



# BRASS

Brigham and Women's Rheumatoid Arthritis Sequential Study

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## From the Directors

*Nancy A. Shadick, MD and Michael E. Weinblatt, MD*

BRASS had a wonderful year thanks to you! We have 941 people participating in our study with plans to reach 1000 by the end of the year. Your participation has led to a number of advances including research on genetics and susceptibility to RA, exercise beliefs of people with RA, response to anti-TNF alpha therapy and much more. Summaries of two research areas are in the Research and Publications article (p.4). At this year's American College of Rheumatology's Annual Scientific Meeting in Washington, DC, we will present seven of our research projects — an indication of the breadth of our research and interest by the RA community. As we move into our third year we look forward to continuing to work with you to improve the lives of people with RA.

## Patient-Centered Outcomes

*by Sally Miller*

Did you know research has found that effective communication between you and your rheumatologist can make a difference in how well you feel and how your disease progresses? What you discuss during your clinic visit helps you and your doctor monitor your progress, decide about different courses of treatment, and think about the best ways to manage your rheumatoid arthritis. ...cont'd on page 2



## Patient-Centered Outcomes: cont'd from page 1

There is exciting and innovative work being done nationally on patient-physician communication to shift medical care toward a focus on patient priorities and perspectives for treatments and care. The National Institutes of Health have recently funded several studies across the country in different medical specialties to make the healthcare experience more patient-driven. Now Brigham and Women's Hospital has received funding from the Bristol

Myers Squibb Foundation to work with our patients and rheumatologists to find new ways to help you and your doctor share information during clinic visits.

*We hope over the next year or two to learn from you and your rheumatologist in the clinic about what works well and what doesn't in your visits; what aspects of your treatment are important to you; and what makes you satisfied or dissatisfied with your treatment.*

Under the direction of Dr. Nancy Shadick, we will be learning from you and your rheumatologist over the next two years what works well and what doesn't during your visits; what aspects of your treatment are important to you; and what makes you satisfied or dissatisfied with your treatment. Armed with this knowledge, we plan to find new ways to assist you in communicating your

perspective and how you are feeling to your doctor—and your doctor will communicate his or her knowledge and expertise of RA to you. Some possible ideas include new paper and computer-based tools that would make it easier for you to indicate your concerns to your doctor.

If you have visited our little cubbyhole in the arthritis clinic recently, you have probably been asked if you'd be interested in helping us with our exciting initiative — known as Patient-Centered Outcomes, or PACO. We are currently recruiting for focus groups and have people signed up for the project already. We will be calling more people each week until we enroll enough for our focus groups. People who participate in PACO will gather for one focus group meeting with other RA patients to discuss their experiences with RA and their priorities for care.

We have run 2 focus groups and have 3 others scheduled. If you have any questions or would like more information about PACO please contact the Project Manager, Melanie Zibit at 617-525-8367 or send email to [PACO@brassstudy.org](mailto:PACO@brassstudy.org)



## FDA Approves Two New Drugs for RA – Abatacept (Orencia) and Rituximab (Rituxan)

by Sarah Bell

You may have heard about two medications recently approved for use in rheumatoid arthritis—abatacept (Orencia) and rituximab (Rituxan). Both treatments are categorized as biologics—medications that mimic the effects of substances made naturally by your immune system. Other biologics that treat RA are etanercept (Enbrel), infliximab (Remicade), and adalimumab (Humira).

Early arthritis medications acted on the immune system as a whole, tending to cause destruction of both diseased and healthy cells. More recently, drugs such as etanercept, infliximab, and adalimumab were developed to block the production of tumor necrosis factor alpha (TNF- $\alpha$ ), a protein found in large quantities in rheumatoid joints. In comparison, abatacept and rituximab are engineered

to target certain cells that play a role in the overactive immune response. Specifically, RA patients have antibodies that recognize parts of the joint lining as foreign and mount an attack against the body itself. Abatacept works by deactivating T-cells and rituximab focuses on clearing out B-cells. Both types of cells play a role in the overactive immune response. These two new medications help to quell the pain and inflammation of the autoimmune response.



Both medications have been shown in clinical trials to be effective for patients who have not responded well to methotrexate or other biologics. Results show that after six months on abatacept, half of the patients experienced at least a 20% improvement, one out of every five patients experienced a 50% improvement, and one out of every ten patients experienced remission. Similarly, in rituximab trials at week 24, 43% of patients taking rituximab in combination with methotrxate achieved a 50% improvement. Thirty-three percent of patients taking rituximab alone showed a 30% improvement rate.

*Both medications have side effects that you should discuss with your rheumatologist.*

### ***Abatacept (Orencia):***

*½ hour infusions every 2 weeks for the first month, then every 4 weeks*

### ***Rituximab (Rituxan):***

*A single treatment (2 infusions) often followed up in 6 months.*



## Highlights from Our Publications and Academic Collaborations

We have been busy over the last few years gathering, analyzing and presenting the data you have so generously given us. Here are a few highlights of our publications and collaborations with other academic and medical centers:

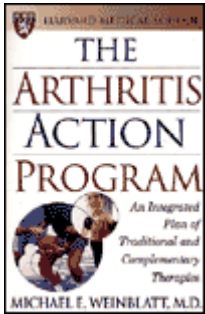


- We have been collaborating with researchers at the Harvard and MIT Broad Institute to analyze and classify your genetic data. With help from the BRASS data, researchers there have developed a new method, called EIGENSTRAT, to more accurately stratify populations—including our BRASS group—and better identify genetic associations with diseases.
- We recently presented data in two areas that might be of particular interest to you. Here's a short synopsis of each:
  - Our program director Nancy Maher—whom many of you have met in clinic—presented data at the American College of Rheumatology Conference on the topic “Do differences in how patients and their doctors view overall disease activity lead to a change in medications?” She compared your general overall health rating from your questionnaire (how you feel on a 0-10 scale) with a similar rating given by your rheumatologist. She found that 70% of the time rheumatologists and patients agree about overall disease activity. Then looking at what motivates a change in medications, she found that when the rheumatologist rates disease activity higher than the patient or the patient had rheumatoid arthritis for less than 5 years or the patient reports high disease activity on the numerical scale, there was more likely to be a change in medication.
  - You may have heard that caffeine could interfere with your methotrexate. Among our patients who take methotrexate, this did not hold true. You may remember filling out information about food and drink consumption on your first questionnaire. We used that to divide you into three groups by the amount of caffeine you drink—low, medium and high. From the questions we ask you about how well you are able to do certain tasks, as well as blood tests for inflammation level such as C-reactive protein, we were able to determine how effectively your methotrexate is working. We found that there were no differences in the effectiveness of methotrexate across the three levels of caffeine intake. This research suggests that your response to methotrexate is not affected by how much coffee you drink and the medication continues to work effectively. This research was published in the Journal of Rheumatology. If you would like to learn more about these articles, send an email to [questions@BRASSstudy.org](mailto:questions@BRASSstudy.org).
- We will be presenting several abstracts at the annual American College of Rheumatology Conference—in Washington D.C. this year.



## BRASS Bookshelf

by Alison Grant



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

*Pub.Date: Dec. 2001*

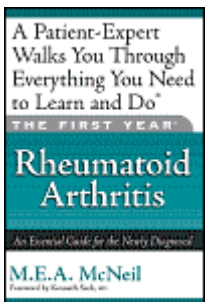
Dr. Weinblatt, one of the primary investigators of BRASS, offers a medical guide to rheumatoid arthritis, including background information about RA and an analysis of alternative therapies. He compares current medications and their risks and offers a physician's perspective on managing the illness. This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



### **Pain Was My Middle Name** – Anita Li Chun

*Pub.Date: Feb. 2006*

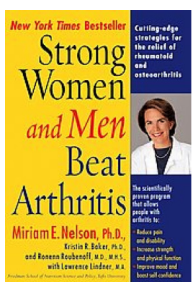
In this stirring memoir, Ms. Chun shares the challenges she has encountered living with RA since she was diagnosed at 26. She describes how, through tenacity and a positive approach, she has been able to conquer the difficulties of her illness and live a happy and complete life.



### **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 regime to reduce arthritis symptoms.

## Tips on Making the Most of Your Clinic Appointment

by Rheumatologist Kerri Batra, MD

We understand that a visit to see one of us at the Arthritis Clinic can be stressful. After rearranging your schedule, navigating Boston traffic and finally arriving at the Brigham & Women's Hospital, you can barely remember why you're here. With so much on your mind, how can you get the most out of your appointment?

Here are a few recommendations. All of them involve being an active participant in your care. We strongly encourage you to take ownership of both your appointment time and your illness. Studies have shown that involvement with your own care can actually lead to a decrease in disease activity. While we will always provide you with guidance and information, you are the ultimate driver of your own health care.



### 1. Prepare for your visit:

- a. *Bring your questions:* Between appointments, write down your concerns and questions. Starting with these questions will allow you to take control of the appointment and direct the discussion where it will most help you.
- b. *Make a medication list:* Write down your medications, including dosages. If you don't have time, put all of your medications in a bag and bring them with you. This will save us a lot of time that we can then use to answer all of your questions!
- c. *Keep a notebook of symptoms:* If you're feeling well at the time of your appointment, you may forget what was bothering you so much last week. Keep a record of symptoms and when you have them.

*Between appointments, write down your concerns and questions. Starting with these questions will allow you to take control of the appointment and direct the discussion where it will most help you.*

**2. Tell us what really worries you (but don't wait until you have one foot out the door):** Do you have a friend or family member who ended up very sick with RA? Are you afraid that your medication will cause cancer? A lot of people have these nagging concerns, but don't tell us because they think they are irrelevant or irrational. If something bothers you, it is neither irrelevant nor irrational. If you are worried about something, we want to know. But be sure to tell us at the beginning of your appointment so we have enough time to fully address your concerns. ...cont'd on page 8

## RA Resources, Forums Online as We Launch our New Site



While your rheumatologist is your best resource, you may sometimes feel that you want to search for information on your own. Patients, particularly those with chronic illnesses like RA, are increasingly turning to the Internet to better understand their illnesses and to find support from people with similar conditions. There are many websites out there about Rheumatoid Arthritis—many with high quality information—but it is not always easy to know where to look and which sites to trust.

The BRASS staff, therefore, is designing a website specifically for you—with answers to questions, support networks and links to other sites that we think our participants will find useful. We plan to have information that will keep you up-to-date on new treatments and medications, as well as articles about nutrition and exercise to help you maintain a healthy lifestyle. The website will also provide updates on BRASS research, photos and brief biographies of BRASS staff.

There will also be a place for you to exchange thoughts and questions with other BRASS participants. Connecting with others who have RA can be another source of support and an opportunity to share ideas on anything from treatment options to managing your RA.



*We are interested in your comments and suggestions. If there is anything in particular you would like to see on the website, we welcome your thoughts. If you would like to contribute an article or a personal story we would be delighted. Or, if there is simply some interesting nugget you want to share, you can send Melanie Zibit an email [questions@BRASSstudy.org](mailto:questions@BRASSstudy.org) or contact her by phone (617 552 8367).*

### Helpful RA related Websites

[www.arthritis.org/](http://www.arthritis.org/)

[www.cdc.gov/arthritis/](http://www.cdc.gov/arthritis/)

[www.niams.nih.gov/](http://www.niams.nih.gov/)

[www.nlm.nih.gov/medlineplus/rheumatoidarthritis.html](http://www.nlm.nih.gov/medlineplus/rheumatoidarthritis.html)

[www.rheumatology.org/public/factsheets/ra\\_new.asp](http://www.rheumatology.org/public/factsheets/ra_new.asp)

## Tips on Making the Most of Your Clinic Appointment: cont'd from page 6

- 3. Please tell us if you don't understand something:** We spend many years learning medical terminology and speak all day with other doctors in medical language. Occasionally we mistakenly slip into our technical jargon—which we certainly don't expect you to be experts on—so please ask us to explain if something sounds unfamiliar. Also, if you don't understand how a medication works, or what kind of treatment we are talking about, just ask us to explain.
- 4. Write it all down:** Ask your doctor for a piece of paper and pen so that you can write any new information down. Ask your doctor for good sources of information from the clinic, the community and the internet.
- 5. Request another appointment:** Some appointments feel rushed and confusing, because there's so much information to absorb and so much to talk about. Feel free to request another appointment. You can use this appointment to ask more questions.

## How to Make the Most of a Nap\*

A nap is any quiet rest period—not necessarily sleep—during daylight hours when you'd normally be awake. Naps are helpful only if they don't interfere with your nighttime sleep.

### Where:

A sofa, recliner, a bed (on top of, not under, the bed covers). You can even nap with your head down on a desk

### How often:

One to three times per day (daylight hours), when you'd normally be active

### How long:

- 10–30 minutes, as often as three times per day
- 1–2 hours, not more than once per day

### Helpful hints:

- Turn TV and music off or go to a quiet environment
- Loosen tight clothes (don't put on sleepwear)
- Dim the lights; if you can't do that, face a corner or use an eye mask
- Close curtains or blinds
- Use light covers or sweater or jacket to avoid getting chilled or overheated

### BRASS Newsletter

Nancy Shadick, MD  
Kerri Batra, MD  
Nancy Maher, MPH  
Melanie Zibit, M Ed, editor  
Jenny Heller, editor  
Sally Miller  
Sarah Bell  
Alison Grant  
Mark Favazza

\*National Multiple Sclerosis Society, (2005) Fatigue: What You Should Know A guide for People with Multiple Sclerosis,  
<http://www.nationalmssociety.org/pdf/Brochures/pvafatigue.pdf>