

Patient Rheumatoid Arthritis Social Support Initiative

# BRIGHAM AND WOMEN'S HOSPITAL Rheumatology Division – Arthritis Center

# Brigham and Women Resource Guide

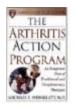
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## Books:

Arthritis Action Program: An Integrated Plan of Traditional and Complementary Therapies - Michael Weinblatt, M.D.

Pub. Date: Dec. 2001



Dr. Michael Weinblatt, one of the primary investigators of BRASS, offers a medical guide to rheumatoid arthritis, including background information about RA and an analysis of alternative therapies. He compares current medications and their risks and offers a physician's perspective on managing the illness. This guide is a valuable reference and resource.

Pain Was My Middle Name - Anita Li Chun

Pub. Date: Feb. 2006



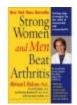
In this stirring memoir, Ms. Chun shares the challenges she has encountered living with RA since she was diagnosed at 26. She describes how, through tenacity and a positive approach, she has been able to conquer the difficulties of her illness and live a happy and complete life.

The First Year-Rheumatoid Arthritis: An Essential Guide for the Newly Diagnosed - M.E.A McNeal and Kevin Sack

Pub. Date: Jan. 2006



Drawing on the knowledge she amassed about RA since her own diagnosis, Ms. McNeil has compiled this excellent manual for the newly diagnosed. She details what to expect during the first year after diagnosis, including lifestyle and habit changes helpful to tackling RA. Ms. McNeil also addresses the emotional impact of RA and how to find support groups.



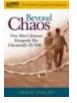
Strong Women and Men Beat Arthritis - Miriam E. Nelson, Kristin Baker, Lawrence Lindner, Ronenn Roubenoff

Pub. Date: March 2003

The authors of this book have developed a simple and practical plan that has been proven to help reduce the pain and immobility of arthritis. This book contains a home strength-training regimen as well as a nutritional plan to reduce stiffness, inflammation, and other arthritis symptoms.

Beyond Chaos: One Man's Journey Alongside His Chronically III Wife - Gregg Pilburn

Pub. Date: 2000



Gregg Pilburn shares the courageous and heartwarming story of how his wife's fibromyalgia changed not only her life, but their relationship and his life as well. Learn how he worked through the frustration, anger and guilt to re-examine his priorities and expectations. Discover how living with chronic illness brought a new level of trust and intimacy to his marriage, and let his experiences guide you through your own journey.



Wellness Book: The Comprehensive Guide to Maintaining Health and Treating Stress-Related Illness

Pub. Date: 1993

Herbert Benson and Eileen M., R.N. Stuart share their extensive knowledge, providing patients insight into gaining control of their health and wellbeing. This book outlines many relaxation techniques useful for treating stress related illnesses.



Get a Grip! : A Take-Charge Approach to Living with Arthritis

Pub. Date: 2002

Amye Leong and Joe Layden share Amye's personal story coping with a life changing diagnosis of Rheumatoid Arthritis at the age of eighteen. Amye discusses her struggles and eventual triumphs over her disease, bringing a fresh outlook on the day-to-day issues faced by the millions of Americans with RA.

### **BWH Clinical Resources**

Pain Management Clinic: Offers a range of services from simple office procedures, such as trigger point injections and epidural steroid injections, to fluoroscopically guided procedures, such as facet injections or lumbar sympathetic blocks.

617-732-9060 850 Boylston Street Chestnut Hill, MA 02467 http://www.brighamandwomens.org/anesthesiology/Pain/

**Sleep clinic:** Our department is proud to serve the patient community and their families. We provide state-of-the-art evaluation and treatment services, and delivering quality patient care is the center of everything we do. For individual service descriptions and other resources for patients, please visit the Patient Resources section of our site.



Sleep Clinic Sleep Health Center Suite 109 1400 Centre Street Newton, MA 02459 Tel: (617) 527-2227 http://www.brighamandwomens.org/sleepdisorders/

**Outpatient Physical and Occupational Therapy:**\_The department of Rehabilitation services of Brigham & Women's Hospital provides Physical and Occupational Therapy Services, Speech and Swallowing Services and Orthopedic Technician Services.

Brigham & Women's Hospital Department of Rehabilitation Services Ambulatory Service (45 Francis Street): 617-732-5304 Brigham & Women's Department of Rehabilitation Services Ambulatory Service (850 Boylston Street): 617-732-9525 http://www.brighamandwomens.org/RehabilitationServices/default.aspx

# Osher Clinical Center for Complimentary and Integrated Medical Therapies:

The Osher Center staff has worked and trained together for several years, becoming a cohesive team whose members understand the value of each other's unique treatment approach. When appropriate, we offer a combination of therapies under one roof, documented in the patient's Brigham and Women's Hospital unified electronic medical record. Most important is that we encourage patients to participate actively in any decisions regarding their health care. Services we provide are acupuncture, chiropractic, massage, mindfulness-based stress reduction, occupational therapy, consults on herbs, vitamins and supplements and more.

Osher Clinical Center for Complementary and Integrative Medical Therapies Brigham and Women's Ambulatory Care Center 850 Boylston Street Boston, MA 02115 Phone: (617) 732-9700 http://www.brighamandwomens.org/medicine/oshercenter/default.aspx

#### Brigham and Women's Patient Services

Patient services can assist you with questions regarding insurance, billing, and medical visits.

Brigham and Women's Outpatient Services Outpatient services: 617-732-5964 Patient billing: 617-724-1914 Inpatient accounts: 617-732-5538 Doctors referral services: 1-800-608-6294

If you have trouble paying for medication or services, speak with your doctor about potential monetary assistance.

#### Brigham and Women's Medical Records The medical records department provides patients access to their records. Having access to your records can ease the stress of changing doctors or relocating to a new area.

Brigham and Women's Medical Records: 617-732-6071 Radiological films: 617-732-7180 Financial Assistance for Medications Rheumatoid Arthritis Patients



1. Enliven - A program funded by Amgen, provides financial assistance to individuals without insurance who are on Enbrel. Patients must be on Enbrel and can not have insurance.

Residents of Massachusetts can not use Enliven services.

Contact Information:

An Enliven representative can be reached at 1-888-436-2735. <u>http://www.enlivenservices.com</u>

2. Encourage Foundation - Foundation that provides financial assistance to patients on Enbrel who have insurance. Assists with medication and medical visit co-payments.

To receive information contact the Enliven program listed above.

- 3. HealthWell Foundation The HealthWell Foundation<sup>®</sup> is a 501(c)(3) non-profit, charitable organization that helps individuals afford prescription medications they are taking for specific illnesses. The Foundation provides financial assistance to eligible patients to cover certain out-of-pocket health care costs, including:
  - Prescription drug coinsurance, co-payments, and deductibles
  - Health insurance premiums
  - Other selected out-of-pocket health care costs

Contact Information:

The HealthWell Foundation<sup>®</sup> P.O. Box 4133 Gaithersburg, MD 20878 1-800-675-8416

http://www.healthwellfoundation.org



| Arthritis Foundation     |
|--------------------------|
| P.O. Box 7669            |
| Atlanta, GA 30357-0669   |
| 1-800-283-7800           |
| http://www.arthritis.org |
|                          |

Massachusetts Chapter 29 Crafts Street, Suite 450

Newton, MA 02458-1287

info.ma@arthritis.org

Phone: 617-244-1800

Toll-free: 800-766-9449

# **Arthritis Foundation**

The Arthritis Foundation is a national not-for-profit organization that supports different types of arthritis and related conditions with social support, advocacy, programs, services, and research.

The Arthritis Foundation publishes a bi-monthly magazine called "Arthritis Today" which covers medications, lifestyle issues, nutrition, and many other topics. A free issue is provided by signing up on the Arthritis Foundations website http://www.arthritis.org.



#### Massachusetts Chapter

The Massachusetts branch of the AF offers variety of programs and events throughout the year and continues working hard to expand our reach into communities and areas that need our services. For example, you can find a list of aquatic and exercise programs offered across the state on their website.<u>http://www.arthritis.org/chapters/massachusetts/</u>

#### *RA*Connect

A special section on the AF website, *RA*Connect, connects people with arthritis to talk to others or to ask experts. It contains a wealth of information including a number of personal areas - chats, personal stories, personal profiles, expression gallery where people post pictures or brief



summaries of themselves. This community was designed to be easily accessible despite location or lack of resources, whether you are undergoing treatment and may not be physically able to attend a traditional support group or if you feel uncomfortable sharing your experiences, concerns and fears in public settings. The service is free, convenient around the clock via the Internet.

Connect with the online discussion group to talk with others on any issue related to living with RA. Hearing about other's experiences and stories gives emotional relief, helps you feel less isolated, and provides a place to discuss things you might not be comfortable talking about with your physician. Topics can range from dealing with the nausea and fatigue from Methotrexate vacations.

http://ww2.arthritis.org/communitiesnew/forum/radiscussion.aspx

## Websites

- 1. The BRASS Study website can be accessed at <a href="http://www.brassstudy.org">http://www.brassstudy.org</a>. This website contains information about the Brigham and Women's Sequential Arthritis Study (BRASS), stories of patients with RA, newsletters, and a forum for discussion between participants.
- 2. The PACO website can be found at <u>www.pacostudy.org.</u> The Patient Centered Outcome Initiative (PACO) website provides information about patient tools, upcoming seminars, and community outreach.
- 3. The Arthritis foundation website can be accessed at <a href="http://www.arthritis.org/">http://www.arthritis.org/</a>. This website offers information on the latest research, literature, and other information regarding RA management.
- 4. HealthTalk has an RA community at <u>http://www.healthtalk.com</u>.

Resources found on the Brigham and Women's Rheumatoid Arthritis Sequential Study (BRASS) website.

 Medications - issues around drugs, which drug might be better, and drug side effects are better discussed with the doctor. However, a peer coach can talk about their own experiences e.g., fatigue from methotrexate. Basic information about the different medications is available at: http://www.brassstudy.org/?page\_id=22

> There is also video of Dr. Weinblatt's June 4<sup>th</sup> presentation on RA mediation history, current drugs and recent developments, and future research. http://www.brassstudy.org/?page\_id=75

- 2. Latest research Patients should ask their doctors for the latest relevant research.
- Fatigue If the person is having overwhelming fatigue, again it is important to have them talk with their doctor. A brief article of some self-management techniques is available at: <u>http://www.brassstudy.org/?page\_id=3</u>
- 4. Pain management This is an important topic for the patient to take up either with the nurse or their doctor. (Pain can

lead to a cycle of depression, fatigue, and sleeplessness leading to more depression and pain.)

- Herbs, vitamins, and alternative therapies. The research isn't clear about the benefits of particular herbs and some interact negatively with RA medications. It is best for the person to check with their doctor if there is any question whatsoever. You can read an overview about "Herbs, Acupuncture, Massage and Exercise at: <u>http://www.brassstudy.org/?page\_id=65</u>
- 6. Cardiovascular health -

Research has shown that rheumatoid arthritis (RA) patients have a shorter life expectancy than the general population. This is mostly due to the increased prevalence of cardiovascular disease (CVD) in RA patients. Researchers have yet to determine the exact reason for this high occurrence rate, but we do know that there are several things that you can do to decrease either your risk or severity of CVD. To read about ways to decrease risk, go to: http://www.brassstudy.org/?page\_id=5

## **Transportation Resources**

To apply for a Handicap plate:

Application forms for a disabled license plate and placard can be found at: <u>http://www.mass.gov/rmv/forms/disabled.htm</u>

The forms need to be completed by the applicant as well as signed by a medical professional.

There are several different services that provide transportation to medical appointments in and around the Boston area.

1. MARTA (Massachusetts Association of Regional Transit Authorities): MARTA provides shuttle services to veterans, elderly, and disabled individuals to medical appointments around Boston and surrounding areas for a fee. For service information call the numbers listed below are you can access information on the MARTA website. Individuals on Medicaid can be deemed eligible for free transportation.

MARTA 978-353-0333 1-800-854-9928 #2 <u>info@MontachusettRTA.org</u>.

2. The Ride:

The Ride is a paratransit program of the MBTA. This service provides door to door transportation to people with physical limitations that are unable to use general transportation all or some of the time. The ride costs 2.00 each way per individual. An application is necessary and can be accessed on the MBTA website or by calling the numbers listed below.

MBTA Office for Transportation Access 10 Park Plaza - Room 5750 Boston, MA 02116 (800) 533-6282 in-state toll free (617) 222-5123 TTY (617) 222-5415 http://www.mbta.com