executive%2520Summary%2520Developing%2520an%2520Action%2520Plan%2520to%2520Improve%2520the%2520Quality%2520and%2520Quantity%2520of%2520Data%2520About%2520Paralysis.pdf+%22health+promotion+programs%22+%22people+with+paralysis%22&hl=en&ct=clnk&cd=3&q=us>

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VETERANS

Title Paralyzed Veterans of America (PVA)

Source Paralyzed Veterans of America (PVA)

Format Service Organization

Description PVA, a congressionally chartered veterans service organization, works to maximize the quality of life for its members and all people with Spinal Cord Injury/Spinal Cord Diseases (SCI/D) as a leading advocate for health care, SCI/D research and education, veterans' benefits and rights, accessibility and the removal of architectural barriers, sports programs, and disability rights. PVA is a leading advocate for: quality health care for its members, research and education addressing spinal cord injury and dysfunction, benefits available as a result of its members' military service, and civil rights and opportunities which maximize the independence of its members.

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WOMEN

Title Wellness for Women With Polio

Source Department of Physical Medicine and Rehabilitation Medicine, University of Michigan

Format Curriculum

Description This health promotion curriculum established for women with polio consisted of four, three-hour classes on physical activity, stress management, and

nutrition, all of which were related to the late effects of polio. During the health education module, participants received individualized feedback in a session with class facilitators, during which wellness goals and issues geared toward each individual participant with polio were discussed. The health education component was conducted by an individual with polio. Educational materials were compiled into an extensive manual that was distributed to each participant. The exercise module consisted of topics on managing pain and fatigue in the affected muscle groups, appropriate rest intervals during exercise, and avoiding overuse injury. Home exercises were provided to each participant. The nutrition module consisted of topics related to good nutrition and weight management, and the stress management module showed techniques to control stress related to the participants' condition.

Contact URL

http://www.ncpad.org/wellness/fact_sheet.php?sheet=182§ion=1350&PHPSESSID=be6e1ae9d8880ff9595432df98ede06e

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