How to S.E.A.R.C.H.[SM] for the Right MS Therapy For You!

The Changing Landscape

The first treatment for relapsing-remitting multiple sclerosis (RRMS) was approved by the United States Food and Drug Administration (FDA) in 1993. This forever changed the landscape of how MS could be managed. The approval of Betaseron® (interferon beta-1b) for RRMS ushered in a remarkable surge of MS treatments designed to reduce the number and severity of exacerbations and help lessen disease progression. Throughout the 1990s and into the 2000s, several effective medications for MS have become available, giving neurologists and patients a variety of treatment options for slowing disease activity.

Along with these treatments, known as disease-modifying therapies (DMTs), came the expanded use and improved technology of magnetic resonance imaging (MRI). Through diagnostic and follow-up MRI scans of the brain and spinal cord, physicians could now better diagnose, treat, track and manage the ever-changing course of MS in a more definitive and proactive manner. As the recommendation and usage of MRIs grew, MSAA recognized the need to assist MS patients who required these valuable tests but lacked insurance coverage or the financial means to pay for the exams. As a result, MSAA developed and implemented the MRI Diagnostic Fund and MRI Institute programs. To date, these two programs have combined to serve nearly 5,000 MS clients who have benefited from an initial or follow-up MRI exam. For more details on these two programs, please visit the MSAA website, www.msassociation.org, or call (800) 532-7667, ext. 120.

Advances in MRI techniques, along with years of consistent research data, have demonstrated that most patients who begin and maintain a DMT will experience fewer active lesions on the brain and spinal cord, fewer and less severe exacerbations, a reduction in symptoms, and a delay in disease progression and disability. In addition, more recent clinical trials have found that many of these DMTs also delay time to a second MS-like event, in cases of clinically isolated syndrome (CIS). CIS refers to the first presenting symptom of MS, prior to a confirmed diagnosis.

These impressive results led the MS medical community to universally adopt and support the position of treating MS with approved DMTs as early as possible and for patients to maintain adherence. Since the mid-2000s, the issue of treatment adherence has been aggressively advocated by leaders in the MS medical and healthcare communities, including MSAA.

Framing the Discussion

Supporting the critically important message for patients to begin and stay on an MS therapy, MSAA launched a national public awareness campaign in 2007 titled, "*These Treatments Work, Let Them Work for You*." The campaign featured brochures, articles and other print materials distributed to MS patients and MS centers across the country. It also included a series of radio and television public service announcements and airport dioramas. Over the last few years, this national initiative has been widely successful, generating nearly 70,000 broadcasts and $6 million of free radio and television airtime to support the message of treatment adherence.

While the issue of treatment adherence continues to gain awareness and momentum, MSAA also recognizes the complexity of the situation. Healthcare providers continue to encourage their patients to become more health literate and to take an active, decision-making role in selecting a treatment. In doing so, an extraordinary number of factors need to be considered when choosing an appropriate MS therapy or switching from one DMT to another. Among the numerous questions to consider include: What are the therapies? Am I a candidate? What should I know about each one? How will my body react to taking one of these medications? How are the different medications administered? What about the costs or insurance? Once I have begun taking a DMT, how do I know if the one I am prescribed is working?

These and other important considerations require ongoing conversations with your doctor and other healthcare professionals. The treatment decision for each patient is unique and must be addressed individually between the person and his or her healthcare team. Additionally, patients must recognize the need to prioritize their issues, questions, and concerns in order to maximize the time with their doctor and healthcare team. With so much information to remember, organize, and prioritize, MSAA recognized the need to help frame these important discussions. By doing so, MSAA is able to support patients and their physicians in their S.E.A.R.C.H.^{SM} for the most appropriate therapy for each individual.

What is S.E.A.R.C.H.^{SM}?

Designed as a memory aid, the S.E.A.R.C.H.^{SM} acronym represents the key areas that should be considered when "searching" for the most appropriate MS treatment. Each letter represents an important topic that must be considered by patients, physicians, and other healthcare and social service professionals. S.E.A.R.C.H.^{SM} stands for:

S. = Safety
E. = Effectiveness
A. = Affordability
R. = Risks
C. = Convenience
H. = Health Outcomes (overall wellness and quality of life)

"The S.E.A.R.C.H.SM acronym is not only a useful tool to help frame and remember these important issues, but gives patients a way to start the conversation with their healthcare team," explains MSAA President and CEO Doug Franklin. "Our goal is to foster a positive doctor-patient relationship and allow the dialog to take its own course. MSAA recognizes that MS is a uniquely individual disease that affects each person differently. We are not advocating any one treatment or approach, but rather looking to help guide the conversation between patients and their medical team toward issues that matter most."

To assist with this conversation, MSAA has prepared a sampling of key questions within each aspect of S.E.A.R.C.H.SM These questions represent a broad overview of many different factors to consider and investigate. They also allow the flexibility for patients to adapt their specific medical history, current disease state, experiences and other physical, emotional, and financial aspects into the decision-making process.

The S.E.A.R.C.H.SM Questions

MSAA has developed the following S.E.A.R.C.H.SM questions to serve as a sample, or guide, for you to consider when evaluating your own healthcare needs. These S.E.A.R.C.H.SM questions merely reflect a starting point to help you think about your own medical situation, issues to prioritize, and ways to develop questions which address your specific healthcare needs.

When using the S.E.A.R.C.H.SM model, it is also important to recognize that reviewing key topics and questions will likely require more than one office visit with members of your healthcare team. The S.E.A.R.C.H.SM framework can also be helpful when conducting your own research before or after visiting your healthcare provider. Please see a comprehensive resource guide at the end of this article.

Safety

- What are the long-term safety profiles of these FDA-approved MS disease modifying therapies (DMTs)?
- What tests are required prior to taking DMTs? What tests are required while receiving DMTs?
- How will DMTs interact with my current medical treatments, other medical conditions, and any complementary and alternative medicines?

Effectiveness

- How effective are these DMTs in reducing MS relapses, disability, and MRI activity?
- What are my realistic expectations regarding the effectiveness of these DMTs?
- How can I tell if my DMT is working?

Affordability (These questions could be directed to other healthcare team members including your social worker, insurance representative, MS organization, etc.)

- What are the costs and insurance coverage for these DMTs?
- Does the insurance coverage have caps, gaps or limitations?
- Are there assistance programs through the pharmaceutical companies, government, or charities?

Risks

- What are the risks of side effects associated with these DMTs?
- How frequent and severe are the side effects? How soon do they subside?
- Can these side effects be managed, and if so, how?

Convenience

- How are the DMTs administered?
- How often do I take these DMTs?
- Must I have regular tests or visits to other healthcare providers to monitor the effects of my treatment?

Health Outcomes

- How will my general health and quality of life be affected by these DMTs?
- Will taking a DMT lower my immune system and cause other problems?
- Can these DMTs assist with my mobility, cognition, and other health factors?

Maximizing S.E.A.R.C.H.SM

As mentioned in the beginning of this article, the MS landscape has dramatically changed over the past two decades. With the recent introduction of an oral medication, and with new investigational drugs nearing completion of their trials, changes in this landscape continue to evolve at a rapid pace.

Much like the design of a Global Positioning System (GPS), MS patients and their physicians can employ the S.E.A.R.C.H.SM model to navigate through this dynamic, ever-changing landscape to reach their desired destination. Also, similar to a GPS's feature to recalculate direction, patients can continue to utilize the S.E.A.R.C.H.SM tool to "recalculate" their decisions and adjust treatments if necessary in order to optimize health outcomes.

Another way to derive maximum benefit from S.E.A.R.C.H.SM is to use it as a time saver. Unfortunately, doctors today face an increasing workload of patients, restrictive managed-care regulations, and other factors that prevent many physicians from spending as much time with their patients as they were able to do in the past. The reality of these brief and often rushed doctor visits can leave both the patient and physician feeling dissatisfied with the outcome and "searching" for a better way to manage their time.

“As a neurologist, I find tremendous value in the S.E.A.R.C.H.SM model because it brings to light the key issues involved in treating MS in a way that focuses the conversation,” explains MSAA Chief Medical Officer Dr. Jack Burks. “Patients can present their questions and concerns in a clear cut, easy, and efficient way. I see S.E.A.R.C.H.SM as a template from which patients can choose the issues most important to them.”

“Patients sometimes call or revisit me after an appointment with additional questions that they forgot to ask. S.E.A.R.C.H.SM will effectively reduce the time needed to cover the important topics. This will give patients more confidence in their medical decisions.”

The S.E.A.R.C.H.SM Toolkit

In addition to this article, MSAA has produced a variety of informational tools to help people maximum their success with S.E.A.R.C.H.SM The S.E.A.R.C.H.SM tools are available as PDF documents at www.msassociation.org. The first tool is a laminated wallet-size, reference card which includes the six key elements of S.E.A.R.C.H.SM. Designed as a simple guide that is convenient to carry and readily available, this four-sided card provides a basic explanation of S.E.A.R.C.H.SM and offers suggested questions to begin the conversation with your healthcare team.

As a secondary and more comprehensive tool to help organize and manage the many aspects of S.E.A.R.C.H.SM, MSAA has created a very useful patient workbook. The MSAA S.E.A.R.C.H.SM Patient Workbook serves as an effective tool to help you research, collect, organize, and store information about your decision to start an MS disease modifying therapy or re-evaluate your current treatment options. With so much information to manage, this Workbook offers you a convenient way to journal and maintain accurate notes on research information, key questions and answers from your healthcare providers, and additional resources. The Workbook concludes with a office visit questionnaire which serves as a guide to help prioritize your S.E.A.R.C.H.SM questions and maximize your office visit.

As the S.E.A.R.C.H.SM campaign begins to gain awareness and momentum, MSAA plans to roll out additional activities and tools including an on-demand educational video, live webcasts, a series of in-person public education programs, a smart-phone application, and the development of additional support materials for healthcare professionals and patients.

Treatment Chart

Below please see an easy-to-follow reference chart on the currently approved and available MS disease modifying therapies. This chart does not address the issues of efficacy, safety, and risk. All of the disease-modifying therapies for MS have different benefits and risks. The effectiveness and side effects of each drug may vary from one patient to another. Additionally, patients who do not respond well to one DMT may benefit by switching to a different treatment. Individuals need to consult with their healthcare team to determine which treatment might be the best option for them.

Currently Approved MS Treatments

DRUG	FDA APPROVAL	MECHANISM OF ACTION	ADMINISTERED
Avonex (interferon beta-1a) Parent company: *Biogen Idec*	Approved for relapsing forms of MS in 1996 and for individuals with clinically isolated syndrome (CIS).	Avonex is an interferon. Interferons appear to reduce inflammation by modulating a favorable balance between cells that increase inflammation and cells that decrease it.	30 micrograms taken via weekly intermuscular injections
Betaseron (interferon beta-1b) Parent company: *Bayer Healthcare Pharmaceuticals*	Approved for relapsing forms of MS in 1993 and for individuals with clinically isolated syndrome (CIS).	Betaseron is an interferon. Interferons appear to reduce inflammation by modulating a favorable balance between cells that increase inflammation and cells that decrease it.	250 micrograms taken via subcutaneous injections every other day
Copaxone (glatiramer acetate) Parent company: *Teva Neuroscience*	Approved for relapsing forms of MS in 1996 and for individuals with clinically isolated syndrome (CIS).	Copaxone is a synthetic polypeptide that mimics myelin basic protein, a key component of the myelin sheath that is damaged in MS. By a different mechanism of action than the interferons, Copaxone also appears to reduce inflammation by modulating a favorable balance between cells that increase inflammation and cells that decrease it.	20 milligrams taken via daily subcutaneous injections
Extavia (interferon beta-1b) Parent company: *Novartis Pharmaceuticals Corp.*	Approved for relapsing forms of MS in 2010 and for individuals with CIS.	Extavia is an interferon beta-1b that is biologically identical to Betaseron and made in an identical process, but marketed by a different company.	250 micrograms taken via subcutaneous injections every other day
Gilenya (fingolimod, FTY720) Parent company: *Novartis Pharmaceuticals Corp*	Approved for relapsing forms of MS in 2010	Gilenya blocks potentially damaging T cells from leaving lymph nodes, thereby lowering their number in the blood, central nervous system and tissues.	First oral DMT for MS. 0.5 mg capsule taken orally once per day
Novantrone (mitoxantrone) Parent company: *EMD Serono, Inc.*	Approved for use in secondary-progressive MS (SPMS), progressive-relapsing MS (PRMS) and worsening RRMS in 2000	Novantrone is an immunosuppressant that has been used for years to treat cancer. It targets rapidly dividing cells, including those believed to be involved in MS.	IV infusion once every 3 months (for two to three years maximum). 12 mg/m2 approximately 5 to 15 minutes
Rebif (interferon beta-1a) Parent companies: *EMD Serono, Inc. and Pfizer Inc.*	Approved for relapsing forms of MS in 2002.	Rebif is an interferon. Interferons appear to reduce inflammation by modulating a favorable balance between cells that increase inflammation and cells that decrease it.	44 micrograms taken via subcutaneous injections three times weekly
Tysabri (natalizumab) Parent companies: *Biogen Idec and Elan Pharmaceuticals*	Approved for relapsing forms of MS in 2006	This laboratory-produced monoclonal antibody acts against a molecule involved in the activation and function of lymphocytes and their migration into the central nervous system (CNS). It is thought to prevent damaging immune cells from crossing the blood-brain barrier.	IV infusion every four weeks 300 milligrams (mg) over 1 hour

MS Resource Guide

MSAA: For more information on FDA-approved therapies, symptom management treatments, and MSAA programs and services, please access additional sections of this website or contact MSAA at (800) 532-7667 or MSquestions@msassociation.org**.**

MS Coalition: The MS Coalition is a collaborative network of independent MS organizations. The MS Coalition's mission is to increase opportunities for cooperation and provide greater opportunity to leverage the effective use of resources for the benefit of the MS community. Please visit: **www.multiplesclerosiscoalition.org.**

In addition to MSAA, the MS Coalition members include:
(listed alphabetically)

Accelerated Cure Project for Multiple Sclerosis
Phone: (781) 487-0008; Website: www.acceleratedcure.org

Consortium of Multiple Sclerosis Centers (CMSC)
Phone: (201) 837-0727; Website: www.mscare.org or www.narcoms.org

Can Do Multiple Sclerosis
Phone: (800) 367-3101; Website: www.mscando.org

International Organization of Multiple Sclerosis Nurses
Phone: (201) 487-1050; Website: www.iomsn.org

Multiple Sclerosis Foundation
Phone: (800) 225-6495; Website: www.msfocus.org

National Multiple Sclerosis Society
Phone: (800) 344-4867; Website: www.nmss.org

United Spinal Association
Phone: (718) 803-3782; Website: www.unitedspinal.org

Assistance Programs of Approved MS Therapies:
The following pharmaceutical companies offer patient programs to provide information, instruction, and resources for advocacy and financial assistance.
(listed alphabetically)

Avonex - MS ActiveSource
(800) 456-2255
www.avonex.com

Betaseron - Betaplus MS Support
(800) 788-1467
www.betaseron.com

Copaxone - Shared Solutions
(800) 887-8100
www.sharedsolutions.com

Extavia Patient Support Program
(866) 925-2333
www.extavia.com

Gilenya Patient Support Program
(877) 408-4974
www.gilenya.com

Rebif - MS LifeLines
(877) 447-3243
www.MSLifeLines.com

Novantrone - MS LifeLines
(877) 447-3243
www.novantrone.com

Tysabri
(800) 456-2255
www.tysabri.com

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