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**bstracts - Works-in-Progress**

# Works-In-Progress



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**(W01) CARE MANAGEMENT AS PART OF A SYSTEM OF CARE: GOING THE EXTRA MILE**

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In Systems of Care, local public and private organizations work in teams to plan and implement services for individuals in need of assistance. In many areas, this charge is met by isolated systems of care that do not interact with each other to evaluate the needs of individuals with disabilities, no matter what their age.

The CT chapters of the NMSS have diligently pursued a 'road map' to be used by their members in finding the resources to assist them in living as independently as possible; having current complex needs met and future planning in place.

The Chapters have teamed with CCCI, a CT based not-for-profit care management agency, to help their members traverse the difficult challenges faced by individuals with MS.

Chapter staff can be in the situation of identifying multiple complex needs and not always knowing where to turn, or how to help. The first step in the process is the use of a screening tool developed by CCCI to identify members whose needs and future planning is in chaos. The next step is the intervention of a professional care manager.

The core objective of this workshop would be to train participants in the following areas:

- Understanding the components of care management;
- Recognizing when care management intervention is needed;
- How to locate, screen and develop a local care management provider resource;
- How to identify during screening if the potential care management provider has the requisite skill and experience to assist the Chapter member in need;
- Enhance skills, develop confidence to communicate with the member how a care manager can assist them with their needs while increasing their independence and autonomy.

Exercises and case studies will be included to illustrate the positive impact of care management.

*Study Supported By: National MS Society Western CT Chapter (The National MS Society chapters in Connecticut, including Western Connecticut and Greater Connecticut Chapters, both contract with Connecticut Community Care, Inc. to provide in-depth assessments of clients with MS in need of care management services.)*

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**(W02) EPSTEIN-BARR VIRUS AND THE ETIOLOGY OF MULTIPLE SCLEROSIS**

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The geographical distribution and changes in risk among migrants provide compelling evidence of the role of environmental factors in MS. One of the most consistent findings is that Epstein-Barr Virus (EBV) infection is a strong risk factor for MS — the risk of MS among individuals with evidence of prior EBV infection is about 10-folds higher than among individuals seronegative for EBV. Recent confirmation of this finding in a study of pediatric MS virtually rules out genetic and other alternative explanations for the EBV-MS association. Further, the risk of MS among individuals with history of infectious mononucleosis is 2-3 folds higher than among EBV positive individuals without history of IM. Collectively, the results of several prospective investigations indicate that:

- Antibody titers to the EBV nuclear antigen 1 (EBNA-1) measured among healthy young adults are strongly predictive of their risk of developing MS. A several fold increase in risk has been observed among individuals with the highest titers as compared with those with the lowest;
- The elevation in titers of anti-EBNA-1 antibodies among individuals with MS appears to occur most commonly between the ages of 20-25, suggesting a window of susceptibility for some triggering factor;
- Preliminary results suggest that EBV viral load in plasma is also related to increased risk of developing MS.

Finally, in a new study among participants in a large integrated health plan, we found that an elevation in anti-EBNA-1 titers in young adulthood precede the MS onset of 15-20 years.

Overall, there is strong evidence that EBV plays a role in the etiology of MS. However, as we will discuss, some aspects of MS epidemiology could only be explained if either different strains of EBV have different propensity to cause MS, or if there are still unknown interactions between EBV and other factors.

*Study Supported By: NIH/NINDS, NMSS*

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**(W03) INTERDISCIPLINARY MOTOR AND COGNITIVE TREATMENT  
IN MULTIPLE SCLEROSIS PATIENTS**

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**I**ntroduction: Multiple Sclerosis (MS) is a demyelinating disease which attacks preferably the Central Nervous System of young adults, often evolving into from a relapsing to progressive form. Initial symptoms are often mild, but as the disease evolves there is an accumulation of impairments that create a great impact on patients quality of life. These impairments may benefit from specialized treatment and care. Rehabilitation of MS patients aims the reduce symptoms, improve of function, and the prevent secondary complications.

**Objective:** To analyze in quantitative ways if there is an improvement in the quality of life of MS patients with use of an interdisciplinary care provided by physiotherapists and neuropsychologists.

**Method:** 5 Multiple Sclerosis patients – 3 women and 2 men – with ages from 42 to 52 years, who submitted to quantitative and qualitative evaluation scales: the Barthel Scale, the Visual Analog Scale (VAS) and the Determination of Functional Quality of Life (DEFU), in Multiple Sclerosis. Evaluation was done at the beginning of study and after a 5 month period under physiotherapeutic and cognitive rehabilitation treatment.

**Results:** Initial results of the interdisciplinary treatment including motor and cognitive rehabilitation, show indications of being an effective and comprehensive way to improve MS patients quality of life. A larger study is needed to prove this point.

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**(W04) EUROPEAN TRANSLATIONS OF THE MS NEUROPSYCHOLOGICAL SCREENING QUESTIONNAIRE (MSNQ)**

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The MSNQ is a 15-item, disease-specific questionnaire that quantifies perceptions of cognitive and neuropsychiatric impairment in MS patients. There are two forms of the test: patient self-report and informant-report.

Our previous work (Benedict et al, 2003; 2004) with the MSNQ showed that it has excellent internal consistency and test-retest reliability. Neuropsychological (NP) impairment was correlated with elevated informant-reported deficiencies in everyday activities ( $r = -.45$  to  $-.59$ ), and to a lesser degree patient self-reported deficiencies ( $r = -.37$  to  $-.46$ ). In contrast, depression was more strongly correlated with patient self-report MSNQ scores. Bayesian statistics for the informant-report form revealed good sensitivity and specificity for detecting cognitive impairment. The patient self-report form was found to be predictive of either cognitive impairment or depressive disorder. Most recently, analysis of patient/informant discrepancy scores has shown that marked underreporting of NP dysfunction among MS patients is associated with cognitive impairment, neuropsychiatric indices of euphoria sclerotica, and vocational disability (Carone et al, submitted).

These findings generated considerable interest among both American and European clinicians interested in screening for neuropsychological disorders in the MS clinic setting. Therefore, we endeavored to translate the MSNQ into the following languages: German, French, Spanish, Swedish, Russian. The procedure (same for all languages) began with forward translations by two independent translators. Next, a second expert translated the forward translations back to English (back translation). The back translations were then reviewed by the first author, and discrepancies between them were discussed at length with the second expert. This review session culminated in a first draft of each foreign-language MSNQ. Finally, each draft was reviewed by yet another translator for final comments and changes. This process ran smoothly for all languages, with the possible exception of Spanish, where the American translators used some idioms unique to Latin America as compared to Spain.

Thus, the MSNQ is available in five European languages. Studies concerning reliability and validity are planned. This study was supported by an educational grant from Schering AG, Berlin, Germany.

*Study Supported By: Schering AG (One of the authors works for Schering)*

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**(W05) REAL-WORLD ADHERENCE TOLERABILITY OF SUBCUTANEOUS INTERFERON BETA 1A (IFN $\beta$ -1A) THERAPY: INFLUENCE OF SEX, BODY WEIGHT**

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**Objective:** IFN $\beta$  can be associated with adverse side effects, which might affect treatment adherence. Subset analyses from a dataset of MS patients on subcutaneous IFN $\beta$ -1a treatment were performed to evaluate tolerability and adherence.

**Methods:** The study included a total of 122 MS patients (either previously treated or naive to immunomodulatory therapy) on IFN $\beta$ -1a sc (Rebif): RRMS (109), SPMS (12), PRMS (1). Treatment regimen, as well as reported side effects and laboratory parameters before and during interferon beta-1a therapy were compiled for analyses.

**Results:** Of the 122 patients on IFN $\beta$ -1a sc any time, (94 women and 28 men; mean time since diagnosis 5.61 years), only 7 patients discontinued treatment due to common side effects (adherence rate 94.3%). Out of 115 patients on IFN $\beta$ -1a sc, 50 patients reported injection site reactions (ISRs) at any one time; only 9 patients had their dose reduced due to ISRs, compared to 17 patients who had their dose reduced due to other side effects. 24 patients (all women) remained on a reduced maintenance dose of IFN $\beta$ -1a. This group had a lower mean weight (138.79 lbs) than patients on full-dose (170.06 lbs) ( $p = 0.003$ ). ISRs occurred more often in patients of lower weight ( $p = 0.021$ ), whereas other side effects (e.g. flu-like side effects) and laboratory changes (transaminase increase, leukopenia) showed no correlation with body weight.

**Conclusions:** Excellent adherence to IFN $\beta$ -1a can be achieved. In some cases, dose reduction may be considered to augment adherence. Patients of lower body weight had more ISRs and were more likely to be on reduced maintenance dose of IFN $\beta$ -1a. Use of an auto injector device or finer gauge needle may further improve common side effects and improve adherence.

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**(W06) MULTIPLE SCLEROSIS SOCIETY OF CANADA, BC DIVISION  
VOLUNTEER LEGAL ADVOCACY PROGRAM**

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People with multiple sclerosis are often faced with a variety of legal challenges such as human rights, employment equity, insurance, income security, estate planning and family law. While staff and volunteers at the MS Society of Canada's British Columbia Division and Chapter offices have provided support on a wide range of these issues, the demand for professional legal advice and advocacy became too great for existing Society resources to meet.

As the demand for this level of support continued to grow, so did the need for volunteer legal advocates with an understanding of the unique nature and scope of the often debilitating and unpredictable disease – multiple sclerosis. The Volunteer Legal Advocacy Program was implemented to meet this demand – providing an organized legal delivery system through a resource of volunteers with legal/advocacy training who are available to support our members with their unique legal challenges.

The overall goal of the Volunteer Legal Advocacy Program is to make legal advice, representation and advocacy available to people throughout the province who are living with MS. This support program can be accessed by telephone, e-mail or in person. In addition, and as part of this program, five legal informational booklets have been developed to help members who are in need of information in the following areas: disability insurance, human rights, Canadian Pension Plan disability benefits, self-advocacy and knowledge about legal resources in their community.

The Volunteer Legal Advocacy Program is taking the Multiple Sclerosis Society of Canada one step closer to fulfilling its mandate of enabling people affected by MS to enhance their quality of life.

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**(W07) CONTINUOUS COMBINED THERAPY IN MULTIPLE SCLEROSIS****Background:**

The annualized relapse rate (ARR) in recently reported open label studies using interferon  $\beta$  (INFB) 1-a (Avonex 30 mcg i.m. weekly) in multiple sclerosis (MS) patients treated over two years was indicated in the range of < 0.5-0.61.

**Objective:**

To compare ARR in MS patients on continuous combined therapy using Avonex, prednisone and azathioprine (AZA) with the recently reported studies.

**Patients and Design:**

ARR and Expanded Disability Status Scale (EDSS) rating in 125 MS patients on Avonex (21 on Avonex monotherapy-median duration of treatment (MDT) 4.0 years; 83 on Avonex and prednisone-average daily dose not exceeding in the average physiologic dose 0.12 mg/kg per day, MDT 5.5 years and 21 individuals on Avonex, prednisone and AZA- 1.5 to 3.0 mg/kg per day, MDT 3.4 years) were determined.

**Results:**

ARR in 16.8% patients on Avonex monotherapy with break-through symptoms (BTS) during the first four months of treatment and at the time of infections was 0.12. In patients on Avonex and prednisone the ARR was 0.08. In individuals on Avonex, prednisone and AZA the ARR was 0.44. There were no significant changes in EDSS rating during the treatment. EDSS d" 2.0 was established in 76.1% of patients on Avonex monotherapy, in 86.7% in the Avonex and prednisone cohort and in 47.6% individuals on Avonex, prednisone and AZA. There was one patient with EDSS e" 6.0 in the individuals on Avonex and prednisone (9.5%) and two individuals with EDSS e" 6.0 in the patients on triple therapy with Avonex, prednisone and AZA.

**Conclusions:**

With BTS in MS patients on INFB monotherapy, continuous combined therapy using physiologic dose of prednisone and if inadequate with added-on AZA should be tried without delay in case of BTS, by adequately trained clinicians, prior to introduction on I.V. treatment with immunosuppressive medications.

*Study Supported By: Biogen Idec, Inc. (Margaret Frazer, M.D. is employed by Pfizer, Inc.; Raquel Washington, R.Ph. is employed by Biogen Idec, Inc.; Oldrich Kolar, M.D., Ph.D. has received grants from Biogen Idec, Inc., Pfizer Inc./ Serono Inc. and Roche. He has received Advisory Board Fees from Biogen Idec, Inc., Pfizer Inc./ Serono Inc. and Genentech.)*

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**(W08) NUTRITION MANAGEMENT FOR THE PATIENT WITH MULTIPLE SCLEROSIS**

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**M**ultiple Sclerosis (MS) is an autoimmune disease associated with inflammation of the central nervous system. MS mainly affects young adults, with peak incidence at age 30. Although the course of MS varies greatly between individuals, secondary complications often arise that can influence overall health and quality of life. Nutrition care is a critical component to the overall management of this disease. The goal of nutrition therapy at the MS Clinic in Winnipeg is directed at minimizing secondary complications associated with MS, preventing potential ailments, and maximizing ones quality of life. Since the cure for MS remains elusive, patients often seek alternative methods that may alleviate symptoms or delay disease progression. Decisions are not always based on sound nutritional information; therefore, it is necessary to discuss the safety and efficacy of alternative / complimentary products with the patient.

The role of the clinical dietitian is an integral component to the multidisciplinary team and to the overall care for the patient with MS. Upon admission to the clinic, each patient completes a pre-screening tool that allows us to identify various patient issues related to MS. A similar tool is completed at each follow-up visit. Nutrition related concerns are addressed by the dietitian and the following management strategies are implemented:

- 1) Education and counseling regarding disease-induced changes. Focus on empowering patients to better manage their disease through positive lifestyle changes.
- 2) Medical nutrition therapy for symptom management and treatment of secondary complications.
- 3) Provide appropriate follow-up to the patient and family members.
- 4) Incorporate evidence-based research and materials to develop clinical practice guidelines. Much attention has been focused on current scientific literature pertaining to the role of vitamin D and appropriate recommendations for patients with MS.

As the disease progresses and recurrent or additional complications occur, it is imperative to reassess the nutrition care plan in order to continue to provide the best possible service and optimize the quality of life for our patients.

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**(W09) ESTABLISHMENT OF A BLADDER / BOWEL CLINIC  
FOR PATIENTS WITH MULTIPLE SCLEROSIS**

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This poster will describe the establishment of a bladder /bowel clinic within an MS Clinic, to address the needs of MS patients experiencing difficulties or requiring in-depth teaching of bladder health. Prescreening and follow-up tools revealed bladder function to be among the priority concerns of MS patients attending this clinic. These findings are consistent with current literature that 75% of MS patients will experience "some type of bladder dysfunction during the course of their disease" (Halper, 2001, p. 179). Additionally, it was noted that the wait for Urology and Continence consultations was lengthy and the services sparse.

The Canadian MS Nursing Care Plan (2000) and Canadian Continence Guidelines (2000) were used as a framework for development. Objectives were identified as facilitating or providing linkages with services, patient teaching, monitoring of specific patient groups, and promotion of bladder health. The existing algorithm "Management of Bladder Dysfunction" (2000, p 2-11) was modified to include strategies to identify the need for consultation to a Urologist and /or Continence Advisor (for more conservative management). Additional resources links within the community were also incorporated. Multidisciplinary involvement is evident in the dietary counseling and assessment of functional aspects of continence and provision of equipment and supplies.

MS Clinic physicians, clinicians, Clinical Nurse Specialist and allied health team members identify patients with bladder /bowel issues for referral. An in-depth history, review of voiding diaries and fluid intake records, ultrasound bladder scans and physical examinations are completed.

Priority issues identified by patients provide a common goal for an education process that includes, but is not limited to, lifestyle changes, voiding modifications, medication changes or initiations, further investigations and possible self catheterization teaching. Follow-up visits to the clinic are provided as necessary and reports are issued to the primary care physicians to maintain communication.

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**(W10) CELLULITIS RELATED TO SELF-INJECTION:  
MS CASE STUDY OF MEMORY LOSS & MISDIAGNOSIS**

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A case study will be presented involving a person with MS who has been on subcutaneous injections for her relapsing remitting MS for 7 years. This person experienced major complications from a self-injection in her left thigh. MS related memory loss was the major contributor to misdiagnosis. The patient initially denied injecting into the area where cellulitis subsequently developed. She insisted that she did not use her legs to inject her medication. Six months previously she had chickenpox therefore the initial diagnosis was shingles. The repercussions of the misdiagnosis were extremely serious.

A time line will be presented emphasizing complications that can arise with patient management related to memory loss.

Photographs of affected areas will be included.

Nursing implications will be reviewed specifically with regards to patients who have been on therapy long term and who do experience a degree of memory difficulties. Long term care of skin health will be emphasized as well as memory aids.

A discussion on the possible causes of cellulitis related to disease modifying therapies will be presented including trauma to the skin tissue as the most plausible explanation.

*Study Supported By: MS Society Ontario Division, Kingston General Hospital, Queen's University*

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**(W11) CHALLENGES AND TRAINING NEEDS OF CAREGIVERS OF PEOPLE AGING WITH MS**

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Approximately 45% of people with MS in the USA are over 55 years of age. The interaction between aging and the presence of a chronic illness can have important health and social implications. Consequently, many people with MS require the assistance and support of family members and friends in order to conduct and manage their everyday activities. During the course of the study "Aging with MS: Unmet Needs in the Great Lakes Region", 302 caregivers of people with MS aged 45-90 were interviewed by telephone. Although the focus of these interviews was on the unmet needs of the people with MS, stories from the caregivers indicated that they were experiencing many challenges in their role, and had numerous training needs related to their caregiving responsibilities. These challenges and training needs were reported regardless of the type of caregiver: spousal, adult child, paid helper or friend. This poster presentation will highlight the major challenges and training needs that they reported. Examples of challenges reported include dealing with the health care system, community accessibility, and their own poor health. Examples of training needs identified included first aid and CPR, medication administration, doing safe transfers, and strategies for supporting the person with MS do be as active as possible. Overall, findings indicate that caregivers receive little to no training to assist them in their role, and that many feel shut out by the health care providers who are providing services to the person with MS. They want and need more information and education to enable them to provide assistance to the person with MS with confidence and security. The findings have many implications for health care professionals providing services to people with MS, and suggest many avenues for caregiver support and education.

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**(W12) DEVELOPMENT AND DISSEMINATION OF COPING SKILL MODULES  
IN MS REHABILITATION**

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The University of Washington MS Rehabilitation Research and Training Center is in the second of two five year funding cycles sponsored by the National Institute of Disability and Rehabilitation Research (NIDRR). A Center priority within the second funding cycle is to develop a sequence of coping skill modules for consumers that can be accessed on the internet or in published format. These modules were to be substantially based upon research from the core University of Washington investigator group with input from outside experts (Foley, Bowling, McKee, Wittenberg, Manley and Holland as necessary).

This presentation describes an MS focus group's input in identifying priority areas for coping skill module development to include: Optimizing Your Medical Management, Mood Management, Finding a Psychotherapist, Understanding Your Cognitive Issues, Getting Things Done: Working with Your Fatigue, Tapping Spiritual Resources, and Getting a Job: Utilizing Community Resources. With input from Center researchers and clinicians, module coverage was expanded to other areas including: Evaluating Alternative Therapies, Disclosure of Disability to Employer and Job Site Accommodations, Dealing with Health Insurance and Financial Concerns, Working Through SSI and SSDI Systems, Partnerships in Caregiving, Optimizing One's Love and Sex Life, and Securing Community Resources.

The challenge in module development was to make these coping skill segments not only "user friendly", but truly useful in planning/organizing and implementing one's personal efforts in medical and psychosocial social adaptation. Editorial staff of a major self-help focused publishing company was invaluable in critiquing modules and advocating for reformatting of material that could be viewed as too "academic" into module segments that could be used as a true work book, in the consumer's efforts towards optimal adaptation with this disability. Examples of modules material most endorsed by the focus group of consumers will be presented with representative checklist, quiz material, planning/work sheets, and other formatting shifts enabling the material to be more engaging and have increased utility in the self-help efforts of those with MS.

Appreciation is extended to the National Institute of Disability and Rehabilitation (grant # H133B03129) for support of this activity and the Editorial Staff of New Harbinger Press for materials critique and advisement.

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**(W13) COGNITIVE DYSFUNCTION IN CIS AND EARLY MULTIPLE SCLEROSIS**

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**R**esearch into clinically isolated syndrome (CIS) has identified pathological markers that characterize the phase before diagnosis of definite multiple sclerosis (MS), and predict progression to MS. However, many useful parameters, such as magnetic resonance imaging, are not always applicable for daily routine. Patients who have made a full clinical recovery from a first demyelinating event may show significant cognitive impairments, even before fulfilling the diagnostic criteria for MS. Disease-modifying medication given to CIS patients has been shown to slow progression to MS and reduce the subsequent relapse rate in the short term. This study plans to investigate the nature of cognitive impairment in CIS and MS further and whether cognitive status at CIS can predict likely progression to MS.

There will be two complementary observational, longitudinal studies, both international and multicenter. CogniCIS will recruit and assess patients with CIS; enrolment of 600 patients is anticipated. If, and when, these patients progress to a diagnosis of MS, and start treatment with interferon beta-1b (IFNB-1b; Betaseron(r)) they will enter the CogniMS study, which will also recruit MS patients at diagnosis who have not participated in CogniCIS. Recruitment of 2000 patients into CogniMS is anticipated. CogniCIS and CogniMS will assess patients at 6 monthly intervals, over 2 years. Clinical data will be collected, and cognition (for all Faces Symbol Test and MS Neuropsychological Questionnaire, Brief Repeatable Battery for a subset), depression, fatigue and health-related quality of life (HRQoL) will be assessed.

The studies are designed to characterize the profile and time dynamics of cognitive impairment in CIS and early MS patients, in the context of current treatment practice. They will examine how associated variables (subjective cognitive status, depression, fatigue and HRQoL) relate to cognition in CIS and early MS. Whether cognitive status in CIS can predict progression to MS will also be investigated.

*Study Supported By: Schering AG, Berlin, Germany. (Drs Scherer and Fredrikson have received honoraria from Schering AG. Dr Langdon has received personal compensation for speaking at scientific meetings and speaker travel expenses from Schering AG.)*

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**(W14) INTERFERON BETA-1B 16-YEAR LONG-TERM FOLLOW-UP: CLINICAL OUTCOMES**

The pivotal interferon beta-1b (IFNB-1b; Betaseron(r)) trial demonstrated the safety, tolerability, and short-term efficacy (2–3 years) of IFNB-1b in relapsing forms of multiple sclerosis (MS). This remains among the longest controlled studies in MS to date, and led to the first approval of a treatment for MS. However, in a disease evolving over several decades, longer-term data on treatment outcomes are needed, as will be provided in this study.

The study aim is to evaluate the impact of IFNB-1b treatment on long-term (16-year) outcomes in patients with relapsing forms of MS, and to generate hypotheses regarding the relationship of clinical and imaging parameters to these outcomes.

This study employs cross-sectional data collection from patients eligible to participate, i.e. those who were enrolled in the pivotal trial. Data are being collected during one study visit and include clinical evaluations of survival, disease status, relapse rate, Expanded Disability Status Scale score, MS Functional Composite score, and adverse events. Other evaluations include MRI measures, neutralizing antibodies, cognitive testing, quality of life, and resource use. In a novel approach, these data will be compared with well-characterized natural history data (derived from the London, Ontario, natural history cohort) and to a control cohort of approximately 60 untreated UK patients. The primary analysis will examine outcomes in patients treated with IFNB-1b. Patients will be stratified by original dose group (250 mcg, 50 mcg, placebo) and by overall length of exposure to IFNB-1b. Secondary analyses include comparison with the two natural-history cohorts. All analyses will be exploratory in nature. Detailed results of this study will be presented but follow-up in the London cohort is 100% at 16 years.

Combining cross-sectional data collection and a comparison with matched controls will expand the available information on the long-term effectiveness of IFNB-1b in patients with relapsing forms of MS.

*Study Supported By: Schering AG, Berlin, Germany and Berlex Pharmaceuticals, Montville, USA. (Drs Wolf, Kaskel and Salazar-Grueso are salaried employees of the Schering Germany Group of companies. Drs Ebers, Rice and Traboulsee have received honoraria from Schering/Berlex. Dr Langdon has received personal compensation for speaking at scientific meetings and speaker travel expenses from Schering/Berlex.)*

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**(W15) FATIGUE MANAGEMENT:  
ACCESS ISSUES FOR RURAL/REMOTE VICTORIA, AUSTRALIA**

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The state of Victoria, Australia is slightly larger than the US state of Utah so providing a comprehensive group program to all people with MS (pwms) in Victoria is a challenge of distance and time.

The MS Society of Victoria has developed a six week Fatigue Management group program that runs out of our two city offices in Melbourne. Rural/remote clients can only access this program by visiting Melbourne, which could involve a drive of up to nine hours.

The MS Society of Victoria (MSSV) employs six rural resource workers based in rural/remote regions of Victoria who provide general information and referral for pwms. Community occupational therapists, social workers and physiotherapists working in general health services, in rural/remote regions of Victoria, have a great deal of expertise and local knowledge of the pwms in their catchment.

To achieve equitable service delivery across the state of Victoria a community partnership plan was formulated, bringing together the skills and knowledge of MSSV rural resource workers, local therapists and the MSSV workers in Melbourne.

A one day train-the-trainer program will be rolled out in 2005 and the presentation will include the "lesson's learnt" from our experience of transforming a client program into a train-the trainer package.

This is an innovative and collaborative model of working, providing MSSV rural resource workers and local therapists with training and the resources to co-facilitate the MSSV Fatigue Management program. It allows rural/remote therapists to increase their knowledge of MS, and MS fatigue, and pwms gain greater access to specialist services as well as developing closer links with their local therapists.

This model of service delivery is exciting and one that can grow to other specialist programs developed by the MS Society of Victoria to overcome the barriers of distance and time.

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**(W16) POSTURAL SUPPORT AND PULMONARY FUNCTION IN MULTIPLE SCLEROSIS**

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**N**euromuscular diseases such as multiple sclerosis (MS) frequently result in progressive weakness of the trunk and neck, postural instability, and over time compromise respiratory status. Studies of respiratory function suggest that individuals who have moderate to severe impairment from MS have significantly lower forced vital capacity, inspiratory and expiratory muscle strength, and poor cough efficacy as measured by the Pulmonary Index.

Individuals with MS who are at an EDSS level of 7.0 or higher require a wheelchair for mobility. Over time, prolonged sitting in a wheelchair combined with spinal muscle imbalance can lead to a forward head position, rounded shoulders, scoliosis, or kyphosis and subsequently contribute to the individual's already weakened respiratory system. To counter changes in an individual's posture in a wheelchair, clinicians usually provide modifications based on best clinical practice and observation of positioning in the wheelchair. The impact of wheelchair modifications on the respiratory function of individuals with MS has yet to be investigated.

This poster presents three case studies about changes in respiratory function resulting from modifications to the individuals' wheelchair positioning. Baseline measurements of each individual's respiratory function including spirometry, pulse oxymetry, and Index of Pulmonary Function (IPF) were taken in their usual posture in their wheelchair. Respiratory function measures were repeated after each individual was repositioned (1) with a lumbar support behind their back, (2) with a wheelchair laptray supporting the arms, and (3) with bilateral shoulder straps in place. Results of the evaluation were reviewed with each individual and permanent wheelchair modifications were provided to optimize each individual's pulmonary function in the wheelchair.

Use of clinical measures of respiratory function will help clinicians determine the most appropriate wheelchair modifications to optimize pulmonary function in individuals who have multiple sclerosis.

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**(W17) RATIONALE AND DESIGN OF THE AVONEX COMBINATION TRIAL (ACT)**

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**OBJECTIVES:** To describe the rationale and design of the Avonex Combination Trial (ACT), a multicenter investigator-run trial of interferon beta-1a (IFN $\beta$ -1a, Avonex) combined with methotrexate (MTX), intravenous methylprednisolone (IVMP), or both for patients with relapsing-remitting multiple sclerosis (RR-MS) and breakthrough disease on IFN $\beta$ -1a monotherapy.

**BACKGROUND:** Breakthrough disease occurs in some patients on all approved RR-MS therapies. The best therapeutic approach for such patients is unknown. Preliminary data support the efficacy and tolerability of MTX and IVMP, both alone and combined with IFN $\beta$ -1a.

**DESIGN/METHODS:** Approximately 900 RR-MS subjects, Expanded Disability Status Scale (EDSS) 0.0-5.0, and breakthrough disease on IFN $\beta$ -1a monotherapy will be enrolled. Subjects continue IFN $\beta$ -1a 30 mcg weekly and are randomized to add-on therapy in equal allocation to four cells of a 2x2 factorial design: 1) oral placebo weekly + no IVMP, 2) oral MTX 20 mg weekly + no IVMP, 3) oral placebo + IVMP 1000 mg/day 3 days every 2 months, or 4) MTX + IVMP. Clinical efficacy measures include relapse rate (MTX primary outcome), MS Functional Composite, and EDSS. MRI efficacy measures include the brain parenchymal fraction (IVMP primary outcome), GdE lesions, T2-hyperintense lesions, and T1-hypointense lesions. For MTX, the study is placebo-controlled and blinded to subjects, treating clinicians, evaluating clinicians, and MRI analysis. IVMP vs. no-IVMP is evaluator-blind for MRI and clinical endpoints.

ACT is conducted as an investigator-run trial. The Cleveland Clinic MS Academic Coordinating Center is responsible for randomization, site management, quantitative MRI analysis, data management, and statistical analysis.

**RESULTS:** Subject enrollment commenced in June 2003, update of study status will be provided.

**CONCLUSIONS:** ACT will determine the safety and efficacy of adding MTX, IVMP, or both to IFN $\beta$ -1a for patients with breakthrough disease on IFN $\beta$ -1a monotherapy. This trial will create an infrastructure and a new model for future academic-industry collaborative studies of MS therapies.

*Study Supported By: BiogenIdec (Two of the members of the Steering Committee (Volker Knappertz, MD and Hao Zhang, PhD) are fulltime Biogen Idec employees. None of the remaining authors or their immediate family members has a substantial personal financial relationship with Biogen Idec, including salary, ownership, equity positions, stock options, royalties, material support and other financial arrangements from Biogen Idec. All of the Steering Committee members have received consulting fees and/or honoraria for speaking from Biogen Idec.)*

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**(W18) RISE: AN INTERDISCIPLINARY EDUCATION PROGRAM  
IN INPATIENT MS REHABILITATION**

**Background and Purpose.** As multiple sclerosis (MS) progresses, rehabilitation becomes necessary to assist individuals in maintaining their independence. Education of the patient and family is important for successful rehabilitation. This education must be adapted to the unique needs of people with MS. Educational strategies must deal not only with the patient's current status but also their anticipated needs.

**Intervention.** The Specialty Rehabilitation team at The Institute for Rehabilitation and Research (TIRR) has developed an interdisciplinary education program, RISE (Resourcing for Independence and Support within your Environment), to meet the unique educational needs of the MS population in rehabilitation. This program consists of daily groups, which are led by team members. Topics addressed include:

- Energy Conservation: identifying ways to conserve energy throughout the day.
- Spasticity: defining spasticity and explaining medical and therapy approaches to treatment.
- Intimacy: affirming the importance of expressing intimacy despite physical barriers.
- Community Resources: providing information related to MS specific organizations and services.
- Support: assisting in coping and adjustment to disability.

Since many MS patients have spinal cord involvement, patients are included in education groups developed for patients with spinal cord injury including skin management, bowel and bladder management, and driving modifications. These groups are incorporated into the schedule of RISE classes.

**Outcomes.** Currently, survey information is being collected from participants in RISE to determine patient satisfaction with the groups and to assist group leaders in assessing the relative value of each group. Future research will gather pre- and post-intervention data on patient's level of MS education and understanding of the topics presented in RISE.

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**(W19) WORKING TOGETHER TO IMPROVE THE QUALITY OF LIFE OF VA MS PATIENTS.**

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**Issue:**

Multiple Sclerosis is a lifelong debilitating disorder whose therapies are limited to treatment of the underlying disease process and management of symptoms, as there are no therapies available yet to stop the disease. Multiple Sclerosis symptoms can present themselves differently from person to person. They can also differ in the same person from time to time. Many newly diagnosed MS patients do not have a clear understanding of the disease. A diagnosis of MS also represents a threat to independence and control, which is especially important in the veteran population, and leaves many patients ill equipped to plan for the future.

**Analysis:**

"People who learn all there is to know about their illness enjoy better outcomes". The VA Pittsburgh Neurology clinic did not have an established support group or informational class for patients diagnosed with Multiple Sclerosis. It was decided one meeting would be inadequate to allow patients to process information and did not enable them an opportunity to ask questions. Social fear and anxiety, isolation, inability to express self to family and friends were also important factors we felt also needed addressed. No extra staffing or funding would be available to initiate or continue the group/classes.

**Action:**

The goals for the program were initiated. They included a non-threatening atmosphere where patient participation would be encouraged and would be able to meet the needs of all veteran MS patients. A Support Program was started in conjunction with Adult Day Care. The daycare had the space and staff available. The program is limited to one day a month to allow for spoke patients to come in for a day but veterans are encouraged to participate in adult day care on a daily basis for socialization, recreation, and exercise. The nurse in the neurology clinic leads an hour group session and plans for other services such as behavioral health with stress reduction, physical therapy with YOGA, and dietary with nutritional information are all expected to be " guest speakers".

**Lessons Learned/ Barriers:**

Patients need to be informed and asked to take an active role in their care to expand their participation. Transportation is still considered an issue.

**Implementation/Feedback:**

This process could easily be implemented at another facility.

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**(W20) INTRODUCING THE MULTIPLE SCLEROSIS CARE NEEDS CHART**

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When it was reported that persons with Multiple Sclerosis (MS) from the Capital region of Alberta, Canada expressed concern that inequality in service existed across health regions in Alberta, a project was initiated to determine if these concerns were justified. As a first step in this project, an extensive review of the MS and chronic disease/ illness literature from 1970-2004, was undertaken so as to identify the care needs of persons with MS. A need was defined as a problem to be solved (Corbin & Strauss, 1988). A list of thirty-one care needs was compiled. These 31 needs were then further categorized into four main groups: biomedical needs, psychosocial needs, functional needs, and care delivery needs.

A convenience sample of four expert Canadian MS nurses was chosen to review the care needs list. Revisions were made based on their recommendations. The list was then reviewed by a convenience sample of ten health care professionals, with greater than 40 years cumulative experience in MS care delivery in the Capital region of Alberta, and one person living with MS. All commented that the list was comprehensive and complete.

The purpose of this poster presentation is to introduce these MS Care Needs. Supporting references for each identified need are provided. Further validation by persons and families living with MS is required. The MS Care Needs Chart is presented for critique and discussion.

Corbin, J. M., & Strauss, A. (1988). *Unending work and care: Managing chronic illness at home*. London: Jossey-Bass

*Study Supported By: Teva Neuroscience*

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**(W21) FROM PATIENT SELECTION TO PUMP IMPLANTATION:  
EVALUATING THE UNIVERSITY OF CALGARY INTRATHECAL BACLOFEN PROGRAM**

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**Background:** The University of Calgary MS Clinic has been involved in intrathecal baclofen therapy (ITB) since 1990. ITB is effective in the treatment of severe spasticity, and certain aspects of quality of life. (Becker et al, 1990; Middel et al, 1997). Although this therapy has positive patient outcomes, it is complex and requires a multidisciplinary team. Complications can be challenging as there are often urgent diagnostic and surgical requirements. Over the past year activity to our ITB program has increased and changes have been made to the referral process, test dosing and post implantation follow up. In this study we evaluated the processes involved in our program from patient selection to pump implantation.

**Methods:** A case presentation will be outlined to demonstrate the process of the ITB program. The evaluation of our program was accomplished by questionnaire feedback provided by members of the multidisciplinary team as well as patients who have received baclofen pump implants in the past year. The questionnaire asked respondents to rate their satisfaction with current program procedures and included several open ended questions that asked them to comment on areas of weaknesses and suggestions for improvements. MS clinic staff assisted patients to complete the questionnaire, as needed.

**Results:** Feedback will be presented from two neurosurgeons, two neurologists, one physiatrist, two nurse practitioners, four inpatient nurse clinicians, and three MS clinic nurses and six patients. Results of questionnaires demonstrated definite improvements to new program structure but respondents did indicate several areas that could be improved.

**Conclusion:** The current changes to our ITB program have made improvements to patient selection, referral and post implant follow-up. Further program changes are necessary and ongoing feedback from the multidisciplinary team can facilitate this process.

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2. Middel B, Upmeijer H, Bouma J, Staal M, Oenema D, Postma T, Terpstra S, and Stewart R. Effects of intrathecal baclofen delivered by an implanted programmable pump on health related quality of life in patients with severe spasticity. J Neurol Neurosurg Psychiatry 1997; 63:204-209.

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**(W22) THE CONCEPT OF PATIENT, FAMILY CENTERED CARE APPLIED IN THE MS CLINIC:  
ENHANCING THE QUALITY OF HEALTH DELIVERY**

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**M**ultiple Sclerosis is a disease that has a far-reaching impact on the patient and their family. A life long disease with unpredictable and fluctuating medical and rehabilitative needs, the impact on the patient's perception of self -efficacy (ability to respond effectively to challenges in their lives) has been well documented.

The concept of Patient, Family centered care (PFCC) is a fundamental shift in the delivery of health care. PFCC recognizes the essential central role of the patient and their family and the need for their active partnership in the delivery of their health care. As well as restoring dignity and control to patients and their families, PFCC has been shown to lead to better health outcomes, wiser allocation of resources and greater patient and family satisfaction.

While the concepts of PFCC have been embraced by the Institute of Medicine in their report, Crossing the Quality Chasm (2001), and endorsed by prominent organizations such as the American Academy of Pediatrics and Joint Commission of Accreditation of Healthcare Organization (JCAHO), the extension to adult medical conditions has been limited. This presentation will describe a novel model for the incorporation of PFCC concepts in the MS clinic. The development and role of the patient and family advisory council and its role in program, facility and resource development will be discussed. Tangible benefits of the application of the PFCC in the August MS Center has resulted in enhancement of clinical services, redesign of the MS facility and improved patient satisfaction evaluations.

Embracing the concept of PFCC has been an effective approach to addressing the issues of loss of self-efficacy in this patient population thus enhancing the quality of lives of those living with MS.

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**(W23) DIFFUSION TENSOR IMAGING USING VOXEL-BASED ANALYSIS FOR PATIENTS WITH CLINICALLY SUSPECTED OR KNOWN MULTIPLE SCLEROSIS AT 3T**

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**Purpose:** To develop MRI DTI FA voxel based analysis and compare the findings of those in normal individuals to those with known MS and clinically isolated syndrome. The goal is to improve detection of MS burden, allow earlier diagnosis, and correlate with clinical symptoms.

**Materials and Methods:** Normal control DTI's were collected at 3T and their fractional anisotropy (FA) findings were co-registered by voxel. These FA templates were utilized for comparison analysis of known or clinically suspected MS patients. Only adult patients with known relapsing remitting MS or clinically isolated syndrome and an EDSS score of 5.5 or less participated in this study and were graded according to the McDonald Criteria.

**Preliminary Results:** More than 80 normal DTI's were collected, and their FA measurements co-registered. This study is ongoing, but more lesions were detected using template subtraction of normal FA DTI images from patient images ( $p < 0.05$ )

**Conclusion:** This rigorous image FA voxel based analysis results in detection of a higher lesion burden than does conventional MRI at 3T.

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**(W24) BLOODWORK MONITORING IN BETA INTERFERON THERAPY  
FOR MULTIPLE SCLEROSIS**

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**Background:**

Little evidence is available to guide clinical monitoring of bloodwork in MS patients being treated with interferon Beta 1a (Avonex and Rebif) and 1b (Betaseron). Post marketing experience with serious hepatic injury occurs predominantly during the first six months of therapy, prompting Health Canada to issue recommendations for monthly monitoring of liver function for six months and every six months thereafter (Health Canada Protection Advisories/ Warnings website, Dec 2003). A small number of studies can be cited related to safety with thyroid, hematologic and liver function.

**Method:**

A retrospective chart review of approximately 400 MS patients on beta Interferon therapy was completed. An audit tool was utilized, which was developed and pilot tested by the researchers.

**Results:**

The data will be analyzed with the following outcome goals:

1. To determine the incidence and frequency of lab abnormalities including liver function, complete blood count with differential and thyroid stimulating hormone, in the short term (< 1 year) and the longer term (> 1 year) of therapy.
2. To assess the utility and adherence to the modified WHO guidelines for grading toxicities, dose modification and discontinuation of therapy.

**Conclusion:**

Research findings and implications for clinical practice will be presented.

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**(W25) ASSISTED COGNITION AND MS**

Changes in cognitive status serve as one of the significant barriers to maintaining employment for people with MS. We have described in detail how cognitive changes, fatigue, and stress combine to present considerable challenges in finding and maintaining employment (e.g., Johnson et al, 2004; Yorkston et al, 2003). Individuals with MS who are working and have cognitive changes report that their employment status may be tenuous and that they are very fearful of change in the circumstances of their employment. They also are very concerned about disclosing their cognitive deficits to coworkers and employers. Many traditional approaches to supporting people with disabilities in employment, such as formal co-worker supports and job coaches, are often not available to people with MS who are typically well educated and often employed in higher level jobs. Other formal accommodations require disclosure to the employer. Rehabilitation specialists providing consultation and/or structuring accommodations in the workplace would be perceived to be an untenable intrusion. We will introduce a variety of strategies to accommodate cognitive changes, grouped under the rubric of assisted cognition. These include use of features built into existing operating systems and software, off the shelf technologies such as cell phones, text pagers, and PDA, and cognitive behavioral strategies that enhance employability and independence. We will also describe emerging technologies which combine sensors worn by the individual, GPS or WAP or GSM location devices, RFID, ubiquitous computing and artificial intelligent agents, and intelligent feedback to the device user to support navigation, independent living, and employment. When properly used, combinations of assisted cognition and cognitive behavioral strategies reduce the demands on individual cognitive resources, allowing the individual to function more effectively. These strategies are self-initiated and unobtrusive and blend easily into the environment of the workplace or community

*Study Supported By: In part by the Department of Education, National Institute on Disability and Rehabilitation Research grant #H133B031129-04*

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**(W26) ASSISTIVE TECHNOLOGY INTERVENTIONS FOR PEOPLE WITH MS**

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People with MS confront a number of barriers to participation in their preferred activities. Assistive technology (AT) may increase independence for many people with MS. We will exemplify issues around AT use for people with MS with three case studies of people with significant physical disability secondary to MS. Two of the three have no use of upper or lower extremities and one of the three has no use of lower extremities and limited use of upper extremities. All three were skilled professional workers prior to retirement due to MS disability and retain requisite computer knowledge to serve as a base for successful AT use. All three are living in residential living facilities and have virtually no discretionary income. They reported that they were extremely isolated with little access to social opportunity, recreation, and productivity that would contribute to self-worth. They requested assistance in gaining access to the internet to communicate by email, read books and other documents on the web, conduct research about their medical conditions, and communicate with others with MS. Functional limitations included changes in vision, lack of use of hands and arms, and for one, changes in voice. Barriers to internet access included lack of computers, limited space in room shared with roommates, and the AT that would allow them to use the computers. Cost was also a significant barrier since there is no funding for AT that enhances quality of life unless there is a clear medical necessity or employment justification. Through an endowment funded by the MS Foundation, we were able to conduct AT evaluations on site and provide AT to these three individuals and conduct follow-up. We will demonstrate the technologies used, provide multiple images of the individuals using their technologies, discuss cost and funding issues, and respond to questions.

*Study Supported By: By the National Rehabilitation Research and Training Center on Multiple Sclerosis, NIDRR grant #H133B031129-04 and an endowment by the MS Foundation*

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**(W27) TECHNIQUES TO MANAGE STRESS IN PATIENTS WITH MULTIPLE SCLEROSIS**

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**F**or many years practitioners believed that stress aggravates the symptoms of Multiple Sclerosis. This year science confirmed these beliefs. In their study published March 19, 2004, Association between stressful life events and exacerbation in multiple sclerosis: a meta-analysis (BMJ, Mar 2004; 328: 731.) David Mohr and his colleagues stated "There is a consistent association between stressful life events and subsequent exacerbations in Multiple Sclerosis".

While managing stress is important to the health and well being of everyone, to someone with Multiple Sclerosis it is critical. Physical responses to stress include increased heart rate, blood pressure, perspiration, and muscle tension. All of these can be alleviated with relaxation techniques. Patients need stress management techniques that are inexpensive, effective and easy to learn. This presentation will highlight three techniques, yoga, progressive relaxation, and guided imagery. We will explain each and discuss ways of educating patients in their use.

Yoga uses breathing and non-impact movement to relax the muscles and focus the mind. Sometimes called moving meditation, this technique is used to increase flexibility, strength and endurance, as well as promoting serenity and a sense of well-being.

Progressive relaxation has been utilized since the early 1900s as a method of anxiety and stress reduction. It combines focused breathing along with a progressive tensing and relaxing of muscles designed to deepen physical relaxation and heighten awareness of areas and levels of tension. When used properly this technique will elicit a relaxation response and create mental and emotional calm for the patient.

Guided imagery is a meditative technique. Although often done with a live "guide", it can be easily done with an audio tape or by the patient alone as a self-guide. It is much like self-hypnosis in that it uses breathing and rhythm to guide the patient to a state of extreme relaxation.

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**(W28) HEALTH RELATED QUALITY OF LIFE AND IFNB-1B TREATMENT IN MS:  
CURRENT EVIDENCE AND LONG-TERM PERSPECTIVES**

Patient reported outcomes (PRO) have become a priority during the last decade. Health-related quality of life (HRQoL) comprises physical, psychological and social components. HRQoL instruments assess how a health problem and its treatment affect a patient's ability to perform activities and roles that they value. Cognitive impairment, experienced by 40-60% of patients with MS, affects HRQoL, disease management and adherence to treatment. The relationship between HRQoL and cognitive impairment is complex and not well understood, particularly in more long term disease.

A long-term follow-up trial of the original cohort of the interferon beta-1b (IFNB-1b) pivotal study, a double-blind, placebo-controlled trial to evaluate the safety, tolerability, and efficacy of IFNB-1b in 372 patients with relapsing forms of MS, is now ongoing. Cognitive and HRQoL evaluation is one of the key objectives of this observational study.

The HRQoL battery included (i) FAMS, a self-report multidimensional MS-specific index comprising the dimensions mobility, symptoms, emotional well-being, general contentment, thinking and fatigue, family/social well-being, and additional concerns; (ii) EQ-5D, a generic multidimensional measure comprising mobility, self-care, usual activity, pain/discomfort, anxiety/depression and a visual analogue scale; (iii) MS-SHCS, an instrument to assess cost and resource use data; (iv) HADS, a generic instrument to evaluate emotional distress. For cognitive testing, a test battery has been selected which is robust in the context of sensory and motor deficits.

This is a novel combination of HRQoL scales. Measuring PRO is painless and inexpensive. Revealing multiple aspects of disease, this battery is yielding a large amount of information that goes beyond the EDSS. Therefore, in the context of clinical and surrogate markers, this study presents a possible methodological solution to evaluate long-term HRQoL and cognition. Furthermore, it will increase our understanding of HRQoL and cognition in more advanced disease and under long-term treatment with IFNB-1b.

*Study Supported By: Study supported by Berlex Inc., Montville, NJ (DL, AT, DC and GE received travel expenses for attending investigator meetings from Berlex. DL received personal compensation for speaking and speaker travel expenses from Berlex and Schering. GE received honoraria from Schering. PK, CW, ESG, and CM are full-time employees of Schering AG, Berlin, Germany, rsp. Berlex Inc., Montville, NJ.)*

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**(W29) NATIONAL MS SOCIETY NATIONWIDE PROGRAMS  
FOR FAMILIES, CHILDREN AND PERSONS WITH MS**

The National Multiple Sclerosis Society is committed to expanding knowledge of MS, enhancing access to MS specialty medical care, and empowering people with MS to live as independently as possible within the limits of their disabilities, and to the maximum of their capabilities, within the least restrictive environment. These goals are achieved, in large part, through national and local programs and activities.

The Client Programs Department has developed a wide range of programs to help people with MS and their families “*navigate the world of MS*”. These programs range in content from employment to children with MS to self-help groups. Nationwide client education programs that will be highlighted at the conference include:

- **MS Journey Club**—a new group-based program for parents with MS and their children (ages 5-12).
- **Keep S’mylein**—a newsletter for children ages 5-12 with a parent with MS.
- **Young Persons with MS: A Network for Families with a Child or Teen with MS**—a support network that provides programs for parents of and children with MS. The Network is a collaborative program of the National MS Society and the MS Society of Canada.
- **Career Crossroads: Employment and MS**—a new program addressing the work-related concerns of individuals who are newly diagnosed and still employed, or for persons who are not newly diagnosed, but are employed and experiencing MS-related work issues for the first time.
- **Fatigue: Take Control**— a group-based course designed by MS experts to teach individuals living with MS fatigue how to manage this common, complex, and disabling symptom.
- **Gateway to Wellness**— a group-based health and education program that enhances the quality of life of individuals with multiple sclerosis through the development of self-management skills.

*Study Supported By: The Fatigue: Take Control and Young Persons with MS Network programs were funded by unrestricted educational grants from Teva Neuroscience. The Career Crossroads project was funded by an unrestricted educational grant from BIOGEN Idec.*

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**(W30) A GUIDE FOR MULTIPLE SCLEROSIS (MS) SUPPORT STAFF**

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**Background:**

Information readily available to non-clinician support staff is currently limited. Frequently, staff without a clinical background in neurology is limited in their knowledge of multiple sclerosis (MS). Guidance through the myriad of available information can assist support staff in their communication with patients, caregivers and healthcare professionals.

**Objective:**

To provide knowledge and resources to support staff who are servicing patients with MS.

**Materials and Methods:**

Structured questionnaires addressing this project will be sent to CMSC members, state chapters of the NMSS and regional MSAA offices, patients and healthcare professionals. Potential participants will be contacted by telephone, written survey or if possible via internet based correspondence. Additional information may be gathered from previous completed research.

**Discussion:**

This project is expected to reflect a cooperative effort to provide updated information regarding clinical presentation of MS, significance of timely therapeutic intervention, management of potential side effects of the initiated treatment and the necessary support to maintain compliance with the going therapy. It is important for support staff to understand the disease and potential impact to optimize management of MS in the healthcare setting.

**Conclusion:**

It is hopeful that this information will assist support staff in their interactions with patients, caregivers and other healthcare professionals. Potentially the knowledge gained will provide a medium for enhanced understanding of the disease by non-clinicians. Helping support staff navigate through the highway of information will enable them to assist patients more efficiently which may hopefully translate into increased medication compliance.

*Study Supported By: Currently unsponsored.*

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**(W31) REHABILITATION EFFECTIVENESS ON QUALITY OF LIFE OF MS PATIENTS**

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The health-related quality of life of patients with multiple sclerosis (MS) is an important care outcome and it is well accepted that rehabilitative treatment can be effective in reducing disability and optimizing quality of life (QoL) of people with multiple sclerosis (MS). The aim of this study is to evaluate the effects of a comprehensive outpatient rehabilitative treatment on QoL in MS patients, measured with generic multi-item SF-36 scales before and after treatment, related to the disability status measured with Kurtzke's EDSS scale. We selected fifty patients with EDSS between 1 and 7.5 consecutively admitted to the Italian MS Society Rehabilitation centre of Genoa that accepted to participate in the study and participate in all rehabilitation programme and follow up. On admission the patients must be assessed with the EDSS, SF-36 (primary outcome) and with the followed scales (secondary outcome): FIM, Rivermead Mobility Index (RMI), Hamilton Rating Scale for depression, Modified Fatigue Impact Scale (MFIS), Ambulation Index (AI). All the patients must be submitted to a comprehensive rehabilitation programme goal-oriented for two months: physiotherapy 16 sessions, occupational therapy 8 sessions, speech therapy 10 sessions, psychological support 4 sessions, rehabilitation of urinary dysfunction 10 sessions. On discharge the patients must be submitted to SF-36 and the scales of secondary outcomes. We classified 3 groups of disability status: first group EDSS 1.0-3.5; second group EDSS 4.0-5.5; third group EDSS 6.0-7.5. The data must be analysed with the T student test before and after treatment for each outcome scales used into the 3 groups of disability status. The correlation of SF-36 and the other scales must be calculate with the Bravais-Pearson coefficients. The work is still in course. Results will be presented.

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**(W33) THE EFFECTS OF STATIC AND DYNAMIC STANDING IN MULTIPLE SCLEROSIS**

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**M**ultiple Sclerosis (MS) affects approximately 400,000 persons in the US. Symptoms can include muscle weakness, fatigue, impaired balance, elimination dysfunction, depression and decreased quality of life. Clinical observation have shown that deconditioning occurs as activity declines, leading to disuse weakness, limited standing endurance, and labored ambulation. Exercise in MS is beneficial in terms of increased aerobic capacity, muscle strength, fatigue, and quality of life. Standing devices have had limited study in MS. Short-term results for MS patients trained to use passive standing devices have shown a high compliance rate and a trend towards increased coping skills indicating the need for longer-term follow-up. Short-term studies using passive standing for spinal cord injured (SCI) patients have shown reductions in overall muscle spasticity, but are limited to immediate response. The use of assisted standing devices (ASDs) in SCI patients has positive psychological affects on paralyzed males, improvements in elimination dysfunction and quality of life, and reduction in pressure sores and leg spasticity. ASDs have the potential to provide benefits for the gait impaired MS patients including improved range of motion, reflex activity, decreased muscle spasm, improved bowel and bladder function, and overall well-being. This 2 phase 32 week pilot trial compares assisted static vs. assisted dynamic standing technology vs. no standing treatment on functional ambulation, spasticity, posture, balance, standing endurance, functional strength, bowel and bladder function, self-efficacy, depression, fatigue and quality of life in persons with MS. A screened convenience sample of 22 volunteers yielded 18 who entered the trial. Participants were randomized and stratified by gender into one of three groups. The active treatment Phase 1 data are presented in this poster. Phase 2 evaluations will take place at 8 and 16 weeks following the standing phase to assess any carry-over benefit.

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**(W34) THE EFFICACY OF AN ACADEMIC DETAILING EDUCATIONAL INTERVENTION FOR RESIDENTS WHO TREAT MS PATIENTS IN THE VETERANS HEALTH ADMINISTRATION**

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**A**cademic detailing (AD) is an educational method designed to influence the way health care providers deliver care. Content delivery is based on a model of drug detailing by pharmaceutical companies; however AD utilizes a set of unbiased learning objectives using evidence-based medicine. There is little doubt that the delivery format of AD is preferred over other types of education such as didactics or printed materials. However, despite prescribing habit change in several studies, there was little indication that the cause for change was attributed only to academic detailing and not to additional factors. While change in prescribing habits can be viewed as a successful end result of AD, examination of an intermediate step is necessary, (i.e., assessing the knowledge, attitudes, and preconceptions about both disease and treatment) prior to establishing a history of prescribing habit for a specific disease.

This study evaluates the efficacy of AD on Resident knowledge and self-efficacy regarding the use and indications of disease modifying therapies (DMT) used to treat multiple sclerosis (MS) in the Veterans Health Administration (VHA). Residents treating veterans with MS were randomized to experimental (AD) and control groups by location. The AD intervention was delivered via video teleconference to VHA MS Clinics in the Eastern U.S. and included 1) a presentation from an MS specialist covering DMTs 2) a fact sheet, 3) interactive discussion and role play facilitated by the academic detailer and the MS Clinic Coordinator for each participating VISN, and 4) a question and answer period.

We will analyze pre- and post-intervention results and analyses regarding resident prescribing practices for MS patients, self-efficacy beliefs regarding DMT prescribing, and general MS knowledge. Although it is too early in the project to report statistical significance at the time this abstract was submitted, analyses are promising. Of the data received thus far, there is improvement in the resident confidence in prescribing DMT therapies and in knowledge of side effects associated with DMT attributed to the AD intervention.

*Study Supported By: MS Center of Excellence-East*

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**(W35) AN OPEN-LABEL TRIAL OF COMBINATION THERAPY  
WITH IM IFN  $\beta$ -1A AND ORAL DOXYCYCLINE IN MS**

The use of treatment regimens involving therapeutic agents that possess distinctly different pharmacologic activities represents a major advance in the management of multiple sclerosis (MS). Doxycycline, a potent matrix metalloproteinase (MMP) inhibitor, can potentially suppress destruction of the extracellular matrix, which is a crucial step in transendothelial migration of activated leukocytes. Intramuscular interferon  $\beta$ -1a (IM IFN $\beta$ -1a) is effective in reducing relapse rates and decreasing disability progression, however MS patients are likely to progress and concomitant therapies may be necessary. The purpose of this open-label, single-center study was to determine the safety, tolerability, and mechanism of action of oral doxycycline 100 mg combined with weekly IM IFN $\beta$ -1a 30 mcg in multiple sclerosis (MS) patients who continue to relapse while on therapy. Patients aged 18 to 55 years with a diagnosis of relapsing MS were eligible to participate. Patients had to have been treated with IM IFN $\beta$ -1a for a minimum of 6 months, have an expanded disability status scale score of 1.5 to 4.5, one or more gadolinium-enhancing (Gd+) lesions on MRI, and to have had a relapse within 60 days of their baseline visit (month -3). Exclusion criteria included a history of combination therapy with immune modulators or other immunosuppressants (with the exception of corticosteroids) or the presence of neutralizing antibodies. Patients underwent MRIs at months -3, -2, -1, 0, +1, +2, +3. Patients began drug therapy with doxycycline at month 0. In addition to safety and tolerability, objectives of the study included determining the effects of combination therapy on the number of new Gd+ lesions and relapse rate. In addition, pre- and post-treatment measurement of serum cytokines and MMPs, using ELISA, were conducted. To date, 16 patients were screened, 1 has completed the study and 5 failed the screening. Demographics and preliminary MRI and safety data will be presented.

*Study Supported By: Biogen-Idec (This study is supported by a grant from Biogen-Idec. Apart from this grant, the PI and other co-authors do not have any financial affiliation with Biogen-Idec and nothing to disclose.)*

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**(W36) CORRELATIONS OF LAB VALUES AND ASSESSMENTS  
IN MS PATIENTS RECEIVING MITOXANTRONE**

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**Background:** Mitoxantrone (MX), an antineoplastic agent approved by the FDA for use in multiple sclerosis (MS) patients in 2000, has been found to be beneficial in aggressive relapsing-remitting and secondary progressive MS. MX has proven immunomodulatory effects on T and B cells. Although MX is generally well tolerated in clinical trials, the long-term risk of potential drug related adverse effects for MS patients is unknown. MX is not indicated for all patients with MS, and the profile of patients who are most likely to respond to therapy is still being determined. Previous predictors have studied specific data of MRIs and clinical exacerbations.

**Problem/Significance to Nursing:** Several studies have shown MX efficacy in decreasing new gadolinium (Gd) DTPA-enhancing lesions, creating a positive change in neurological status, increasing the time to first relapse, reduction in Expanded Disability Status Scale (EDSS) score, change in ambulation index, and decreasing the number of treated relapses with MS patients. It is of prime importance to determine which patients are the best candidates for MX therapy in clinical practice.

**Purpose:** In this retrospective chart review, data are obtained to examine what correlations between laboratory data related to Complete blood counts with differentials, demographics, type and severity of MS, dosages, MRI changes and clinical data of patients treated with MX. It was the intent of this study to determine if a profile of variables that a patient with MS exhibits, can predict the effectiveness of MX therapy and possible the risk of side effects.

**Methods:** Approximately 60 medical records have been selected from patients who have received MX for 9 months or longer. Data are entered into a database for analysis of trends and correlations.

**Results:** This retrospective chart analysis is an ongoing study to examine correlations between numerous variables and MX effectiveness in patients with MS.

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**(W37) SPECIALTY CASE MANAGEMENT: ADVOCACY FOR NAVIGATING  
THE WORLD OF MULTIPLE SCLEROSIS**

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According to statistics provided by the Vermont Division of the National Multiple Sclerosis Society, the prevalence of multiple sclerosis in Vermont is extremely high at ~ 200-250/100,000, leaving 1600 Vermonters and their families to navigate the world of multiple sclerosis. Blue Cross and Blue Shield of Vermont (BCBSVT) is the state's only Vermont-based health insurance carrier and is by far the largest insurer in the state, offering high quality health coverage to all Vermonters, regardless of age, occupation or the condition of their health. Dedicated to the Vermont community, BCBSVT has designed a member-centered care management program designed to assist in improving and/or optimizing our members' health care and quality of life.

The Specialty Case Management Program is a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's health needs through communication and available resources to promote quality cost-effective outcomes (CMSA). The BCBSVT program utilizes a registered nurse, certified in both case management and multiple sclerosis nursing, who provides comprehensive, supportive individualized multiple sclerosis education, coordination, psychosocial support, and assistance with problem-solving through personalized care planning. We work together with the member, the member's family (with member consent), and the member's physician(s) to achieve optimal disease and symptom management. The Specialty Nurse Case Manager works as the member's advocate across the healthcare continuum, assisting the member in understanding and managing their health benefits and empowering them to navigate the complexities of our current health care system. The BCBSVT case management program has been recognized by the Blue Cross and Blue Shield Association, FEHBP, and URAC as a valued resource to both patients and providers of care, and is readily adaptable by other health plans to improve health status and quality of life for their members.

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**(W38) PROOF: EFFICACY AND TOLERABILITY OF AVONEX®  
COMPARED WITH REBIF® IN RELAPSING MS**

The three interferon beta (IFN $\beta$ ) products available for relapsing MS (RMS) patients have similar effects on disease activity. However, sustained benefits from these therapies also rely on adherence to therapy, which is affected by many factors, including clinical efficacy, tolerability, and convenience. PROOF is a phase IV, retrospective and prospective, open-label observational study that was conducted to evaluate the efficacy and tolerability of IFN $\beta$ -1a (Avonex) 30 mcg IM once weekly compared with IFN $\beta$ -1a (Rebif) 44 mcg SC three times weekly in RMS patients. Outcomes included clinical outcomes (relapse rate, EDSS), brain atrophy (BPF) and other MRI measures, safety (adverse events), and tolerability (injection-site reactions). Prior to enrollment, subjects must have been receiving either IM or SC IFN $\beta$ -1a for 12 to 24 months without switch or an interruption of greater than four weeks and must have had an EDSS of 0.0-5.5. Endpoints were evaluated for the retrospective treatment period and at 6 and 12 months post-enrollment. A total of 136 patients (n=69, IM; n=67, SC) were enrolled in the study. The two groups were well matched for demographic and baseline disease characteristics. Baseline mean duration of therapy was 19.6 $\pm$ 3.7 and 17.4 $\pm$ 3.7 months for IM IFN $\beta$ -1a and SC IFN $\beta$ -1a, respectively. Prior to initiation of IFN $\beta$ -1a treatment, baseline EDSS was 1.8 $\pm$ 1.1 for IM IFN $\beta$ -1a and 2.2 $\pm$ 1.3 for SC IFN $\beta$ -1a. Month 6 outcome measures, reflecting 18-30 months on active therapy, will be reported for relapse rate, EDSS, T2 lesions, Gd+ lesions, T1 lesions, and BPF. Adverse events, injection site reactions, and reasons for study discontinuation will be reported as tolerability endpoints. Based on this retrospective/prospective trial including a mixed cohort of IM and SC IFN $\beta$ -1a, efficacy endpoints appeared comparable between the two treatment groups after 18-30 months of therapy.

*Study Supported By: An educational grant from Biogen Idec.*

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**(W39) TAKING "HEALTHY STEPS"**

The Baptist Hospital East (BHE) MS Center has been operational since 1996. Approximately 400 clients receive interdisciplinary monitoring, treatment, and education for their MS. As healthcare professionals, we all know the benefits of promoting a healthy lifestyle. This is no different for an individual with MS. Fortunately, BHE's services include the BHE/Milestone Wellness Center.

The BHE MS treatment team recognized the opportunity to expand the service we offer our MS clients by partnering with the Wellness Center to offer a day of education, relaxation, fun, and support. We titled the program: Healthy Steps, which is a one day, six hour program. The program is offered as a complement to the care provided by the client's physician. Healthy Steps takes place at the Wellness Center. The class size is limited to 6-8 participants, which facilitates an informal atmosphere promoting discussion, questions, and sharing. The monthly program began in May 2004. We offered seven programs in 2004, with a total of 30 participants. The agenda has been modified over the months based on the participants' feedback.

The current day of topics includes:

- "Importance of Overall Wellness" BHE MS Center Medical Director
- "Get Up and Get Moving" Wellness Center Exercise Physiologist
- "Nutrition and MS" BHE Dietician
- "Remind Your Bladder That You Are In Charge" MS Nurse Educator
- "Let's Relax, Stress Management" BHE MSSW
- "Yoga Demonstration and Discussion" Wellness Center Yoga Instructor

The Wellness Center Café provides a healthy lunch and snacks. At the end of the day, participants are offered a chair massage given by the Wellness Spa staff.

Next steps include:

- Implement the use of the SF36 as a long-term follow-up component
- Begin monthly yoga classes for MS clients
- Provide information and resources from the local MS chapter
- Monthly classes are scheduled for 2005

*Study Supported By: Berlex Laboratories*

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**(W40) DELTA32/32 GENOTYPE IN RUSSIAN MULTIPLE SCLEROSIS PATIENTS  
(SIBERIAN REGION)**

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**M**ultiple sclerosis (MS) is a chronic inflammatory disease of central nervous system mediated by T helper type-1 cells. Chemokines and their receptors participate in the development of MS by guiding immune cells into the brain tissue. A CCR5 delta32 deletion mutation decreases functional CCR5 on the cell surface and may reduce leukocyte entry into the lesion sites.

To analyze the significance of this mutation in MS, we compared the frequencies of CCR5 genotype in peripheral blood mononuclear cells from 60 MS patients and 124 healthy controls. There was no MS patient with the Delta32/32 genotype, whereas it was present in 5.6% of the controls (0/60 vs. 7/124). In all MS patients, the Delta32/wild genotype was found with 21.6% frequency, whereas in controls it was present in 13.7% (13/60 vs. 17/124),  $p = 0.08$ . There was no significant difference in the allele frequency of CCR5 Delta32 mutation and between different subtypes of MS. None of the primary progressive MS patients had the Delta32/wild genotype. We also examined the levels of CD3, CD4, CD8, CD16, CD22, and CD95 cells in MS patients. The level of CD95-positive cells in MS patients with CCR5 Delta32 mutation was 24.6%, whereas in patients with wild genotype, the level of CD95-positive cells was 17.9% ( $p < 0.05$ ).

These results suggest that the CCR5 Delta32 polymorphism is not a major determinant of susceptibility to develop MS in the Russian population (Siberian region), but may participate in the pathogenesis of disease.

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**(W41) EFFECTIVE MANAGEMENT OF MULTIPLE SCLEROSIS  
THROUGH IMPROVED PATIENT ASSESSMENT**

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The multidisciplinary approach for optimum management of multiple sclerosis includes, disease modifying drug therapies, patient education, strategies to minimize adverse events, involvement of support groups and an open communication between the patient and their physician and /or healthcare professional.

Recently, a meeting of MS nurse specialists convened to discuss management issues that can enhance compliance to disease modifying therapies and improve patient satisfaction and quality of life. In our experience, one useful tool is the MS patient intake and follow-up questionnaire which are given to patients before or upon their visit to the physician's or healthcare professional's office. These close-ended questionnaires combines multiple choice and short answer fill-in questions, related to the purpose of the visit, current medication, adherence, disease symptoms (movement, bladder, bowel, speech), treatment of side effects (headache, flu-like symptoms, fever, injection-site disorders), psychological parameters (memory, mood disorders, depression) and socioeconomic questions (financial and family and business relationships). Examples of typical intake and follow-up questionnaires will be presented. The information is entered into a database to follow patient disease status, response to therapy and adherence for the individual center. The data can also be used to recruit patients for clinical trials. In addition, these questionnaires are critical to improve communication between the patient and their physician and/or healthcare professional leading to patient satisfaction, effective disease management, improved adherence to therapy and expediting office and clinical visits.

*Study Supported By: Serono Inc. (Receipt of honoraria/members of speakers bureau: Serono, Pfizer, Teva, Berlex, and Biogen Idec. Receipt of consulting fees and speaker honoraria: Serono and Teva.)*

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**(W42) INNOVATIVE BLADDER AND BOWEL MANAGEMENT  
FOR PEOPLE WITH ADVANCED MS**

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**B**ladder and bowel management is always a challenging area for health care providers dealing with individuals with Multiple Sclerosis (MS), the greater the disability the greater the challenge. This individual case study presents creative options for bladder and bowel management in a person with chronic progressive MS.

A 57 year old woman with secondary progressive MS has undergone the Mitrofanoff procedure for bladder management. This procedure involves creating a bladder pouch using the cecum and ileum to form a conduit between her bladder and her umbilicus. This allows her to self catheterize through her umbilicus without having to transfer from her chair. The problem of urinary incontinence is solved.

Chronic constipation and bowel incontinence was another issue for this woman. Following many bowel management interventions, she underwent the insertion of a permanent percutaneous tube to create a cecostomy. This enables her to give herself regular enemas through the catheter to allow her to have more predictable bowel movements.

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**(W43) ALLIED HEALTH PROFESSIONAL GUIDE TO MS: AN EDUCATIONAL PROGRAM**

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**Rationale:**

The staff of the Multiple Sclerosis Center of the Lehigh Valley (MSCLV) identified a gap in the knowledge base of allied health professionals (AHP) working with people with MS in the Lehigh Valley. We defined 3 target groups for a focused educational intervention, with plans to extend this to other health care workers involved in MS care in our region. With the help of the health studies department at LVHNN, we developed an educational program targeted for AHP as well as measurement tools for acquisition of information and change in activity as a result of this educational event.

**Program:**

The program consisted of a 3-hour dinner seminar with modules as follows: A. Introduction to MS and medical therapy, B. Rehabilitation strategies in MS, C. Adjusting to the diagnosis of MS, D. Psychological challenges in MS, and E. Nursing Challenges. These presentations were case based and focused on the target audience in terms of caregiver and health professional information.

**Assessment tools:**

We developed a demographic questionnaire, a pre-and post-intervention information questionnaire, and a follow-up change in practice questionnaire.

**Initial target groups:**

Long term care staff (GSRH); Neurosciences unit staff; Neurosciences ICU staff.  
Results from the initial three educational programs will be presented.

**Conclusions:**

Education of allied health professionals in the care of people with MS is an important component of educational programs provided by MS centers. We present one model of such an educational program

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**(W44) THINGS ARE NOT ALWAYS WHAT THEY SEEM**

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Children living in families where one parent has MS, have a different experience of growing up. Open communication is important, children need to feel they can ask questions and voice concerns at any time. This can give them a sense of stability and consistency, despite the ups and downs of the disease. (1.) The cost of a chronic illness may lead to reductions in financial resources which may deprive the children of material possessions and the opportunity for recreational experiences. (2.)

In response, the MS Society of Victoria, Australia has developed Kids Day. Kids Day is an education program for children between 6 and 12 years of age. The aim is to provide an opportunity for children to meet other children with a parent who has MS, have fun, learn more about MS, have their questions answered and experience the support of the MS Society of Victoria. Days are run with a collaborative approach from Occupational Therapy, Social work, immunotherapy educators, students and volunteers including a magician and a story teller.

The poster will demonstrate the need for programs aimed at supporting the healthy development of children living in families with MS as reported in current literature.

The poster will highlight the 2004 Kids Day program with the theme "Things are not always what they seem" focusing on the invisible symptoms and changes experienced. The program details will form part of the poster display.

Children and family responses to the program indicate the positive response to the program.

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**(W45) GINSENG FOR MULTIPLE SCLEROSIS RELATED FATIGUE:  
RATIONALE AND STUDY DESIGN**

**F**atigue is a major cause of disability in multiple sclerosis (MS) and is associated with a decreased quality of life. Fatigue is reported in 75-95% of people with MS, with 50-60% reporting fatigue as their worst problem. Treatment options for MS fatigue include central nervous system stimulants and amantadine. These medications are of limited efficacy, are often poorly tolerated, and can be expensive. Ginseng may represent a novel approach to treating MS related fatigue.

Ginseng has been tested in clinical trials for its ability to improve mental alertness and fatigue. However, there have been no published clinical trials addressing the effect of ginseng in patients with MS, even though many people with MS use ginseng and report deriving benefit from it. A recent survey study of >1000 people with MS in Oregon reported ginseng use in 15%, with >75% reporting benefit from the medication.

Ginseng is an herbal product that has been used in Chinese medicine for centuries. The major chemical constituents are steroidal saponins, or "ginsenosides". Ginsenosides are reported to have a wide range of biological effects including antioxidant activity and stimulation of hypothalamic-pituitary-adrenal (HPA) system. It is hypothesized that ginseng may benefit fatigue through action on the HPA system.

We are initiating a study to determine the safety and tolerability of ginseng in people with MS, and will gather preliminary data on the efficacy of ginseng vs. placebo for the treatment of MS fatigue. This is a double blind, placebo controlled, cross over study involving 46 subjects with MS fatigue. American ginseng extract HT-1001 in 200 mg capsules and an identical placebo will be used in a dose escalation protocol. The primary outcome measure will be improvement in fatigue as measured by the Fatigue Severity Scale (FSS). Study design and HPLC/MS characterization of HT-1001 will be presented.

*Study Supported By: CV Technologies Inc.*

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**(W46) IMPACT OF URINARY TRACT INFECTIONS ON RELAPSE  
IN SUBJECTS WITH MULTIPLE SCLEROSIS**

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Bladder infections have long been considered a trigger of relapses in multiple sclerosis (MS). There are few research studies that have explored this relationship. Bladder dysfunction occurs in 50-90% of the MS population. This study will explore the occurrence of urinary tract infections in the patients at our clinic and the occurrence of relapse. The goal of this study is to determine if the presence of a UTI increases the risk of relapse or if it is just coincidental. Patients with relapsing forms of MS will be asked to participate, until we enroll 50 subjects with urinary tract infections and 50 without. Subjects will be asked to complete questionnaires regarding MS symptoms, bladder symptoms (Bladder Control Scale), infections in the past 4 weeks, and current medications. Urine will be tested by dip-stick and sent for urinalysis and culture and post void residual. Bladder volumes will be measured by ultrasound. Neurological exams, 25-foot timed walk and relapse assessment will be done as part of their normal visit. To assess the relationship between urinary tract infections and relapses both the 2 week period before the visit and the two weeks post visit will be viewed as the "at-risk period". Subjects will be contacted by phone 2 weeks post visit to determine if a relapse has occurred since their visit. The data will be analyzed to determine the relative risk of relapse in patients with and without a UTI. In addition we will be evaluating the accuracy of the dip-stick in diagnosing infection. The 25-foot timed walk will be analyzed to determine if the risk of UTI can be predicted by walking times.

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**(W47) SPOUSE? CAREGIVER? DOCTOR?**

In "Spouse? Caregiver? Doctor?", Dr. Sims tells of his journey with his wife through the maze of MS. He deals with the advantages and disadvantages of being a Doctor while he is being spouse and caregiver to his wife. He describes in a provocative way how he has been able through psychotherapy, support groups, education, and humor to overcome depression, denial, and guilt and be the support his wife needs to remain an active and vibrant person in the MS community. As his story unfolds, surprisingly, he finds there are many ways in which his wife enables him to be as emotionally healthy as possible. It is an entertaining, beautiful story of a couple who finds peace and serenity while living in the quagmire of MS, and how one man finds that he most definitely is the spouse, caregiver at times, and never the doctor! Many of the examples have been of help to caregivers and spouses who have heard this presentation.

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**(W48) ABILITIES ASSESSMENT**

There is a growing awareness of the vital role which rehabilitation medicine plays in the treatment of the individual with multiple sclerosis. The Gimbel Multiple Sclerosis Center in conjunction with the Center for Health and Rehabilitation at Holy Name Hospital is piloting a new program where individuals newly admitted by the MS Center are referred to the rehabilitation department for a comprehensive occupational and physical therapy evaluation. This evaluation is being called an "Abilities Assessment" and it will incorporate standardized functional outcome measures. The goal of the assessment will be to establish a functional baseline for each patient which can be reviewed by the physician and nursing staff and then used for discussion in developing a comprehensive plan of care. These findings will be incorporated into the patient's permanent medical record and there will be availability to use the findings of various outcome measures for future studies. We believe that by documenting the initial functional status the patient will benefit from improved services through early intervention. The Abilities Assessment allows the individual to take control of their care, foster an early rapport with the rehabilitation team, and enables them to learn the importance of a proactive treatment approach. Additional findings will be presented regarding patient's response to this early assessment.

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**(W49) DISEASE MODIFYING THERAPY INJECTION SUPPORT TRAINING GROUP**

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Over the last 10 years disease modifying therapies (DMT) have been significant in slowing disease progression and disability, and decreasing MRI lesion load in MS patients. However, the demanding injection regimens of patients injecting either every other day or three times per week or once a week and every day can be great. DMT (interferon-beta and glatiramer acetate) are associated with a number of adverse events including headache, flu-like symptoms and injection site disorders. Fear of injections, pain, and side effects associated with injections all have a negative impact on adherence to therapy.

In order to positively effect the experience of patients on prescribed disease modifying drugs, one MS center has developed a unique program to address factors that impact effective utilization of these drugs. The Ruan MS Center has developed an injection training group, which empowers its participants by reinforcing injection training and provides encouragement and support for patients.

The group meets weekly and is open to MS patients in the community who are currently prescribed DMT. Members are asked to bring in their injection kits and injection training is provided by the MSCN coordinator for the center. There is also an opportunity within the group to discuss specific problems that individuals may have with the injections, as well as strategies to decrease adverse side effects and improve compliance.

The group currently consists of 6 patients (14 people total, including support personnel). Topics include new injection and review training for patients with bad injection techniques, switching therapy and protocol training for patients enrolled in clinical studies. Adherence to therapy has been monitored for 2004 and the results will be discussed. Our goal is that education and support of patients will have a positive impact on improving the patients experience resulting in improvement in drug compliance and coping with symptoms of MS.

*Study Supported By: Serono, Inc. (Sponsorship from Serono, Inc.)*

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**(W50) MINDFULNESS BASED STRESS REDUCTION:  
ADAPTED FOR TWO DISTINCT MS POPULATIONS**

Since MS affects the life cycle of the entire family, starting from the time of diagnosis, compounding and challenging the normal transitions and stresses of everyday living, learning to manage stress is especially important for people living with MS. A "meta-analysis" of previously published studies on the topic of stress and MS which appeared in the British Medical Journal (published online March 19, 2004) suggested that acute attacks of multiple sclerosis may be associated with stressful life events. Mindfulness Based Stress Reduction (MBSR), based on work and training by Jon Kabat-Zinn and Saki Santorelli, primarily uses meditation, selected poetry and gentle movement for managing stress, uncertainty, and life changes.

Factoring in fatigue, cognitive symptoms, mobility diversity, activity level and the unpredictability of MS, two models for implementing MBSR for people with MS were developed and piloted. The first course was for participants with progressive MS and significant to severe impairment. The second course was designed for participants with less impairment and mostly still employed. It was also open to family members at participants' request.

The presentation includes comparisons of the two courses noting adaptations that vary from Kabat-Zinn's model. Course themes of focusing on the present moment, meditation, sitting with uncertainty, non-judgment and loving kindness are related to adapting to life with MS. Comparison outcome data of the two groups includes self reports on the application of mindfulness as an ongoing practice for managing stress and the unpredictability of MS as well as family observations of participants' response to MBSR. A MBSR for MS CD was developed to accompany the courses. This presentation will also include plans for providing community based MBSR practitioners with adaptations for people with MS.

*Study Supported By: Teva Neuroscience (cost of creating CD)*

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**(W51) FACTORS THAT INFLUENCE ADHERENCE TO  
DISEASE-MODIFYING THERAPY IN MULTIPLE SCLEROSIS**

The ability to optimize the effects of disease-modifying therapy is contingent upon the high fidelity use of these agents. This study aims to identify which factors are most crucial in either promoting or compromising strict adherence to recommended disease modifying agent administration schedules in relapsing types of multiple sclerosis.

Flyers were sent to academic and community sites to be distributed by the healthcare team to eligible patients. Participants are required to complete a retrospective web-based survey at baseline, 1 month and 2 months. Included in the internet survey is the validated Multiple Sclerosis Quality of Life- 54, the Hope Herth Index, the Beck Depression Inventory Fast Screen, questions related to support structure, drug factors and a quantitative analysis of drug compliance. Enrollment will continue until a total of 1,040 patients have completed the initial survey. Equal numbers of patients on Rebif, Avonex, Betaseron and Copaxone are being recruited by the sites. The sample size was determined with power analysis (80% power and 95% confidence level), assuming a 15% critical effect value. Response rates are estimated to be 60% for the first wave and 75% for the second wave.

Compliance rates of patients taking different DMA's will be compared within a wave and over time. To identify critical factors driving compliance, regression modeling will be conducted, in which compliance will be the dependent variable, and perception of quality of life, level of depression, level of hope, patient support system, education on disease therapy, drug related side effects and other information collected in the survey will be entered as predictors. Additional analysis will be performed to compare compliance rates between academic and community sites to assess the impact of health care provider factors. The information will be used to educate physicians and refine the process of injection therapy interventions for multiple sclerosis.

*Study Supported By: BiogenIdec (Some of the authors have received honoraria for speaking and consulting fees)*

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**(W52) EFFECTS OF INPATIENT AQUATIC THERAPY ON FATIGUE IN INDIVIDUALS WITH MULTIPLE SCLEROSIS**

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**Background and Purpose:** Aquatic therapy provides many benefits to individuals with MS, including improved range of motion, strength, balance, endurance, pain relief, and tone management. However, heat sensitivities and the potentially detrimental effects of warmer water temperatures on fatigue and overall function prevent many from participating in aquatic programs. Specifically, it has been thought that individuals with MS would not benefit from aquatic therapy conducted in water temperatures greater than 85°F. The difficulty in lowering water temperature for one diagnostic population limits use of this therapeutic approach in many settings. The purpose of this study is to investigate the impact of an aquatic program in warmer water temperatures (approximately 90-94°F) on fatigue in individuals with MS.

**Intervention:** Upon admission to The Institute for Rehabilitation and Research (TIRR), appropriate MS patients will be enrolled in the aquatic program, in addition to various therapeutic/educational groups and daily physical, occupational, and speech therapies. Each 45-55 minute session will be conducted by a physical and occupational therapist in 90-94°F water temperatures. Sessions will include range of motion exercises, strengthening activities, and Neuro Developmental Treatment based therapy to facilitate physical and functional improvements. Participants will attend 3-4 aquatic sessions/week.

**Outcomes:** Pertinent data (level of disease severity, age, and gender) will be collected from participants in the aquatic program. Upon admission and weekly thereafter, two scales will be administered regarding fatigue and its effects on function. The Modified Fatigue Impact Scale (MFIS) and a second fatigue scale, specifically created to assess fatigue for TIRR's aquatic program, will be utilized. Daily water temperatures will also be recorded. This information will provide baseline data on reported fatigue levels of this patient population while engaging in a warmer temperature aquatic program. Future research will compare fatigue levels in aquatic therapy at these higher temperatures versus other therapeutic interventions.

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**(W53) MyoRx IN MULTIPLE SCLEROSIS PATIENTS WITH CHRONIC PAIN**

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**Objective:** To evaluate the effect of MyoRx, a new topical analgesic cream that contains omega-3 fatty acids on chronic pain in MS patients.

Pain is an important symptom in MS patients with an estimated prevalence of 70%. One third of MS patients indicated that pain was the worse symptom of their disease and 41.6% of patients reported that pain interfered with their daily life. MyoRx cream contains omega-3, omega-6 and salicylates that showed sustained benefit in pain syndromes associated with rheumatic diseases. It is lipophilic, and thus is absorbed transdermally. Preparations of omega-3/omega-6 in ratios ranging from 1:3.5 to 1:1.5 were associated with beneficial effects such as suppression of proinflammatory prostaglandins and leukotrienes as well as an increase in pain threshold.

**Methods:** This is an open label study in which 10 patients with clinically definite MS and chronic pain symptoms will be enrolled. Study subjects must have perceived musculoskeletal or dysesthetic/burning pain for at least 8 weeks. Patients will be assessed with the Visual Analog Scale(VAS) and the Pain Effects Scale(PES) as well as a Quality of Life Scale(FS36) and a depression survey. Kurtzke EDSS will be obtained to measure severity of disease. The patients will apply MyoRx 4 times a day to the affected area for a total of 8 weeks. Assessments will be made at baseline, 4 weeks, 8 weeks and 12 weeks (following a 4 week washout period.) Statistical analysis will utilize nonparametric Wilcoxon signed rank test to measure the change in pain scales. Regression modeling techniques will be used to analyze changes over time in quality of life. This poster will describe the study methodology and summarize preliminary findings.

*Study Supported By: Jog for the Jake, Dr. Barry Bockow*

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**(W54) HELPING RESISTIVE PATIENTS ACCEPT TREATMENT IN REHABILITATION**

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**R**ehabilitation professionals provide care for patients with Multiple Sclerosis by managing symptoms and restoring function. It is a challenge for those providing care when interventions are recommended but rejected. Refusal of offered services has consequences for both the treatment team and patient care.

Motivating the disengaged, resistant or hostile Multiple Sclerosis patient or family member to accept treatment in the rehabilitation setting is a goal of interdisciplinary team work at the Rehabilitation Institute of Chicago. Spouse anger or indifference, family burnout, both physical and emotional, and patient ambivalence and lack of hope are seen in the clinical setting.

This poster will illustrate three cases, all of which involve patients and families who initially resisted an evaluation and who eventually accepted interdisciplinary treatment. Working within the patient's concept of their goals and their frame of reference, and offering services to meet their identified needs at a setting best suited to them, enabled the patients over time to become more agreeable to intervention. Interventions offered to enable participation were provided through such services as assisting with transportation needs and maintaining close phone contact. Once in the clinic and therapy setting, suggestions and solutions for self care and treatment to increase independence served to offer hope and maintain patient dignity.

By teaching the patient how to live well with Multiple Sclerosis, interdisciplinary specialized care led patients towards a better understanding of their functional status and allowed for empowerment over their lives. This level of intervention transitioned the resistant, angry and despairing patient to one of better adjustment and acceptance of their disability.

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**(W56) DIMENSIONS OF COMMUNICATIVE PARTICIPATION:  
PERSPECTIVES OF PERSONS WITH MS**

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Although communication is a key component of social interaction and integral to full participation in society, we are only beginning to understand how multiple sclerosis (MS) disrupts communicative participation. In this program of research, communicative participation is defined as taking part in life situations where knowledge, information, ideas or feelings are exchanged. It may take the form of speaking, listening, reading, writing and non-verbal techniques. Communication skills are required in all life domains, including personal and household management, work or education, leisure, community involvement, and relationships. A series of in-depth interviews were conducted and analysis using phenomenological methods. The focus of this report is how "satisfaction with participation" is defined by persons living with MS in a community setting. To start the interview, we presented a series of communication situations (e.g. asking questions about your medication or giving instructions to your caregiver) and then we asked two questions about each situation: (1) How satisfied are you with your ability to participate? (2) What made you rate your satisfaction in that way? Interviews were audio-recorded, transcribed verbatim, and read in their entirety at least twice before coding began. Codes describing the content of the interviews were developed and linked to the transcripts using The Ethnograph, software for indexing text data. Themes that emerged from the interviews and coding experiences across subjects are described. Results suggest that satisfaction with communicative participation is multidimensional phenomenon includes dimensions such as ease of performance, difficulty of the situation, achievement of a specific goal (staying connect, making people relaxed), a sense of "doing one's best", being "adaptable", and the perceived reactions of other. Further, the dimensions of satisfaction with participation vary from one situation to another. Implications for the development of adequate measurement tools will be discussed.

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**(W57) IYENGAR YOGA INTEGRATED INTO REHABILITATION OF PEOPLE WITH MS**

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Several symptoms of Multiple Sclerosis are amenable to rehabilitation treatment. This session will present a rehabilitation approach via case report, where the physical aspect of yoga — various poses, postures, and exercises — are employed. Symptoms of MS that potentially respond well to this approach include fatigue, muscle weakness, spasticity, and pain.

With MS, muscle weakness results from direct damage to the central nervous system (CNS), or indirectly from either disuse or muscle imbalance. The muscle weakness associated with myelin damage is aggravated by atrophy in neighboring healthy muscle fibers. This weakness is also a cause of soft tissue contractures and/or limitations in the range of motion in joints.

Traditional rehabilitation approaches can minimize target muscle weakness, contractures and spasticity. However, yoga postures may be employed to decrease fatigue, influence muscle tone and spasticity, promote muscle relaxation, elongate soft tissues and thereby or indirectly improve muscle strength.

Particularly appropriate for this purpose is the therapeutic approach of the Iyengar School of yoga. This approach emphasizes precision in alignment during postures and exercises, which may be both static and dynamic. In static variations, muscle activity is either isometric or relaxed, with poses held for approximately 5 to 10 breaths, or about 30 to 60 seconds. When static yoga poses (also called restorative poses) are employed with patients who have MS-related muscle weakness, spasticity and soft tissue tightness, the patients may be assisted into the yoga pose, and they stay in each pose longer. They are then passively supported in maintaining the poses through the use of props such as yoga mats, bolsters, chairs or ropes. In dynamic variations, muscle activity may be either isotonic or isometric and may or may not employ gravity as resistance. Therapists provide instructions or assistance to movement into and out of the pose in synchrony with the breath.

At the conclusion of the session, the participant (learner) in this session will be able to:

1. Identify the tenets of Iyengar yoga that can be integrated into rehabilitation for people with a more advance stages of multiple sclerosis.

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