



CONNECTIONS 2009

A conference for Albertans
affected by **Multiple Sclerosis**

October 23 & 24th 2009
Century Casino & Hotel
Edmonton, Alberta





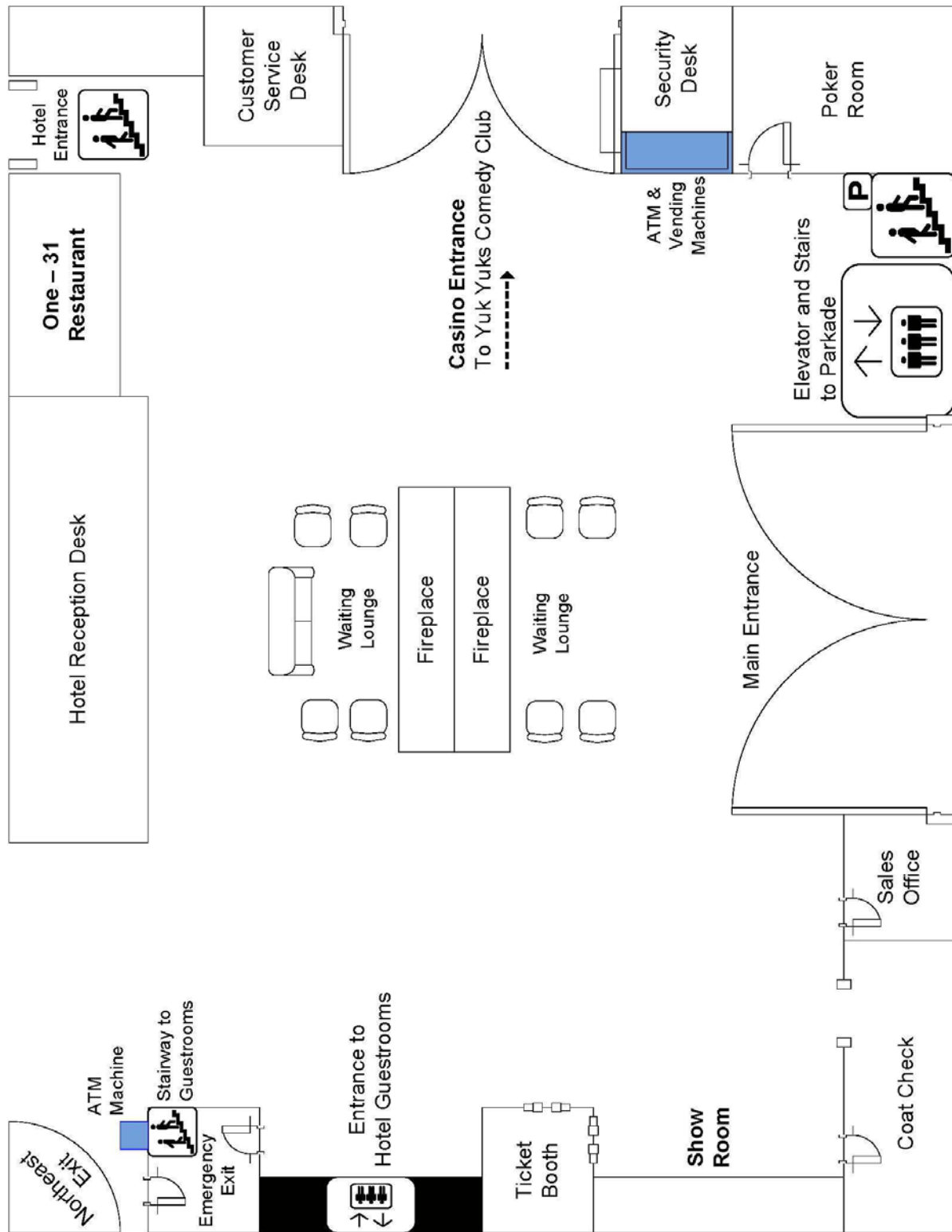
OUR MISSION:

To be a leader in finding a cure for multiple sclerosis
and enabling people affected by MS to enhance
their quality of life.

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MAP OF CENTURY CASINO & HOTEL



WELCOME FROM HONORARY CHAIRPERSONS



Robert Macklon

Welcome to Connections 2009 your opportunity to stay abreast of the latest in Multiple Sclerosis research and therapies. As someone with Multiple Sclerosis it is important to me to understand my disease and how best to cope with its challenges. Connections 2009 gives me the opportunity to get answers to my questions from people knowledgeable in the field, to discover new strategies for living with MS and to network with others involved in living with, treating and finding a cure for Multiple Sclerosis.

Joyce Kropiniski

I am very pleased to be one of the co-chairs for the Connections 2009 Conference, and as such, would like to encourage anyone and everyone that is affected by MS to attend this conference. I am a firm believer in the adage that “knowledge is power” and this conference provides a wonderful opportunity to gain knowledge in a variety of areas. It is not often that we are fortunate enough to have an event like this, with such a superior line-up of speakers and topics. Personally, I found it difficult to select the sessions I would attend – I wanted to attend all of them!



Dr. Mary-Lou Myles

Welcome to Connections 2009 – An MS Conference for persons affected by MS, caregivers, community service providers, students and health professionals. Our theme this year is “Connections 2009.” The concept of *connection* has numerous meanings within the context of this event. First it speaks to the importance of the health care community and community based resources and organizations such as the MS Society, working together to bring the very latest in research and education to persons affected by Multiple Sclerosis. It also speaks to the role of community in self advocacy and to people affected by MS connecting, coming together and working together to solve problems and get community needs met. We are extremely grateful to the wonderful line up of speakers who have agreed to spend time with us over these two days. We certainly hope that you enjoy this two day event and trust that you will take away new ideas and information that will make a meaningful difference.

WELCOME FROM MS SOCIETY PRESIDENT & VICE PRESIDENT

Neil Pierce,
President, Alberta
Division



Welcome to Connections 2009: a conference to connect Albertans affected by MS. I'm delighted that so many people from all over the province are able to attend this important event. Connecting Albertans affected by MS is an important part of the MS Society's strategic plan, and this conference brings us together to make connections with members of the health profession, researchers, community advocates, and each other. Stakeholders working together to advance care, supports and services for MS is a key element in enhancing the quality of life of Albertans affected by MS. I encourage you to meet other delegates and share your stories of hope and inspiration so that we can all build on the strength of making genuine connections with members of our communities.

I'd like to thank the organizing committee and all the volunteers for their hard work in making the conference possible. We have an excellent agenda with world-class speakers. There is indeed something here for everyone. I hope you will be able to take away from the conference your own connections that will enable you to enrich your quality of life in the days and months to come.

Sincerely,

A handwritten signature in black ink that reads "Neil Pierce".



Garry Wheeler,
Vice President,
Edmonton
Chapter

Tabled as an idea in an Edmonton Chapter staff meeting in summer 2008, "Connections 2009" becomes a reality today. I invite you to spend the next two days with the Edmonton Chapter staff team, members of Alberta Division staff, our wonderful volunteers and our line up of speakers in what will be an exciting and informative event.

This conference marks the beginning of an exciting period for the Edmonton Chapter of the MS Society; the beginning of a new year in which we will be focusing on providing an increased level of service to more persons affected by MS in the Capital region. As Edmonton Chapter boundary expands, we will be reaching out to more people with MS with innovative and valuable services and I invite you to speak to the Edmonton Chapter team staff and visit the information booth to find out more about what we do and how we can help. As well, I encourage you to take the time to meet with other delegates and the speakers as the conference unfolds.

My sincere thanks to all the speakers for agreeing to present. Thank you to our external program advisors in securing our speakers; to all the staff who have worked so hard to put this event together, and to our sponsors for making "Connections 2009" possible.

Have a great conference!

A handwritten signature in black ink that reads "Garry Wheeler".

SCHEDULE OF EVENTS

Friday, October 23rd, 2009

<u>Time</u>	<u>Session</u>	<u>Location</u>
6:00-7:30pm	Registration	
7:00-7:15pm	Welcome and Introductions	Showroom
7:15-9:00pm	Keynote Presentation 1: Dr. Rudy Dressendorfer Exercise Therapy and Multiple Sclerosis: State of the Art and Future Considerations & MS ActiveNOW Launch	Showroom

Saturday, October 24th, 2009

<u>Time</u>	<u>Session</u>	<u>Location</u>
8:00-9:00am	Registration	
8:30-9:30am	Keynote Presentation 2: Dr. Michael Yeung The Future of MS Therapeutics	Showroom
9:30-9:45am	Transition Break	
9:45-10:30am	Session A: Dr. Fabrizio Giuliani Neuroprotection and Neuroregeneration in Multiple Sclerosis	Showroom
	Session B: Dr. Rudy Dressendorfer & Jennifer Fuller Postural Alignment Therapy in Multiple Sclerosis	Yuk Yuks
	Session C: Shanna Orvis, Shannon Currie, and Jennifer A. Clarke Navigating Income Support Programs: CPP-D	One 31

<u>Time</u>	<u>Session</u>	<u>Location</u>
10:30-11:00am	Nutrition Break	Showroom
11:00-11:45am	Session D: Dr. Mary-Lou Myles Shining a Light on Vitamin D and MS	Showroom
	Session E: Dr. Rudy Dressendorfer & Jennifer Fuller Postural Alignment Therapy in Multiple Sclerosis (cont...)	Yuk Yuks
	Session F: Colette Grootkarzyn, Alberta Human Rights Commission How to Manage Employment Concerns - Human Rights in the Workplace	One 31
11:45am-12:30pm	Lunch Break	Showroom
12:30-1:45pm	Keynote Presentation 3: Dr. Al Condeluci Pathways to Community	Showroom
1:45-2:00pm	Transition Break	
2:00-2:45pm	Session G: Laurel Morrison Bladder and Bowel Dysfunction in Multiple Sclerosis	Showroom
	Session H: Aprile Royal Red Flags and Green Lights: Navigating the Early Days	Yuk Yuks
	Session I: John Soars Developing the MS Community	One 31
2:45-3:15pm	Nutrition Break	Showroom

<u>Time</u>	<u>Session</u>	<u>Location</u>
3:15-4:00pm	Session J: Dr. Penny Smyth Pregnancy, Menopause and Multiple Sclerosis	Yuk Yuks
	Session K: Dr. Jackie Bakker Battling Fatigue in MS	Showroom
	Session L: Jennifer Mah Navigating the Medical System: The Role of the MS Nurse	One 31
4:00-4:15pm	Transition Break	
4:15-5:00pm	Session M Dr. Shaniff Esmail The Impact of MS on Sexual Functioning and Relationships	Yuk Yuks
	Session N: Dr. Jennifer Rodgers Coping with the Cognitive Aspects of MS	Showroom
	Session O: Dr. Garry Wheeler MS Community Advisory Council: Advocating for Change and a Greater Role for Non-Profits	One 31

MS Fact:

Most people (about 80-85%) are diagnosed with the relapsing-remitting form of MS.

KEYNOTE ABSTRACTS AND SPEAKER INFORMATION

Al Condeluci, PhD



Title: Pathways to Community

Saturday, October 24th, 12:30-1:45pm

Location of Presentation: Showroom

Abstract: All of us are interested in a better community where all people have an opportunity for accessible and affordable homes, jobs or meaningful daytime opportunities and lifestyles of their choice. Yet, many of the vulnerable people we serve were (and most still are) in isolated situations with limited options for friendships and important social relationships. This presentation takes a close look at the reasons why these struggles have existed and offers a community building perspective designed to shift the culture to be more inclusive and supportive to all people.

Learning Objectives:

1. Participants will understand the historical development related to difference, disability, aging and other devaluing aspects.
2. Participants will be introduced to the Interdependent paradigm

3. Major aspects of culture and community will be overviewed
4. The importance of Social Capital will be explored

Biography: Al Condeluci has been an advocate and catalyst for building community capacities and understanding culture since 1970. Born and raised in the steel town of Pittsburgh, PA, still making his home there, Al received his Bachelors Degree in Psychology from Youngstown State University, his Masters in Social Work and Ph.D. in Education from the University of Pittsburgh. Since 1973, he has worked as an attendant, caseworker, advocate, planner, program director and now, CEO of his organization, UCP/CLASS of Pittsburgh. UCP/CLASS has created a family of corporations and is dedicated to its mission - "working towards a community where each belongs." UCP/CLASS, under Al's leadership, has grown to become the 3rd largest disability specific agency in Southwestern PA with a budget of \$28 million and a staff and payroll complement of 675. UCP/CLASS was listed in the 50 "Best Places to Work" in Allegheny County, PA in 2007.

Along with his work at UCP/CLASS, Al is associated with the University of Pittsburgh's School of Social Work and School of Health and Rehabilitation Science and Robert Morris University Graduate School of Business. In these academic roles Al teaches, supervises students, and serves as advisor and consultant.

Since 1975 Al has emerged as a national leader and consultant on human services and community issues. He speaks annually to national and international audiences reaching some 15,000 people each year. His books, INTERDEPENDENCE (1991, 1995, CRC Press), BEYOND DIFFERENCE (1996, CRC Press), CULTURAL SHIFTING (2002, TRN Press)

ADVOCACY FOR CHANGE: A MANUAL FOR ACTION (2004, ANCOR Foundation Press) THE ESSENCE OF INTERDEPENDENCE (2008, Lash Publishing) and TOGETHER IS BETTER (2008, Lash Publishing) have won praises and awards for their thoughtful approach to culture and community and are now used at many colleges, universities and in-service settings.

Along with his professional activities, Al is involved in a variety of civic volunteer roles. He is on the board of the Southwest PA Partnership for Aging, The Advisory Committee of Hattie

Larham Service System and the immediate past chairman of the PA Statewide TBI Advisory Board.

Al has lived his entire life on the family homestead of "Condeluci Hill." Settled in 1917 by his grandfather, Antonio and honed by his father, mother, uncles and aunts, "Condeluci Hill" is currently home to 15 families and was featured in LIFE MAGAZINE (Aug, 1996). Al still lives on the "hill" with his wife Liz, children Dante, Gianna and Santino and some 45 other members of the Condeluci family.

Rudy Dressendorfer, PT, PhD, FACSM



Title: Exercise Training in Multiple Sclerosis: State of the Art and Future Considerations

Friday, October 23rd, 7:00-9:00pm
Location of Presentation: Showroom

Abstract: Exercise prescription for general health promotion and disease management is practiced in many chronic conditions. In multiple sclerosis (MS), incapacitating fatigue and impaired mobility reduce self-efficacy for disease management. Whether exercise is medicine strong enough to lessen *disease outcomes* or promote brain health in MS are questions for further research. Currently, more than 50 randomized controlled trials have provided a favorable body of evidence that supports exercise training for desirable *functional outcomes* in persons with mild or moderate MS. Aerobic and resistive exercise programs increase physical capacity and reduce disability. Aerobic exercise helps alleviate fatigue and improves cognitive function. Stretching exercises may decrease muscle stiffness and spasticity, immediately and over time. Specific functional exercises may improve posture, balance and walking ability, and reduce the risk of falls. Exercise programs have also been shown to promote psychological factors such as self-efficacy and quality of life.

Aerobic, resistance and flexibility exercise programs in MS are generally prescribed using empirical guidelines for type, intensity, duration and frequency of training. Most people with mild MS can achieve during incremental exercise testing 85% of the maximal heart rate (HR) predicted for their age. Initial target HR range for moderate-intensity aerobic training is roughly 50 to 75% of the age-predicted maximum. The recommended duration of exercise in the target range is about 15-30 minutes. However, exercise intensity and duration should always be individualized and modified for individual tolerance to avoid undue fatigue or discomfort, as well as progressed in order to achieve optimal training effects. Subjective exertion can also be used to monitor aerobic exercise intensity. Recreational play, group exercise and enjoyable modalities (e.g., walking, aquatic therapy) increase adherence to regular physical activity.

Up to 80% of MS patients are heat sensitive. Exercise tolerance is greater, therefore, in a cool environment, while wearing a cooling garment, after a cold bath, or in the morning when body temperature is lowest. Exercise-induced motor or sensory symptoms such as increased muscle weakness or numbness that develop with elevated body temperature reflect temporary nerve conduction block. Symptoms associated with heat stress indicate the need to rest and cool down, but they are usually transient.

Demyelination in MS, is the motor asymmetry desynchronization of muscle activation

that controls posture, balance, coordination and general mobility. Functional training such as posture alignment therapy, balance-based-torso-weighting and constraint-induced movement therapy can help restore bilateral symmetry and motor control. Improvements in posture, balance and gait suggest that exercise plays a role in activating alternate circuits in the brain for motor reorganization. In as much as “rewiring of the brain” is likely an ongoing process in MS, the commitment to exercise training should be long term.

Biography: Dr. Dressendorfer received his PhD in medical physiology from the University of Hawaii, School of Medicine and throughout his career has specialized in clinical exercise physiology. He was a certified exercise program director in the American College of Sports Medicine for 25 years. He retired as full professor of Human Performance & Sport at New Mexico Highlands University and subsequently, taught exercise physiology and did collaborative research as adjunct professor in Physical Education & Recreation at the University of Alberta. Currently, he practices sports medicine as a licensed physical therapist in California. Rudy recently authored over 50 articles (to be published online in 2009 as part of a rehabilitation resource) on conditions and injuries treated by physical therapists.

MS FACT:

Approximately 1,000 new cases of MS are diagnosed in Canada each year, which means three more Canadians are diagnosed with MS every day.

Dr. Michael Yeung



Title: The Future of MS Therapeutics

Saturday, October 24th, 8:30-9:30am

Location of Presentation: Showroom

Abstract: Multiple sclerosis is an immune-mediated disease, precipitated by unknown environmental factors in genetically susceptible individuals. The immune system is a complex system, composed of different cell types with diverse functions. As immunological research progresses, several of these cell systems have been shown to be involved in the pathophysiology of MS. We are only starting to define these patterns of interaction.

As we start to understand more about immune function, new “targets” for therapy are being explored. Some treatment regimes are still in the basic science research phase or being studied in animal models. However, many new treatments are currently under clinical trial protocols, looking for treatment options in MS. These therapeutics are primarily looking for preventative treatments, to limit the amount of

damage that is being done within the brain and spinal cord.

Repair mechanisms are also being investigated. Reparative processes are an extremely complicated process. What turns on reparative cells? How do they switch off? Can these processes be stimulated and controlled? Some trials are looking at chemotherapy regimens that suppress or “reboot” the immune system. The introduction of naïve stem cells without immunological memory may stop or lessen the demyelination process. Pluripotent stem cells may be able to repair previous damage.

Tinkering with the immune system may be fraught with new and unforeseen deleterious effects. Many of these new therapeutic areas may have side effects that require closer scrutiny and clinical surveillance.

It has been estimated that by 2012, there will be 10 - 15 new treatment regimes available for MS. This presentation will focus on new areas of therapeutic research based on current knowledge of the immune system.

Biography:

Medical School - University of Alberta.
Internal Medicine Residency - University of Calgary

Neurology Residency - University of Calgary
Stroke & Headache Fellowship - University of Saskatoon

Neurologist - MS Clinic, Foothills Medical Centre, University of Calgary
Clinical Assistant Professor, Department of Clinical Neurosciences, University of Calgary
Director, MS Clinical Trials Research Unit, MS Clinic, University of Calgary

MS FACT:

Research indicates that exercise in persons with mild-to-moderate MS provides similar fitness and psychological benefits as it does in persons without.

CONFERENCE ABSTRACTS AND SPEAKER INFORMATION

(Abstracts are listed by time of presentation in order of session)

BLOCK 1: 9:45-10:30AM

Session A:

Title: Neuroprotection and Neuroregeneration in Multiple Sclerosis

Speaker: Dr. Fabrizio Giuliani

Saturday, October 24th, 9:45-10:30am

Location of Presentation: Showroom

Abstract: Multiple sclerosis (MS) has traditionally been described as a demyelinating disease of the central nervous system (CNS). In the last few years, a shift has occurred and it has become more evident that MS is also a neurodegenerative disease. An increasing number of reports show neuronal and axonal damage in MS patients and in its animal model, the experimental allergic encephalomyelitis (EAE). The mechanisms underlying this neurodegenerative process are still unknown, but experimental data suggest an immune-mediated injury. This immune-mediated pathogenesis is supported by the significant infiltration of inflammatory cells in the brain and spinal cord. In addition, EAE is produced by an autoreactive immune cell response, and there is substantial similarity between active MS plaques and CNS lesions in EAE animals. In this presentation, the findings of immune-mediated injury in MS will be reviewed. New potential neuroprotective strategies and the potential neuroprotective role of some of the currently available MS treatments will also be addressed. Furthermore, we will review the importance and the potential

neuroprotective effects of exercise for MS patients.

Biography: Dr. Fabrizio Giuliani is an MS neurologist and neuroimmunologist at the University of Alberta, Edmonton, Alberta. He is currently Assistant Professor of Medicine at the same institution. Dr. Giuliani earned his medical degree cum laude at the University of Bari, School of Medicine, Italy where he also completed his residency in Adult Neurology. Dr. Giuliani's research training was as an AHFMR clinical fellow at the University of Calgary, Calgary, Alberta under the guidance of Drs. Wee Yong and Luanne Metz. In 2006 Dr. Giuliani was the recipient of the prestigious Donald Paty Career Award from the MS Society of Canada. His research interests are focused on the mechanisms of neurodegenerative processes of multiple sclerosis and the development of new therapeutic strategies to prevent neuronal injury in inflammatory diseases of the CNS.

Session B:

Title: Postural Alignment Therapy in Multiple Sclerosis

Speakers: Rudy Dressendorfer, PT, PhD and Jennifer Fuller, BS, CET

Saturday, October 24th, 9:45-10:30am

Location of Presentation: Yuk Yuks

Abstract: The demyelinating lesions in multiple sclerosis (MS) slow or block nerve conduction. Muscle activation is reduced and sensation is disrupted in the affected nerves. Muscle weakness/ contracture and altered position sense contribute to abnormal limb alignment and impaired range of motion. Posture is often changed more on one side of the body, producing *postural asymmetry* that also disturbs balance and gait. Fatigue, pain and habitual faulty posture (commonly seen in the general population) add to the underlying body alignment pathology.

Various forms of faulty posture will be discussed and demonstrated, with special reference to MS. We will also introduce our practice of postural alignment therapy, describe therapeutic posture exercises, and show examples of our posture-specific “exercise menus” that are individualized for each patient’s home program. Audience participation in the exercises is encouraged. For those wishing to participate, gym clothes are recommended but not required.

The goals of this workshop are to promote awareness/ knowledge of: 1) body alignment problems in persons with MS; 2) some exercises used to correct posture; and 3) how to perform selected posture exercises.

Biographies: Rudy Dressendorfer: Please see biography on page 12.

Jennifer Fuller: Ms. Fuller received her BS in kinesiology from the University of Maine. She is the owner of Fuller Health and an exercise therapist near San Francisco, California where she provides functional coaching to correct postural imbalances associated with pain and disability. The Egoscue method is a cornerstone of the principles used in her work. Jennifer is currently working with Dr. Dressendorfer on a multiple sclerosis research project.

Session C:

Title: Navigating Income Support Programs: CPP-D

Speakers: Jennifer A Clarke, Shannon Currie & Shanna Orvis

Saturday, October 24th, 9:45-10:30am
Location of Presentation: One 31

Abstract: This presentation is focused on CPP Disability benefits: what the benefits are for, eligibility, start and end guidelines, late applications, return to work incentives, automatic reinstatement, reassessment, combination of benefits, international agreements, and the appeal process. The presentation will also provide a tiny snippet on My Service Canada Account, Registered Disability Savings Plan, and Employment Insurance. At the end of this presentation participants will 1) understand of who CPP Disability benefits are for, 2) understand what they entail, and 3) know how to apply.

Biography: Shanna Orvis, Shannon Currie, and Jennifer A. Clarke are all Citizen Services Specialists for Service Canada. They currently each reside in Edmonton AB and have been with Service Canada for the last 5-8 years. Service Canada offers single-window access to a wide range of Government of Canada programs and services in person for citizens throughout Canada and internationally via the internet. Shanna, Shannon, and Jennifer specialize in promoting the Department's service offerings (such as Old Age Security (OAS)/Canada Pension Plan (CPP) Integrity Services, Employment Insurance (EI) electronic services, Apprentice Incentive Grant (AIG), Canada Education Savings Program (CESP), Pleasure Craft License (PCL), Passports, etc.) to citizens, employers, and the community.

BLOCK 2: 11:00-11:45AM

Session D:

Title: **Shining a Light on Vitamin D and MS**

Speakers Dr. Mary Lou Myles

Saturday, October 24th, 11:00-11:45am

Location of Presentation: Showroom

Abstract: The main objective of this presentation is to outline the impact of vitamin D deficiency in the development of MS and the potential role of vitamin D supplementation in the prevention and treatment of MS. The sources of vitamin D and the physiologic role of vitamin D in the human body will first be outlined. The evidence for the impact of vitamin D deficiency in influencing the risk of MS will be summarized. Finally, the evidence suggesting a potential benefit of vitamin D supplements for the prevention and treatment of MS will be explored. Other potential health benefits of vitamin D will also be summarized.

Learning Objectives:

1. Participants will have a better understanding of the role of vitamin D in altering the risk of MS.
2. Participants will be aware of the rationale for Vitamin D supplementation as a primary prevention strategy in MS
3. Participants will be familiar with the evidence suggesting a role for vitamin D in the treatment of MS.

Biography: Dr. Mary Lou Myles is an Associate Clinical Professor of Neurology at the University of Alberta and has a busy community clinical practice with a special interest in multiple sclerosis. She is involved in continuing medical education initiatives to help educate physicians

about MS and has been a presenter for many national patient oriented education series for the MS Society of Canada. She participates as one of the experts for the MS Answers program for the MS Society of Canada website. She is currently national Chair of Client Services and a member of the national board for the MS Society of Canada. She is a member of the MS Special Therapies Panel for Alberta. She has been involved in MS clinical research. She has been active in ongoing efforts to bring access to comprehensive nursing services to all individuals with MS in northern Alberta.

Session E:

Title: **Postural Alignment Therapy in Multiple Sclerosis (continued)**

Speakers: Rudy Dressendorfer, PT, PhD and Jennifer Fuller, BS, CET

Saturday, October 24th, 11:00-11:45am

Location of Presentation: Yuk Yuks

Abstract and Biographies: Please see information on abstract and biographies under Session B on page 14.

Session F:

Title: How to Manage Employment Concerns - Human Rights in the Workplace

Speaker: Colette Grootkarzyn

Saturday, October 24th, 11:00-11:45am

Location of Presentation: One 31

Abstract: This presentation will provide an overview of the human rights legislation in Alberta. Within the presentation the areas and ground of the human rights legislation will be covered. Discussion and focus will also centre on duty to accommodate and disabilities in terms of what does that mean. Information will also be presented on how the complaint resolution process works.

At the end of this presentation participants will 1) understand duty to accommodate and disability and 2) understand how the complaint resolution process works.

Biography: I started my career as a Payroll Information Officer for Alberta Treasury and have over 9 years experience as a Payroll and Benefits Manager. I was promoted into a Human Resource Coordinator position and have over 11 years of Human Resource experience.

In my current position, I am a Human Resource Manager and have successfully implemented policies that pertain to Human Rights and Harassment training in a company that did not have a Human Resource department. In addition I developed and trained employees and management on progressive discipline. One of the projects was to consul management on proper interview techniques and guides. I developed job descriptions and appraisal forms to follow the standards that are set out by Human Rights Legislation.

MS Fact:

Canadians have one of the highest incidence and prevalence rates of multiple sclerosis in the world.

BLOCK 3: 2:00-2:45PM

Session G:

Title: Bladder and Bowel Dysfunction in Multiple Sclerosis

Speaker: Laurel Morrison

Saturday, October 24th, 2:00-2:45pm

Location of Presentation: Showroom

Abstract: The bladder and bowel are commonly affected by multiple sclerosis (MS), a chronic anti-inflammatory and demyelinating neurological disease. Review of the normal anatomy and physiology of both the bowel and the bladder will lay the groundwork for an overview of the reasons why so many individuals with MS experience bladder and or bowel problems. Bladder dysfunction may include such symptoms as urinary frequency, urgency, hesitancy, incontinence, and dysuria (painful urination). These symptoms are due to either the inability of the bladder to store urine, empty urine, or a combination of the two. The symptoms of bowel dysfunction may include constipation, diarrhea, incontinence, and fecal impaction. Methods of assessment and strategies for prevention and management of both bladder and bowel dysfunction will be presented. The effect of bladder and/or bowel dysfunction on one's lifestyle is significant and is known to adversely affect quality of life. Hence, the importance of patient recognition and reporting of these symptoms to their neurologist and/or nurse is an essential first step to start the process of determining the nature of the problem and management of the symptoms.

Biography: Laurel Morrison graduated from the University of Alberta in 1995 with a Bachelors of Science degree in Nursing. She began working at the Multiple Sclerosis Patient

Care and Research Clinic in June of 1994. Her role at the MS Clinic as Research/Clinic Nurse involves working with individuals who have been diagnosed with, or are being investigated for, multiple sclerosis. She provides education, guidance, and supportive counselling to clinic patients and their families and has been actively involved in MS clinical research. Laurel has been a member of the International Organization of Multiple Sclerosis Nurses (IOMSN) since 1997, and obtained her Multiple Sclerosis Certified Nurse (MSCN) designation in 2002. Currently, she works at the MS Clinic on a part-time basis to ensure quality time spent at home with her husband and two children.

Session H:

Title: Red Flags and Green Lights - Navigating the Early Days

Speaker: Aprile Royal

Saturday, October 24th, 2:00-2:45pm

Location of Presentation: Yuk Yuks

Abstract: Getting a diagnosis of MS is overwhelming for a variety of reasons, but there are strategies that can be employed to help ease some of the confusion and fear that threaten to take over. While everyone's journey with MS is unique, there are some common themes that can be considered and planned for, in navigating a path to wellness. Some common territory in adapting to a diagnosis of MS includes reactions to getting the diagnosis itself, disclosing the news to family, friends and employers, sorting through the vast amount of information available to get a

clear and informed picture, considerations with respect to complementary and alternative therapies, as well as considerations for disease modifying treatment and keeping hope alive. Building a plan that incorporates these topics can help to instil a sense of empowerment so important to managing life with MS.

At the end of this presentation participants will 1) understand how to make good choices in managing their MS and 2) learn strategies for adapting to, and coping with life with MS.

Biography: Aprile Royal joined the MS Society of Canada in January of 2007, and is currently the assistant vice-president for Clinical Programs with National Office. Prior to joining the MS Society Aprile worked as National Manager for Professional Education and Research for a pharmaceutical company which marketed a product for MS. Aprile also worked for ten years as the nurse manager of the MS Clinic at St. Michael's Hospital in Toronto.

Session I:

Title: Developing the MS Community

Speaker: John Soars

Saturday, October 24th, 2:00-2:45pm

Location of Presentation: One 31

Abstract: This session will involve a power-point presentation on the evolution of the MS Community followed by an interactive question and answer on the future of Community in the Alberta Division and Edmonton Chapter. Attendees will be invited to share their views on

Dr. Al Condeluci's keynote presentation and how it assists in development of the MS Community going forward.

Learning Objectives:

1. Participants will have a better understanding of MS *Communities*
2. Participants will also gain an understanding of how the Societies' concepts of Community fits with those of Dr. Al Condeluci
3. Participants will have input into future developments.

Biography: Prior to coming to the MS Society John worked for 30 years for a major telecommunications organization. Major job categories performed during that time were in Human Resources Management and as a Process Consultant within the Quality Division. The skills in human resources, team building, facilitation, consultation and process management have proven valuable during his 7 years as Client Services Coordinator with the Edmonton Chapter of the MS Society.

MS FACT:

MS was first identified and described by a French neurologist, Dr. Jean-Martin Charcot, in 1868.

BLOCK 4: 3:15-4:00PM

Session J:

Title: Pregnancy, Menopause, and Multiple Sclerosis

Speaker: Dr. Penny Smyth

Saturday, October 24th, 3:15-4:00pm

Location of Presentation: Yuk Yuks

Abstract: This presentation will highlight and discuss the relative safety of pregnancy for women with multiple sclerosis. It will look at why pregnancy may settle MS relapses. Furthermore, the hormonal changes during menopause will be examined, followed by a discussion how these hormonal changes may affect a woman's MS symptoms. Current and past research studies will be discussed looking at female hormone supplements and their effects on MS, both in animal models of MS and in women who have MS.

Learning Objectives:

1. Participants will be able to better understand and describe the effects of pregnancy on multiple sclerosis relapses and symptoms as well as what happens after pregnancy.
2. Participants will also be able to discuss and distinguish menopausal hormonal changes and how these changes may affect MS symptoms.
3. Participants will discuss and understand the possibility of using female hormone supplementation to affect the course of MS in the future.

Biography: Penny went to the University of Alberta for medical school and residency. She then returned to Vancouver to complete 2 years

of fellowship training in Multiple Sclerosis at the UBC MS Clinic.

Following completion of her fellowship, she stayed in Vancouver at Vancouver General Hospital and worked as an MS specialist at the UBC MS Clinic. She ran a private practice in Neurology in Vancouver and participated in stroke call. She also supported a small community hospital outside of Vancouver for Neurology consults. Penny was involved with the UBC medical school and Neurology residency program in Vancouver, teaching medical students and residents on a regular basis.

In August 2008, Penny moved to Edmonton to become Program Director of the Neurology Residency Program at the University of Alberta. She has joined the MS Clinic at the University of Alberta, and works as a clinical neurologist. Penny has continued to participate in multi-centre clinical trials for MS. She is involved in teaching at the University of Alberta and in MS care across the province of Alberta, through seeing patients and sitting on MS committees.

Session K:

Title: Battling Fatigue in MS

Speaker: Dr. Jacqueline Bakker

Saturday, October 24th, 3:15-4:00pm

Location of Presentation: Showroom

Abstract: Fatigue is extremely common in MS. This presentation will describe and differentiate the various causes for fatigue as well as give information on how to treat it conservatively and

medically. During the presentation participants will gain an understanding of the incidences of fatigue in MS and how it affects them, as well as an understanding of the various causes of fatigue outside of MS. In addition the various types of treatments available, both conservative and medical will be discussed.

Biography: Dr. Jacqueline Bakker is the medical director for the Multiple Sclerosis clinic in Red Deer Alberta. She did her neurology training at the University of Calgary and a clinical fellowship afterwards also at the University of Calgary. She is involved in patient care and clinical research and has done various speaking engagements through the MS Society.

Session L:

Title: Navigating the Medical System:
The Role of the MS Nurse

Speaker: Jennifer Mah

Saturday, October 24th, 3:15-4:00pm
Location of Presentation: One 31

Abstract: Individuals with multiple sclerosis (MS), a chronic inflammatory and demyelinating

neurological disease, try their best to manage their health in what may sometimes seem to be a frustrating and fragmented system. It may not always be clear who should be contacted - the family physician, their neurologist or the MS Clinic? Access to services differs among the MS Clinic and neurologists who serve their patients within the community setting. What can a patient do to minimize this disparity? We will discuss the resources that are available to anyone with MS through self-referral. Ensuring the MS individual has access to appropriate resources is essential in helping them manage their overall well-being. We can empower individuals with MS by helping them recognize and report to the most appropriate care provider or service.

Biography: Jennifer Mah graduated from the University of Alberta with a Bachelors of Science in Nursing degree in 2002. She was involved in a multidisciplinary care program at the Glenrose Rehabilitation Hospital for four years, and began working at the Multiple Sclerosis Patient Care and Research Clinic in May, 2007. Presently, Jennifer works as a Clinic Nurse at the Multiple Sclerosis Patient Care and Research Clinic, where she works closely with MS patients and their families. Her work involves the provision of education, supportive counselling and assisting with symptom management. She is very interested in aspects of sexuality in MS patients.

MS Fact:

Women are more than three times as likely to develop MS as men.

BLOCK 5: 4:15-5:00PM

Session M:

Title: The Impact of MS on Sexual Functioning and Relationships

Speaker: Dr. Shaniff Esmail

Saturday, October 24th, 4:15-5:00pm

Location of Presentation: Yuk Yuks

Abstract: Sexuality is an essential part of the human experience. Physical and emotional changes associated with MS potentially can affect sexual health adjustment and creates concerns surrounding sexuality. This interactive presentation will describe the impact of MS on an individual's sexuality and relationships. Results of a two part qualitative research study will be reviewed - describing the lived experience of couples where one partner had been diagnosed with M.S. Specific information describing how to deal with primary, secondary and tertiary sexual dysfunction will be reviewed. The session will conclude with a summary of strategies, which have been shown to be effective with helping individuals and couples contend with MS as it relates to sexuality. Participants will have an opportunity to participate in a brief discussion related to the topic.

Learning objectives:

1. Gain an understanding of the impact of M.S. on sexuality
2. Appreciate the importance of mutual responsibility when looking at MS as a couple's issue.
3. Learn effective strategies to deal with MS and its impact on sexuality.

Biography: Dr. Esmail is an Occupational Therapist with clinical and research interest

focusing primarily on sexuality and disability. Specific areas of interest and research include

- Sexuality counselling and intervention for couples impacted by disability or illness
- Sexuality training and education for children with disabilities and their parents.

Dr. Esmail is also a professor for the physical assessment courses in the department of Occupational Therapy as well as a variety of human sexuality courses at the University of Alberta, in the faculties of Rehabilitation Medicine, Medicine and Human Ecology.

Session N:

Title: Coping with the Cognitive Aspects of MS

Speaker: Dr. Jennifer Rodgers

Saturday, October 24th, 4:15-5:00pm

Location of Presentation: Showroom

Abstract: In the past, MS is has generally been thought of as a physical illness. Today we know that it is a complex illness with diverse symptoms including the possibility of cognitive changes. Cognitions are mental abilities which include our ability to attend and concentrate, learn and remember, problem solve and understand language.

Although it is estimated that 50% of all individuals diagnosed with MS will experience some cognitive change, the majority will experience mild to moderate disturbances. Very

often simple strategies will compensate for the changes.

For a number of individuals, cognitive changes may be more disabling and interfere with the ability to socialize, work and drive an automobile. It is important for family members, close friends and employers to learn about cognitive changes in MS in order to avoid misunderstanding behaviors that may be symptomatic of those problems.

Individuals can learn to cope and adapt to these cognitive changes. Coping with the Cognitive Aspects of MS will highlight the types of cognitive changes most commonly linked to the diagnosis of MS. Coping techniques and strategies to help individuals and family members understand and live well in spite of these challenges, will be provided.

Learning Objectives:

1. Attendees will better understanding the kinds of cognitive changes that most commonly occur as a result of multiple sclerosis.
2. Attendees will be introduced to various coping strategies that help to minimize the effects of MS related cognitive symptoms.

Biography: Dr. Jennifer Rodgers is a clinical psychologist at the University of Alberta Hospital and Clinical Professor at the University of Alberta. She is actively involved with the National MS Society - Caregivers Advisory Group, the Jayman AB MS Project, the Alberta MS Drug Review Panel, and the Clinical Ethics Committee for Alberta Health Services.

Dr. Rodgers has been working with individuals with MS since 1985. She served on the Board of Directors at the Edmonton Chapter level and the Alberta Division level for 10 years. Her research interests and public talks focus on educating individuals with MS and family members on the cognitive and emotional changes that can occur as a result of the diagnosis. Her work in counselling individuals affected by the

diagnosis of MS is always with the goal of helping them live well with MS.

Session O:

Title: MS Community Advisory Council: Advocating for Change and a Greater Role for Non-Profits

Speaker: Dr. Garry Wheeler

Saturday, October 24th, 4:15-5:00pm

Location of Presentation: One 31

Abstract: On October 29th and 30th, 2008, the MS Society, Alberta Division hosted a gathering of representatives from across Alberta's MS community and the entire spectrum of MS treatment, care and support. Participants included clinicians and health care providers, community support organizations, government officials, and Albertans living with MS. Their purpose was:

- To understand and learn from nine significant and current initiatives that each had the potential to significantly improve health and quality of life outcomes for Albertans with MS,
- To provide stakeholder feedback, input and advice to these initiatives, and
- To develop a 'big picture' perspective and identify how best to leverage and support current efforts.

There was consensus for the development of an ongoing forum or similar mechanism to support and facilitate communication and synergy among stakeholder groups. As a result the MS Community Advisory Council was formed.

In this session we will explore the development of the Council; the role of the council as an advocate for change, and current advocacy initiatives being undertaken by the council.

Biography: Dr. Wheeler is an Exercise Physiologist and Chartered Psychologist. He is currently the Vice President of the Edmonton Chapter and Alberta Division of the Multiple Society of Canada. Dr. Wheeler is also a practicing Registered Psychologist and works with persons with brain injury and stroke in the Glenrose Rehabilitation Hospital in/outpatient brain injury program. Born in England, Dr. Wheeler began his career in the health and fitness industry as a Physical Education Instructor at the King's School in Gloucester, England. He moved to Canada in 1981 to begin a Master's Degree in Physical Education at the University of Alberta,

completing in 1984. In 1989 he completed his Doctorate in Physical Education in the area of exercise, training, hormonal responses to exercises, and dietary behaviour of individuals in exercise programs. In 1993, Dr. Wheeler completed a second Masters Degree in Educational Psychology with a specialty in Counselling Psychology. He chartered as a psychologist in the Province of Alberta in 1994.

Dr Wheeler's career is now focused in the area of Multiple Sclerosis with a particular focus on health and wellness and the role of exercise in symptom management. He continues to practice as a psychologist at the Glenrose Rehabilitation Hospital where he runs a "Managing Anger and Frustrations Group" and in addition works with caregivers of persons with chronic disease or after trauma/injury including Multiple Sclerosis.

OFFICIAL LAUNCH OF



AT CONNECTIONS 2009

What is MS ActiveNOW?

MS ActiveNOW is a health promotion initiative developed in Alberta for persons with MS designed to:

- Increase awareness of the benefits of daily physical activity and exercise for persons with MS, caregivers, and providers in the health, fitness and lifestyle industry;
- Help fitness providers design exercise programs for persons with MS, so that persons with MS may enjoy the benefits of exercise safely and with confidence;
- Increase access to active living and exercise opportunities in the community for persons with MS; and
- Increase intention for physical activity and exercise in persons with MS.

Where in Alberta can I access it?

MS ActiveNOW programs are in various communities including Edmonton, Calgary, Red Deer, Lethbridge, Medicine Hat, and Lloydminster. Some programs are specific to persons with MS, while others are cross-disability and include other user groups. Programs include, but are not limited to: Yoga, Tai Chi, Bowling, Seated Aerobics, Kinesis, Fitness consultations, and group recreation activities. Each community offers something different, so please contact your local chapter to find out more!

How can I learn more about Exercise and MS?

Visit the MS ActiveNOW website at www.mssociety.ca/alberta/active.htm. Here you

will find a wide range of information on the importance of exercise, some examples of exercises that are appropriate, lists of programs and services in Alberta and a variety of links and resources to other related information.

What resources are available?

Currently, the following resources have been developed as part of MS ActiveNOW program:

- About MS DVD
- Exercise and MS DVD
- Activating Your Life: A Guide to Exercise for Persons Living with Multiple Sclerosis
- Understanding MS and Exercise: A Fitness and Lifestyle Provider Guide
- A Health Professionals Guide to Understanding Exercise and Multiple Sclerosis
- Adopting and Maintaining an Active Lifestyle: A Guide for Persons living with Multiple Sclerosis
- Overcoming the Barriers: A Fitness Professionals Guide to Removing Fitness Facility Barriers for Persons with Multiple Sclerosis
- Training Logs for Persons with MS
- Multiple Sclerosis and Exercise Condensed Resource

For more information, or to order any of the aforementioned resources, please email the MS ActiveNOW program at active@mssociety.ca or contact your local chapter toll-free at 1-800-268-7582.

INFORMATION AND RESOURCE FAIR

Presented here is a list of organizations and vendors which offer services to persons living with multiple sclerosis vendors that will be at the conference on Friday and Saturday. We encourage you to take the time to visit them and see what they have to offer/say.

Conference vendors are listed here in alphabetical order.

- Alberta Caregivers Association
- Alberta Easter Seals
- Bayer HealthCare
- City of Edmonton - Advisory Board on Services for Persons with Disabilities
- Dr. Kyli Shelley - Chiropractor
- Employabilities
- Money Matters - Credit Counseling
- MS Society of Canada - Alberta Division Client Services
- MS Society of Canada - Alberta Division Fund Development
- MS Society of Canada - Edmonton Chapter Client Services
- Red Deer MS Clinic
- Safeway Pharmacy
- Serono
- Servus Credit Union Place
- The Steadward Centre for Personal & Physical Achievement
- Yoga for Today

MS Fact:

MS is the most common neurological disease affecting young adults in Canada.

THANK YOU TO SPONSORS

We are indebted to our sponsors for their generous support of the Connections 2009 Conference. Without this support, in monetary and product kind, the conference would simply not have been possible, or the conference fees so high as to exclude many people.

Our sponsors are listed here at time of printing of the conference program. We thank them all.



THANK YOU TO CONNECTIONS 2009 VOLUNTEERS

Volunteers play a fundamental role in nearly every aspect of the MS Society. Whether it is helping out at an event, sitting on a board, or performing one of many other tasks, volunteers are crucial in the fight against MS. The 2009 MS Connections Conference Volunteers are no exception, as it is only with the hard work and support of these spectacular individuals that the execution of the 2009 MS Connections Conference is made possible. The dedication of these volunteers ensures that the Conference runs both smoothly and cost effectively, enabling it to provide a one of a kind opportunity for delegates to connect with a wide variety of individuals from MS related fields. Accordingly, I would like to thank each and every one of the spectacular 2009 MS Connections Conference Volunteers for dedicating their time and efforts in the fight to end MS. It is because of their assistance that this unique conference will be able to touch the lives of many.

Sincerely,



Scott Robson
Manager, Volunteer Resources

CONFERENCE ORGANIZING COMMITTEE

Thank you to the following individuals for making this event such a great success.

Beverly Babuk
Valerie Borggard
Cathy Buchanan
Darrel Gregory
Keith Johnston
Cassy Lawson

Mark Mahl
Jennie Malone
Dr. Mary Lou Myles
Scott Rattray
Scott Robson
John Soars

Crystal Tracy
Dr. Barbara Ward
Dr. Garry Wheeler
Angie Wight
Katrina Wynnyk

MORE INFORMATION

To obtain more information on the Connections 2009 Conference or to request conference materials, please contact the Edmonton Chapter of the MS Society.

Address: #150, 9405-50 Street
Edmonton, Alberta T6B 2T4
Phone: 780-471-3034
Fax: 780-463-7298
Email: info.edmonton@mssociety.ca
Website: www.mssociety.ca/edmonton



CONNECTIONS 2010 CONFERENCE

Dates: October 29 & 30th, 2010
Location: Delta Calgary South, Calgary, Alberta

For more information, please contact the Calgary Chapter of the MS Society of Canada at 403-250-7090 or by email at info@mscalgary.org.



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To contact the Edmonton Chapter directly, please contact:

Address: #150, 9405-50 Street

Edmonton, Alberta T6B 2T4

Phone: 780-471-3034

Fax: 780-463-7298

Email: info.edmonton@mssociety.ca

Website: www.mssociety.ca/edmonton

To contact your local MS Society Chapter in Alberta, please contact:

Toll-Free: 1-800-268-7582

Or visit: www.mssociety.ca/alberta

