

From the Director

Dear Friends:

It is a pleasure to add my greetings to this inaugural edition of the *MS Advocate*. These are exciting times for the MS community in general, and for our Center in particular. We are witnessing the dawn of a new era in MS therapeutics and research. Although treatment with monoclonal antibodies got off to something of a false start with the withdrawal of Tysabri by the FDA, it is my firm opinion that this drug and several other monoclonals in development will bring about a small revolution in the management of MS. Numerous oral medications are in advanced stages of clinical evaluation, and at least two T-cell vaccines are being tested. Although not a viable treatment option yet, stem cell therapy is being explored vigorously. The human genome project has resulted in an explosion of knowledge about the genetic influences in MS and will inevitably lead to novel treatment options. The variety, sophistication, and pace of clinical research in MS are remarkable.

Closer to home, our MS Center, too, has made great strides for the benefit of our clients. Our front desk staff has been fortified and the check-in process streamlined, the clinical and research staff has been expanded, the infusion suite has been renovated, and the waiting room has been redecorated. The addition of a fully integrated database management system, recently launched, has already enhanced the process of patient management, prescription renewal, and appointment confirmation. Computer stations will be added to the waiting room in the next month for general use and educational programming.



During the past two years, our services have been enhanced by the addition of numerous new positions and programs. Personnel additions include a Director of Clinical Programs, Psychiatric Nurse Practitioner, Medical Nurse Practitioner, Occupational Therapist, Neuropsychologist, Patient Advocate, and Coordinator of Professional Education and Client Services. These outstanding professionals, as well as the "old-timers," will gradually be introduced to you through the pages of this publication. The numerous programs, support groups, clinical and research activities undertaken by our dedicated team members will be spotlighted.

My sincere thanks to the editors, the MS Center staff, and most of all, to you, our dear patients.

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- Living Well with MS

From the editor

Maura L. Del Bene, MS, RN, NP-P

As so often happens in a New Year we take time to reflect on the events and experiences of the past year in an effort to make new goals for the year that lies ahead. A major goal in 2005 was to offer services and programs that not only assisted individuals living with MS to obtain medical care but also provided the opportunity to improve their wellness through varied programs and services focused on quality of life.

Our plans were to include an interdisciplinary staff at the Center, increase appointment opportunities, develop specialty clinics, increase the size of our infusion suite, improve communications with our patients and their families, and offer more psychosocial programs and wellness groups. This all seemed wonderful, but how to do all of this without altering the success established by the founding clinicians? Our best answer was a slow and steady approach because we needed to adjust to many more staff members in the same small location, and our patients needed to adjust to many new faces!

The specific MS Center services that have been added this year include: onsite mental health evaluations, counseling, and pharmacologic management; occupational therapy services to provide strategies for every day cognitive and fatigue issues; three new support groups; mental health programs (GRASP ~ see page 3); and neuropsychological evaluations. Along with this we have renovated the IV suite which now includes wireless internet, music, movies, and cable TV. We have more than doubled our staff and the wonderful thing about having more staff is that there are more hands. Therefore, we expanded our already existing services of injection trainings, patient counseling and education, the bladder clinic, and the spasticity clinic.

After so much improvement, the Center staff felt strongly that we should refresh our communications with a quarterly newsletter. The *MS Advocate* (somebody who supports or speaks in favor of, or on behalf of another) represents the many goals we possess as an organization focused on caring for individuals living with the challenges of MS.

We look forward to your feedback as we continue on our journey in 2006, setting new goals and striving for more.

Maura

*The art of living
lies in a fine mingling of
letting go and holding on.*

Havelock Ellis

Calendar of Events



Young Adults with MS Group

1st Wednesday of Month

Feb 1st – July 5th

5-6 pm

MS Clutter Group

Every Tuesday

11-12 noon

MS Open Clinic

Joseph Herbert, MD

Genetics

March 19, 2006

If you are interested, kindly contact

Mary-Grace at 212-598-6305

Join our Team



Call Jennifer Haus at 212-598-6493

Sunday April 23, 2006

Meet our Staff

Lisa Capolino-Laing, RN, MSCN, CRRN

My career in nursing began in 1994 at the Hospital for Joint Diseases where I worked as a staff nurse on the Neuro-Rehabilitation Unit assisting patients who had suffered strokes, head injuries, and MS to regain strength, mobility, and speech. During this time, I obtained certification in Rehabilitation Nursing. The four plus years spent working in Rehabilitation gave me a strong foundation for the skills required to work in the MS Center.

In June of 1998 I became the Study Coordinator at the MS Center. My main responsibility was enrolling patients into research studies while maintaining patient safety and the integrity of the studies. Two years later, I became involved in direct patient care when I moved into the role of Clinic Coordinator. After a few years, I obtained certification as an MS nurse.



At that time, the Center consisted of Dr. Herbert and two nurses. Just seven years later the Center has added a medical nurse practitioner, psychiatric nurse practitioner, social worker, physical therapist, occupational therapist, IV nurse, research assistant, neuropsychologist, and a patient advocate to assist in providing comprehensive care to all our patients. The years spent working in patient care at the Center have been the most fulfilling for me.

(Continued on page 4)

MS Center Program Update

Tamar Fromm, MS, OTR/L

The interdisciplinary team at the Multiple Sclerosis Center has begun to develop numerous programs that focus on comprehensive mental health care for patients. One of these programs is called **GRASP** (Group for community Reintegration through the Arts for Socially isolated Patients). This program involves community reintegration for MS patients who are otherwise homebound due to physical or cognitive challenges. It also affords patients the opportunity to create a small social environment with one another.

The most recent group consisted of 14 individuals who met for lunch at Victor's Café and attended the Broadway show "Hairspray." This particular musical was chosen because of its uplifting and inspirational theme. The plot of the performance follows the efforts of an overweight woman who ignores the preconceptions of others, follows her dreams, and ultimately becomes the star of a Broadway show. "Hairspray" also had the added advantage of being an entertaining musical comedy for those patients who have



Group for community Reintegration through the Arts for Socially isolated Patients —
GRASP

trouble maintaining concentration.

The group served many purposes. Members were responsible for transportation to and from the event which put some of them in the position of accessing New York City's transportation system. The occupational therapist was available to recommend specialized services, such as transportation for people in power wheelchairs who were unable to use standard means of transportation, information on bus and train stations that are accessible, reasonable rental car services for power wheelchairs, and other miscellaneous services that were needed by this group. The transportation aspect of this activity forced the group members to tackle impediments related to commuting and socializing.

Patients who rarely leave their homes had the opportunity to participate in one of New York City's most desirable activities. Group members were also able to meet others with similar medical issues and learn

(Continued on page 4)

MS Open Clinic

On March 19, 2006 Dr. Herbert will be speaking at *Open Clinic*.

This event takes place four times per year and offers patients and families an opportunity to hear about up-to-date information about various topics in MS. Our last *Open Clinic* focused on "Updates in MS ~ an International Perspective" and was sponsored by Biogen Idec.

If you are interested, contact Mary-Grace at 212-598-6305

(MS Center Program Update, Continued from page 3)

various coping mechanisms from each other to help improve their quality of life.



Andrea, Tamar, & Ronald

The event was a very special day for all involved. Patients said that this was a "perfect show for us to see," one that could "affect our own personal lives," and that "we can all get something out of."

None of the patients had previously participated in any type of MS group and all of them reported that they enjoyed becoming acquainted with others living with MS.

If you or someone you know with Multiple Sclerosis can benefit from the GRASP program, please do not hesitate to contact Tamar Fromm, MS, OTR/L at 212-598-6585.

(Meet Our Staff, Continued from page 3)

I enjoy teaching patients about their illness, assisting in the management of the disease (such as the use of medications as well as complimentary medicine), and most important, instilling hope for the future.

In the 11 years I have been working with this patient population, treatment and management of MS have changed dramatically. Patients are doing much better for longer periods of time. Given the amount of progress made over the last decade, I am hopeful that the coming years will unveil treatment options which are both more tolerable to the patient and more effective in controlling or even stopping disease progression.

The journey has been long and at times difficult; however, I hope the information and support I offer to our patients provides them with the tools they need to live fully.

Lisa

How you can fight against MS

Support by the MS Society, Industry, and generous donors allows us to provide the ongoing, comprehensive care that you have come to depend on.

Without this support, we face significant challenges in continuing to provide excellence in MS patient care and research activities.

Your contributions assist us in the areas of:

- MS Research
- Patient Care
- Educational Materials
- Support Groups & Programs

Contributions can be made payable to:

MS Research & Education Fund

Mail to:

MS Care Center
NYU Hospital for Joint Diseases
301 East 17th St., Suite 544
NY, NY 10003

The MS Center is proud to be sponsored by the MS Society of NY for the past eight years.



NEW YORK CITY CHAPTER

MS Updates

Medicare Part D ~ Effective January 1, 2006

As most of you may already know, effective January 1, 2006 Medicare has a prescription drug benefit plan which is available to all Medicare recipients. Both the Social Security Administration (SSA) and private insurance companies have been mailing information regarding the new changes to Medicare recipients. If you are like most people, you are probably confused and unsure of what this change means and how it will affect you. The following provides a basic overview of the new Medicare Part D Prescription Drug Plan.

Since most Medicare recipients do not have a prescription drug plan to assist with the payment of medications prescribed by a physician, the government is requesting Medicare recipients enroll in a drug plan between November 15, 2005 and May 15, 2006. The cost of the drug plan will be approximately \$32.00 per month and plans are available through private insurance carriers. If you do not have prescription drug coverage under a separate plan, and enroll in Medicare Part D Prescription Drug Plan after May 15, 2006, you will be charged a penalty in addition to the monthly premium. If you have a prescription drug plan which is at least as good as the Medicare Prescription Drug Plan, you may switch to the Medicare plan after May 15, 2006, without paying a penalty provided you are not without coverage for more than 63 days. Once elected, the plan of choice may be changed at the end of the month if you find that the plan does not meet your medical needs.

Each drug plan will have its own list of covered drugs, which must include at least two drugs from each drug class. Therefore, before choosing a plan, it is important to compare the medications which you are currently taking with the drugs offered by a particular plan. Medicare law excludes some types of drugs from coverage (such as anti-anxiety drugs, anti-seizure drugs, and over-the-counter drugs). If a drug is not covered by your plan or you get it from a pharmacy outside of your plan's network, you will have to pay the full cost of the drug.

The drug plan will have an annual deductible of \$250.00, which means you will be responsible for the full cost of each prescription you fill until you have spent a total of \$250.00. Afterwards, you will be responsible for 25% of the cost of each prescription filled between \$251.00 and \$2,250.00. After reaching \$2,250.00 you will be responsible for 100% of the costs up to \$5,100.00. This means if your prescriptions total \$5,100.00 for the year, you will have an out-of-pocket expense of \$3,600.00, not including the monthly premium for the drug plan.

You may be eligible for special assistance if your income and assets are limited. You should apply for help through the SSA using the agency's online application (www.ssa.gov). If you do not have internet access you may call SSA directly at 1-800-772-1213.

Individuals with Medicaid insurance were automatically enrolled in a Medicare Prescription Drug Plan on January 1, 2006. Their benefits will remain the same as in 2005, however, over-the-counter medications will no longer be covered by the plan.

In addition to the MS Society, more information may be obtained by contacting the following agencies:

Medicare	www.medicare.gov	1-800-633-4227
Social Security	www.ssa.gov	1-800-772-1213
Medicare Rights Center	www.medicarerights.org	1-800-333-4114
Medicare Interactive	www.medicareinteractive.org	Online Only
NYS Dept. of Health	www.health.state.ny.us	1-800-541-2831
NYS Dept. of Aging	www.aging.state.ny.us	1-800-342-9871

Living Well with MS

Spiritual Assessment

A common definition of spirituality is an inner sense of something greater than oneself. Recognition of a meaning to existence that transcends one's immediate circumstances.

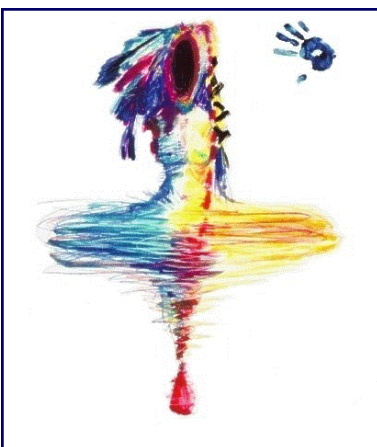
A spiritual assessment is a helpful practice that seems to arise naturally in the course of the profound psychological and spiritual transformations that occur while living with an illness. Since we all share the same human condition, many medically ill people report asking themselves the same questions. They are questions that pierce through the frivolousness at the surface of life and confront us with the value and significance this precious gift of a human life offers.

For individuals with medical illness, it is never too late to take stock of our lives, and for those of us in the midst of life, in the apparent safety and security of our health, it is not too early. No matter how much time we have to live, the answers to the following questions, voiced in the quiet honesty of our own hearts, provide direction to the rest of our living.

- Who have I been all this time?
- How have I used my gift of a human life?
- What gives my life meaning?
- For what am I grateful?
- What have I learned of truth and how truthfully have I learned to live?
- What have I learned of love and how well have I learned to love?
- What have I learned about courage, strength, power, and faith?
- How am I handling my suffering?
- Who am I?

Adapted from **Taking a Spiritual Inventory**
by Kathleen Dowling Singh

MS Creations



“I've always been an artist ~ drawing, painting, and creating but along the way my artwork has become an important part of the healing process and my experience with MS.

I have begun to express through my artwork my thoughts about this illness, the anger it evokes, the vulnerability I feel, the isolation, the unpredictability, and the ‘crazy sensations’ in my body.

Along with my rediscovery of faith and spirituality, my artwork is healing and the best medicine for me! Just being able to express it, it's as simple as that. My paintings have become a portrayal of emotions and life.

Hopefully my paintings will be able to reach out to others in similar circumstances and help them heal too, by knowing they are not alone. Knowing that might happen is just another way I stay well.”

<http://elleclarke.com/>

Thank you Dr. Herbert.

Elle Clarke

At the Center

Preparing for Your Visit to the Center

Visits to the MS Care Center typically occur every 3-4 months, but this can vary. During your visits, you may meet with different team members depending upon your needs. Each visit should afford you and your family the opportunity to address your questions, concerns, and needs. Knowing that there is a plan in place for your continued wellness is important. We offer the following recommendations for team visit preparation:

1. Have goals for the visit:

Please come to your Center visit with a list of items you would like to address. For example:

- ✦ Learning more about the changes that you are experiencing and what can be done to help you adjust, adapt, or improve function
- ✦ Medication adjustments and/or renewals
- ✦ Clinical trials/research update
- ✦ Financial planning, home care needs, forms to be completed
- ✦ Identification of community services
- ✦ Physical wellness, rehabilitation programming, occupational assistance, etc.

2. Take notes:

Come to the Center with a notepad and pen so that you can take notes. At the time of the visit, information is flowing between you and the team members. Our feedback from other patients and families tells us that once you get home you may not recall a lot of what was said. The notes will help you recall or track the “action items” for which you are responsible, as well as what the clinical team will be doing on your behalf.

3. Stay in touch:

Review how to get in touch and stay in touch with team members. Communication in between visits is helpful at times. There are several options for how to get your needs addressed most efficiently; *please note that multiple calls or misdirection of calls may delay our response to your needs.*

Medical Questions & Prescription Refills	212-598-6118
Research Appointments	212-598-6585
Social Work	212-598-6493
Appointments & Billing	212-598-6305

4. Bring a list of your current medications.

5. Plan your return visit:

We strongly encourage all patients to set the return visit date during your checkout time at the front desk. Even if you are unsure of your schedule around the time of the suggested return visit, make the appointment. It is often not possible to get a team appointment at the last minute (when you realize three months have passed!). You must be seen annually at a minimum. Therefore, do not let more than a year go by without a follow up visit because this will also assure that your plan of care does not have any interruptions.

6. In an emergency:

If you feel you need to speak with a clinical staff member immediately or that you may be having symptoms that need to be addressed immediately, please make sure you state this when you call the offices. We have available slots each day for emergency evaluation and have a 24-hour on call system to assure that you receive the proper care in the most efficient manner.

MS Research

How to Get Involved

The number of research studies in Multiple Sclerosis continues to grow - the National Institutes of Health, Industry (Pharmaceutical Companies), MS Society, MS Association, and individual or collaborative groups of physicians and scientists throughout the world are a sampling of who are working daily to find the cause and cure of MS. Under the direction and leadership of Dr. Herbert, the Center conducts studies relating to genetic factors that make people more susceptible to MS; the establishment of a highly sensitive tool for evaluating functional ability; the adherence to MS treatments; and, advanced MRI techniques.

Additionally, we are participating in several multi-center studies of new medications designed to reduce further disability or change the course of the disease. If you are interested, kindly call 212-598-6585.

DAC 1012

This study examines the efficacy of a new monoclonal antibody, Daclizumab, for MS. The study involves subcutaneous (just beneath the skin) injections in patients with active, relapsing forms of MS who have been taking Avonex, Betaseron, or Rebif for at least six months.

Timed Tandem Walk

Tandem walking is “heel to toe” walking along a straight line. This study tests whether a timed tandem walk is more sensitive to mild changes in neurological function than other available measures.

DMQ-Avanir

This study assesses the safety of a combination of Dextromethorphan and Quinidine in the treatment of emotional lability (uncontrolled laughter or crying) which can occur with MS.

CombiRx

This study compares patients treated with Avonex, Copaxone, or both. The goal is to determine whether the combination of Avonex and Copaxone will be more effective in reducing the number of relapses per year in patients with relapsing-remitting MS.

Radiology

In this study, subjects with different forms of MS undergo MRI and highly specialized MR spectroscopy, as well as cognitive and neurological testing, in an effort to develop new imaging methods to better understand treatment and specific aspects of MS.

OMEGA

This study compares intravenous steroid to oral steroid treatment in the management of acute exacerbations in relapsing-remitting MS.

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Dr. Herbert and the MS team are committed to their four-fold mission of providing the finest patient care, rehabilitation, researching the cause and cure for MS, educating tomorrow's healthcare professionals, and reaching out to the communities of the patients we serve.

If you or a loved one has MS, the NYUHJD Comprehensive MS Care Center is prepared to help.