A joint publication of United Spinal Association and the CMSC/North American Research Committee on MS

MSQR

Multiple Sclerosis Quarterly Report

MSQR
United Spinal Association
75-20 Astoria Boulevard
Jackson Heights, NY 11370-1177
www.unitedspinal.org

Volume 29, Number 1
Spring 2010

Preparing Successful Applications for Social Security Disability Insurance

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Volume 29, Number 1, SPRING 2010

MSQR

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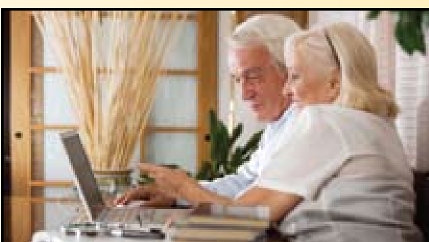

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CMSC and NARCOMS

The Consortium of Multiple Sclerosis Centers (CMSC) was established in 1986 by a group of neurologists interested in improving the care of patients with multiple sclerosis (MS) through a team approach. Its members are comprehensive MS research and treatment centers, MS clinics, corporations, and individual healthcare providers with a special interest in MS. The Consortium's mission is to disseminate information to clinicians, increase resources and opportunities for research, and advance the standard of care for people with MS.

While striving to achieve the Consortium's mission, the CMSC decided to initiate the North American Research Committee on Multiple Sclerosis (NARCOMS). NARCOMS was created to help facilitate multicenter research in the broad field of MS through a Patient Registry and CMSC Web site. NARCOMS' success relies heavily on the support of patients with MS and their participation in the NARCOMS Global MS Patient Registry. The more patients participate and provide complete information to the Registry, the more efficient the studies on MS will be and the closer we will get to a cure.

If you know NARCOMS participants who have not received their MSQR, please ask them to call 1-800-253-7884 to provide their current mailing address.

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United Spinal Association is a non-profit organization dedicated to improving the quality of life for all Americans with spinal cord injuries or disorders, including multiple sclerosis.

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multiple sclerosis quarterly report

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A joint publication of United Spinal Association and the CMSC/North American Research Committee on MS

2010 Subscription rates per Volume year (4 issues):

Domestic (US, Puerto Rico)
Individuals $30
Institutions $60

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Individuals $60
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denise i. campagnolo, md, ms

editor's message

Dear Readers,

In my time here at Barrow Neurological Institute I have enjoyed some aspects of my duties more than others. The hat that I most enjoyed wearing was the one labeled "Medical Editor of the MSQR". The reason why I so enjoyed this responsibility was that I felt like I was able to reach out to each and every one of you with accurate up-to-date information about the disease you all bravely deal with on a day-to-day basis. It was a way to thank you for your contributions to the NARCOMS Registry and at the same time share information about research and aspects of the disease that sometimes little is written about. It is with mixed emotions that I step down from this role. The reason is that I have accepted a position in industry that will not allow me to continue as medical editor. I will still be working for you behind the scenes with one of the leaders in the development of new MS medication(s). This is the last issue that I am responsible for . . . so I leave you with two very practical articles, one on disability applications and the other on depression in MS. Both articles authored by individuals who are expert in their respective areas. The rest of this editor's message is composed by my friend and colleague Tim Vollmer, MD, FAAN who will speak to the importance of spreading the word about NARCOMS.

Warmest Regards to All of You,

Denise I. Campagnolo, MD, MS

2010 MSQR Reader Survey

United Spinal Association would like to give MSQR readers an opportunity to share their feedback. We kindly ask that you take a moment to submit a brief online reader survey that will help us improve the content we publish in the future. To access the survey, please visit **http://www.surveymonkey.com/s/VSGZLFL**.

Once you have finished answering the questions, click "Done" at the bottom of the page to submit your responses. Thank you for your cooperation.

timothy vollmer, md, faan

guest editor's message

Guest Editorial by Timothy Vollmer, MD, FAAN

In 1996 the Consortium of Multiple Sclerosis Centers (CMSC) launched a project to develop a Registry for patients with multiple sclerosis (MS) that would help facilitate research on the nature of the disease, its cause and its cure. I've had the honor of being associated with the organization since its inception and it has been very gratifying to see the Registry grow to become the largest database focused on patients with MS in the world. It has also been gratifying to watch it develop as a research resource for a wide-range of investigators interested in issues related to MS. The database now has data on over 35,000 patients with approximately 15,000 patients actually involved at any given time. The Registry has been used by many different investigators, with generally between 10 and 15 research programs actively using the database at any given moment. Indeed, the database has been extremely productive in terms of academic publications. In the last year alone, 15 peer–reviewed scientific papers were published using information provided by the participants of the NARCOMS project. Overall, more than three times that many peer-reviewed papers on NARCOMS data have been published over the last several years, covering a wide-variety of issues related to the nature and needs of patients with MS.

The project has recently undergone a major reorganization. The database, statistical management and website development are now based at the University of Alabama under the direction of Gary Cutter, PhD. Although I remain the Project Director, the number of physician scientists involved has continued to grow substantially. Key members in the NARCOMS program have included Dr. Ruth Ann Marrie, Dr. Tuula Tyry, Dr. Carolyn Schwartz and last, but not least, Dr. Denise Campagnolo.

Many of you will recognize that the MSQR Editor's Message over the past several years has been from Dr. Denise Campagnolo, MD. Dr. Campagnolo has a vast experience in MS and has special knowledge of rehabilitation therapies in MS. Additionally, she is a basic investigator studying immune dysfunction associated with neurological disease. With her obvious teaching skills, she is a classic example of a true triple threat in academic medicine. She is also a truly wonderful human being. She has been instrumental in the remarkable development of the MSQR and its increasing success. Unfortunately for us, she is moving on to a new stage of her career and will no longer be able to serve as editor for MSQR. This is a great loss to us, but fortunately she has laid a strong foundation for the next editor to continue the development and growth of MSQR as an important instrument for the education and support of patients with MS and their families.

The change in the editorial support of this journal coincides with a period of remarkable change in the opportunities to treat MS. Over the last 5 years the pages of MSQR have described the evolving treatments for MS in several articles. Overall, we have had seven therapies approved since 1993. More importantly, there are at least 5 new therapies that will be submitted to the FDA and other regulatory agencies for possible approval over the next one to two years. Regarding the current therapies available to treat patients with multiple sclerosis, our understanding of their use and mechanisms of action is improving substantially. Indeed, we are making progress in improving the safety profiles and effectiveness of the currently available therapies, right along with the emergence of new therapies.

A key development over the last couple of years is the recognition that although all the therapies we currently have are at most partially effective, even if highly effective, they are not the cure for MS. With this understanding has also come opportunity. It is now clear to most of us in the field that an opportunity exists to rapidly improve both the safety and effectiveness of the treatment of MS by looking at use of these drugs in combination. There are several

large studies investigating combinations of interferons with glatiramer acetate, new antibodies such as daclizumab with interferon, chemotherapy pulses followed by either interferon or glatiramer acetate and so forth. However, in the not-so-distant future, if the new therapies being submitted to the FDA succeed, we will begin to have combinations of therapies that are not related to suppressing the immune system, but may work in the brain to change the environment to one that is less inflammatory and less injurious to the central nervous system. This strategy of combination therapy has had remarkable results in other fields. For example, the majority of cancers that are highly treatable at this time are treated with combinations of therapies, or induction and maintenance therapy programs. An example is childhood acute lymphocytic leukemia (ALL). When the currently available medications were used singly in ALL, the best outcome in terms of long-term survival was that only 15% of children would survive this disease. Nowadays, by combing the several drugs that each has partial effects in childhood ALL, long-term survival and cure occurs in 90% of children with this dreaded disease. Similarly, the field of HIV/AIDS has been fundamentally revolutionized as a result of a combination therapy referred to as HAART therapy. Indeed, HAART therapy has taken HIV infection from one of almost certain death due to overwhelming infections and cancer to being a chronic disease which will allow most patients to live normal or near normal life spans. It is not a cure, but it has dramatically changed the future of patients infected with this deadly virus. Our hope is that, similar to these examples, as more and more therapies emerge for the treatment of MS, they will provide us the opportunity to combine them in unique, effective, and safe ways to dramatically inhibit further damage to the nervous system, such that patients with MS can proceed with their life without an expectation of increasing disability as a result of inadequately treated MS. To accomplish this goal physicians and patients must work together to develop newer, more efficient clinical trial designs. Furthermore, the field of MS needs to organize itself the way that oncology clinics and HIV programs have done by forming regional collaborative networks connected through protocols and information management technology.

We are winning the war. Granted, there is still much to do, but MS is becoming a very treatable disease. Until we have the cure, these therapies have the promise, if used correctly, to dramatically decrease the chance that patients with MS will develop increasing disability over time. There is also some movement in the area of therapies designed to help restore function. Hopefully, we will see evidence of success in these programs in the near future as well.

So, although we are saying farewell to Dr. Campagnolo, we will continue to strive to meet her vision of providing a publication to patients and families dealing with MS, that helps empower them with knowledge based on objective science that best allows them to take full advantage of the opportunities currently available, and to consider their MS in the full context of their lives. The NARCOMS project of the Consortium of MS Centers will also continue to be dedicated to encouraging research that will benefit patients and families dealing with MS. In this vein, I have one request: If you, as a reader of this journal, know of people dealing with MS who are not yet members of the NARCOMS Registry, let them know of the opportunity to participate in this research program designed to benefit them. To join is easy. They can simply go to the Website **www.narcoms.org** or call us at 1-800-253-7884. Anyone diagnosed with MS is invited to join NARCOMS. Although much progress has been made, substantially increasing the number of individuals with MS participating in the NARCOMS project will help in a major way to accelerate the progress in optimizing the treatment of MS and that will ultimately result in a cure for this disease.

Best Regards,

Timothy Vollmer

Timothy Vollmer, MD, FAAN
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Preparing Successful Applications for Social Security Disability Insurance

Dorothy E. Northrop, MSW, ACSW, Vice President of Research & Clinical Operations, National Multiple Sclerosis Society

Introduction

For people with multiple sclerosis (MS), who can no longer remain in the workforce, Social Security Disability Insurance (SSDI) provides access to an important source of income. It also serves as the gateway to coverage by Medicare, and this coverage is often critical when employer-based insurance ends. Unfortunately, getting approved for SSDI benefits can be a frustrating and long-drawn-out process, often requiring the services and expense of an attorney to ultimately be successful.

A nationwide study of working age people with MS, conducted in 2005, found that almost one third had their initial SSDI application denied. Failure to meet disability criteria caused over 60% of the rejections, and inadequate documentation contributed to over 32% of the rejections. The time that elapsed between application and approval was between 12 and 23 months for about 20% of the applicants, and over two years for another 20% (Iezzoni, Ngo, & Kinkle, 2007). This study powerfully illustrates how important it is to fully document the breadth of MS-related impairments in a disability application if that claim is to meet with success.

When applying for SSDI people with MS and their physicians can follow a sequence of steps that can speed up the process and increase the chances of a successful outcome. This article will describe these steps.

Social Security Disability Insurance

SSDI is a program administered by the Social Security Administration (SSA) designed to provide long-term income to those who are "insured" under the Social Security system and who become unable to remain in the work force due to disability. To be eligible for benefits a person must have a sufficient work history and have made contributions to the Social Security trust fund through payment of Social Security taxes on his/her earnings.

Approval of benefits is dependent on an individual being able to document that a "medically determinable" physical or mental impairment will either result in death, or is severe enough that he/she has been or is expected to be unable to work in any substantial gainful activity (SGA) for a continuous period of at least 12 months. A medically determinable impairment is one that "results from anatomical, physiological, or psychological abnormalities that can be shown by medically acceptable clinical and laboratory diagnostic techniques". SGA is defined as any work activity that involves significant and productive physical or mental activities and is performed or intended for pay or profit (SSA Pub. No.64-039). The SSA actually applies a dollar amount to the definition of SGA. In 2009, if an individual had wages of more than $980 per month, that individual would be considered engaged in SGA and would not be eligible for benefits.

The definition of disability as defined by the SSA is extremely strict, more stringent than is found in many private disability policies. Not only is the agency making determinations on whether applicants can do their current job; they are also looking to see if an applicant can do *any* job, even if in a different line of work.

Questions they are looking to have answered are:

1. Is the individual engaged in substantial gainful activity?
2. Is his/her condition "severe"?
3. Is his/her condition listed as impairment by SSA?
4. Can the individual do the work he/she previously did?
5. Can the individual do any other type of work?
6. What is the most the individual can still do in spite of his/her limitations?

In many other countries disability programs allow for partial disability. For example, a person might be adjudged to be 40% disabled and in turn receive partial benefits. This is not true for the SSDI program in the United States. When the SSA makes a determination, the person is either deemed disabled and eligible for cash benefits or not disabled and ineligible for such benefits (O'Day & Berkowitz, 2001).