



**MULTIPLE SCLEROSIS
ASSOCIATION OF AMERICA**

S.E.A.R.C.H.SM Patient Workbook

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

What is S.E.A.R.C.H.SM?

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. Since then, numerous effective disease modifying therapies (DMTs) for MS have become available, giving neurologists and patients a variety of treatment options for slowing disease activity. With the recent introduction of an oral medication, and with new investigational drugs nearing completion of their trials, changes in the MS landscape continue to evolve at a rapid pace.

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 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.

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)

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 and reach their desired destination. Also, patients can use the S.E.A.R.C.H.SM tool to “recalculate” their decisions and adjust treatments if necessary in order to maximize optimum health outcomes.

About this 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 MSAA S.E.A.R.C.H.SM Patient Workbook includes the following sections:

1. MS Disease Modifying Therapy Chart

- an easy-to-follow chart which organizes currently approved MS treatment options

2. MS Resource Guide

- a comprehensive listing of MS resources and services to aid your research efforts

3. S.E.A.R.C.H.SM Questions and Notes

- suggested questions for each aspect of S.E.A.R.C.H.SM with ample space for notes

4. Office Visit Questionnaire

- a guide to help prioritize your S.E.A.R.C.H.SM questions and maximize your office visit

Maximizing Your Visit:

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.

In order to make the most of the limited time with the doctor, patients need to come as prepared as possible and prioritize their issues for discussion. The MSAA S.E.A.R.C.H.SM model helps you learn about and prioritize the keys issues which are most important to your healthcare needs. By concentrating on a few of these key areas, you can present your questions and concerns in a clear cut, easy, and efficient way which will allow the most important topics to be discussed upfront and help maximize your office visit.

Using the S.E.A.R.C.H.SM Questions:

MSAA developed the 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.

Section 1. MS Disease Modifying Therapy Chart

Currently Approved MS Treatments

DRUG	FDA APPROVAL	MECHANISM OF ACTION	ADMINISTERED
Avonex (interferon beta-1a) Parent company: <i>Biogen Idec</i>	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 intramuscular injections
Betaseron (interferon beta-1b) Parent company: <i>Bayer Healthcare Pharmaceuticals</i>	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: <i>Teva Neuroscience</i>	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: <i>Novartis Pharmaceuticals Corporation.</i>	Approved for relapsing forms of MS in 2010 and for individuals with clinically isolated syndrome (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: <i>Novartis Pharmaceuticals Corporation</i>	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: <i>EMD Serono, Inc.</i>	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/m ² approximately 5 to 15 minutes
Rebif (interferon beta-1a) Parent companies: <i>EMD Serono, Inc. and Pfizer Inc.</i>	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: <i>Biogen Idec and Elan Pharmaceuticals</i>	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

Section 2. 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 (listed alphabetically) include:

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.ms-care.org or www.narcoms.org

Can Do Multiple Sclerosis

Phone: (800) 367-3101; Website: www.ms-cando.org

International Organization of Multiple Sclerosis Nurses

Phone: (201) 487-1050; Website: www.iomsn.org

Multiple Sclerosis Foundation

Phone: (800) 225-6495; Website: www.ms-focus.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

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

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

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

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

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

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

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

Section 3. S.E.A.R.C.H.SM Questions and Notes

S = Safety:

Suggested Questions:

- 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?

Additional Questions:

- _____
- _____
- _____
- _____

Notes:

E = Effectiveness:

Suggested Questions:

- 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?

Additional Questions:

- _____
- _____
- _____
- _____

Notes:

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

Suggested Questions:

- 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?

Additional Questions:

- _____
- _____
- _____
- _____

Notes:

R = Risks:

Suggested Questions:

- 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?

Additional Questions:

- _____
- _____
- _____
- _____

Notes:

C = Convenience:

Suggested Questions:

- 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?

Additional Questions:

- _____
- _____
- _____
- _____

Notes:

H = Health Outcomes:

Suggested Questions:

- 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?

Additional Questions:

- _____
- _____
- _____
- _____

Notes:

Section 4. Office Visit Questionnaire

As mentioned in this Workbook, the goal of S.E.A.R.C.H.SM is to help you achieve optimum healthcare by improving your own health literacy and inspiring you to actively manage your MS. By using the S.E.A.R.C.H.SM framework, you should be able to learn more about your specific needs and prioritize questions and concerns in order to maximize your time with your doctor or healthcare provider. Please review all of your Workbook notes, complete the following section, and bring with you during your office visits with your doctor or healthcare provider.

Based on your review of the six elements of S.E.A.R.C.H.SM and a careful evaluation of the notes from this Workbook, please develop and list very specific questions which stand out as the most important issues to discuss with your doctor or healthcare provider. These questions can relate to any of the six aspects of S.E.A.R.C.H.SM

My top priority S.E.A.R.C.H.SM questions are:

1. _____
2. _____
3. _____

Given the comprehensiveness of S.E.A.R.C.H.SM, MSAA recognizes you may also have supplemental questions which factor into this important decision-making process. Please develop and list very specific supplemental questions to discuss with your doctor or healthcare provider. Again, these questions can relate to all aspects of S.E.A.R.C.H.SM

My supplemental S.E.A.R.C.H.SM questions are:

4. _____
5. _____
6. _____

Please know your questions may also be addressed by support staff within your doctor's office or among the many resources listed in this Workbook. It is important to realize you may need to schedule follow-up appointments with your doctor and healthcare team to fully review all aspects of S.E.A.R.C.H.SM before choosing a therapy that is right for you.

Notes:

Notes continued:

The MSAA S.E.A.R.C.H.SM initiative is made possible through unrestricted educational grants from Bayer Healthcare Pharmaceuticals, Biogen Idec, and Teva Neuroscience. MSAA is solely responsible for the development of S.E.A.R.C.H.SM and its content.

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