

# BRASS NEWSLETTER

*annual update*



THIS ISSUE INCLUDES:

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**ANNUAL BRASS UPDATE**

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**PHYSICAL ACTIVITY FOR PATIENTS WITH RA**

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**PATIENT DEFINITIONS OF RA FLARE**

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**STOP-RA TRIAL**

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**UPDATE ON RA MEDICATIONS**

## **BRASS Enters its 15th Year**

*By Christine Iannaccone, MPH*

As always, we are so appreciative of the dedication shown by all of you enrolled in the BRASS study. We are excited to be entering into the fifteenth year of study follow-up with those of you who originally enrolled in 2003!

This was an exciting year for the BRASS team. We presented five scientific abstracts at the annual conference held by the American College of Rheumatology in San Diego in November 2017. Three of the abstracts used data collected from BRASS participants concerning disease activity and RA disease flares. Thank you again to all who contributed data to this project. Please see the associated article in this newsletter for more information.

BRASS will be continuing its study and those of you interested in continuing to increase the understanding of risk factors, co-morbidities and outcomes associated with RA can re-consent to stay in the study another five years! We look forward to working with you.

## Physical Activity Enhancement among Rheumatoid Arthritis Patients

by Nancy Shadick, MD and Maura Iversen, Ph.D

A recent study using BRASS patients' information about the impact of physical activity and attitude towards exercise looked at the clinical, demographic, and psychosocial factors related to patients meeting the recommendations for physical activity as suggested by the Office of Disease Prevention and Health Promotion (at least 150 minutes of moderate exercise or 75 minutes of vigorous activity weekly).

*"Results demonstrated that high RA disease activity was associated with less physical activity participation over 3 years of the study"*

The study found that among patients in BRASS with well controlled disease, only 29% met the recommendations for physical activity. Results indicated that higher RA disease activity was associated with less physical activity over the three years of the study.



Patients who were older, suffered from mental health difficulties, reported physical disabilities, had a higher body mass index (BMI), and those who believed their disease was more severe, were less likely to be physically active.

This study suggests that there is a need to encourage RA patients to participate in different modes of physical activity and stress the importance of meeting the recommendations for physical activity on a weekly basis. If physicians can address the perceptions RA patients have about physical activity as it relates to their RA, patients may be motivated to become more active and possibly live healthier lives.

*Iversen MD, Frits M, von Heideken J, Weinblatt M, Shadick NA. Physical activity and correlates of physical activity participation over three years in adults with rheumatoid arthritis. Arthritis Care Res (Hoboken) 2017;69(10):1535-1545.*

## Understanding Differences in Patient Definitions of Rheumatoid Arthritis Flares

by Gabriella Maica

Flare is an important feature of RA that often renders patients immobile and contributes to a poor quality of life. Recently, the Outcomes in Rheumatology (OMERACT) group defined domains that make up a flare. However, variations in patients' definitions of a flare continue to be observed. BRASS investigators evaluated how demographic and clinical characteristics contribute to these differences.

BRASS participants have completed a flare survey which included the open ended question "What does a flare mean to you?"

Responses to this question were categorized into the OMERACT Core Domains (pain, function, swollen/tender joints, fatigue, stiffness, patient global, participation) and 2 additional research domains (emotional distress, sleep disturbance). RA disease activity was collected at the same visit. Among the 503 subjects, 84% were female, the mean age was 61 years, and the average disease duration was 18 years. On average, 55% of participants reported having at least 1 flare in the past 6 months. Of the 8 OMERACT Core Domains, participants on average indicated 2-3 domains when asked to define a flare. Pain (80%), physical function (44%), and painful joints (36%) were the most commonly recorded. 5 domains showed an association between flare definition and patient characteristics. Participants reported at least one of 8 OMERACT Core domains when defining a flare, however, these domains varied by patients' demographic and clinical states.

### "What does a flare mean to you?"

"Increased pain and/or increased fatigue. There is also swelling during a flare. A flare can make me feel depressed; **threatens my livelihood.**"

"Suddenly feel tired...**know when it's coming.** want to take a nap."



Flare definitions from patients with Low DAS

Flare definitions from patients with Moderate-High DAS



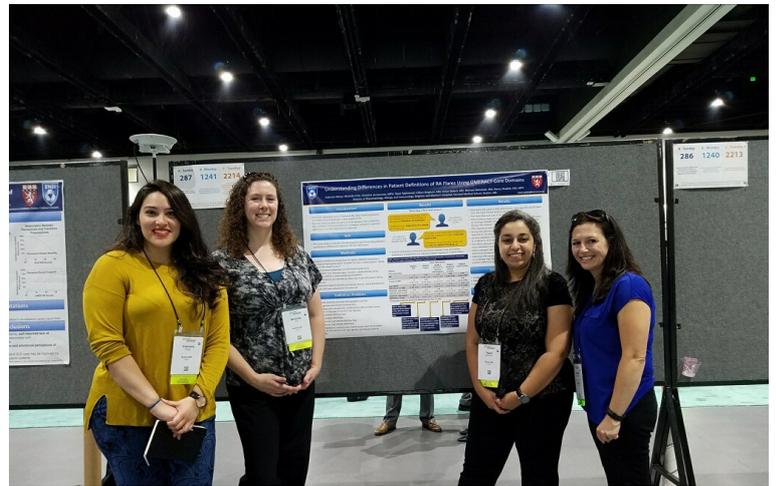
"Flare means a lot of constant pain; no energy level. Horrible day; making a cup of coffee is **a big deal (hard to do).**"

"Incapacitates me. Cannot do daily activities...like having **the flu without throwing up.**"

# RA Patients Definition of a Flare is Related to Disease Activity and Other Factors

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Furthermore, when a participant's current disease activity and experience of a recent flare were evaluated together, differences in participants' descriptions of a flare were observed. Participants were more attuned to describe a flare as pain and fatigue when flaring while in a low disease state. Considering a flare as a decrease in participation was influenced more by being in moderate-high disease activity. Variations in participants' flare definitions can lend insight into how physicians approach RA patients and potentially shed light on the reasoning behind the disagreement that occurs between patient-clinician flare definitions.



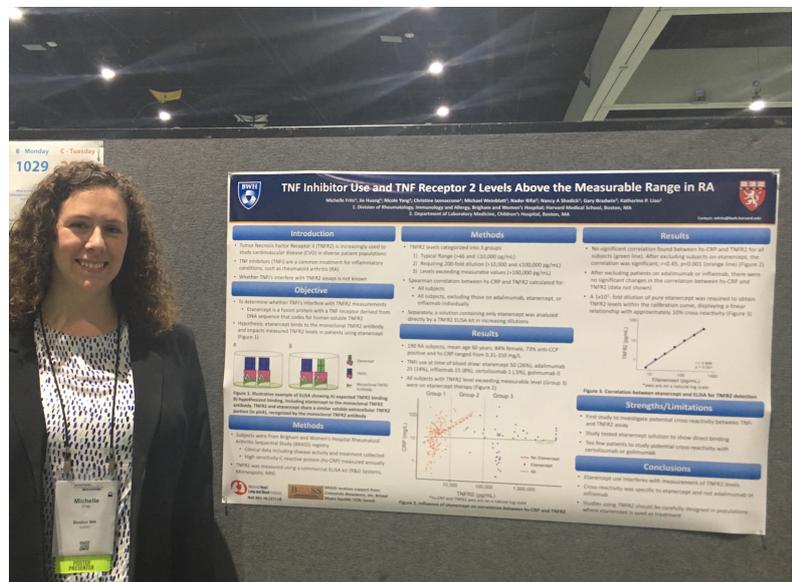
American College of Rheumatology Poster Presentation of "Understanding Differences in Patient Definitions of RA Flares using OMERACT Core Domains"  
From Left to Right: Gabriela Maica, Michelle Frits, Taysir Mahmoud, Christine Iannaccone

Maica G, Frits M, Iannaccone C, Mahmoud T, Bingham C, Bykerk V, Weinblatt M, Shadick N. Understanding Differences in Patient Definitions of RA Flares Using OMERACT Core Domains [abstract]. American College of Rheumatology Conference 2017, San Diego, CA.

## Thank You Michelle Frits!

Michelle Frits joined the BRASS team in the Fall of 2008. After spending almost ten years mastering the data created by all of your questionnaires and interviews, she is going to apply all the skills she learned working with the BRASS registry and work on patient safety and quality of care at the hospital.

Everyone at the BRASS team is incredibly thankful for all of Michelle's contributions to so many important BRASS projects over the last nine years. Congratulations Michelle! We will miss you.



## StopRA: Clinical Trial for Healthy Individuals Without RA

The Rheumatology division at Brigham and Women's Hospital is looking to recruit **first-degree relatives of BRASS participants to screen for RA** for a clinical trial called StopRA.

Led by BWH rheumatologist, **Dr. Jeffrey Sparks**, the research team is looking for healthy individuals who are at increased risk for developing RA based on an RA-related body called cyclic citrullinated peptide (CCP). The first visit will involve blood testing to screen whether your relative has elevated CCP levels. If the CCP test is positive, the research team will further test eligibility for StopRA.

*"For more information or to schedule a visit, contact: [StopRA@bwh.harvard.edu](mailto:StopRA@bwh.harvard.edu)"*

**StopRA** is a national multi-site NIH funded clinical trial. If eligible for the trial portion of Stop RA, your relative will be randomized to hydroxychloroquine or placebo for 12 months and then will be followed for an additional 2 years. He or she will be asked to complete about 11 study visits at Brigham

and Women's Hospital and 7 phone evaluations over the course of the study. Your relative could receive up to \$770 in compensation and parking vouchers if the entire study is completed. **Patients with RA are not eligible.**

Please feel free to share our contact information with any of your first-degree relatives without RA who may be interested in participating in **StopRA!** For more information or to schedule a visit, contact **Alessandra Zaccardelli** at **(617) 264-5902** or **[StopRA@bwh.harvard.edu](mailto:StopRA@bwh.harvard.edu)** Thank you for your support of our research!



This trial is sponsored by the National Institute of Allergy and Infectious Diseases (NIAID) of the National Institutes of Health (NIH)

## An Update on RA Drugs

by Miranda Girard

There are many drugs available to treat rheumatoid arthritis (RA). These medications play an essential role in easing the symptoms of RA, slowing its progression, and inhibiting structural damage brought on by the disease. RA medications typically fall into four categories: Non-steroidal anti-inflammatory drugs (NSAIDs); disease-modifying anti-rheumatic drugs (DMARDs); biologics; non-biologics, and janus kinase (JAK) inhibitors.

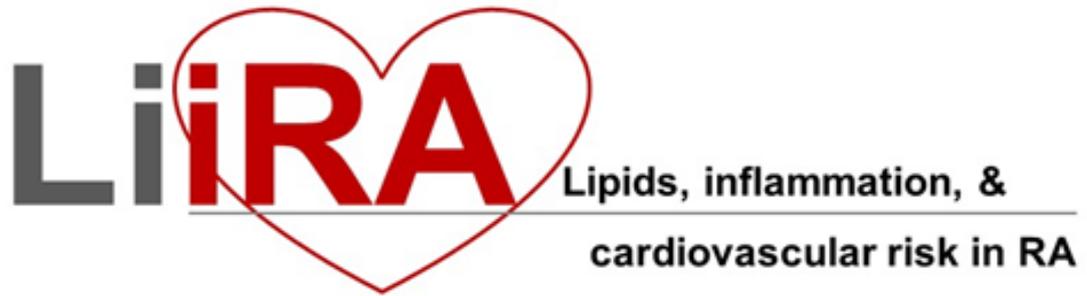
*"Sarilumab (Kevzara®) is the newest drug on the market to treat RA. It is used for the treatment of patients with moderate to severe active RA."*

NSAIDs are used to decrease pain and inflammation. They are available over-the-counter, under names such as Advil™ and Aleve™. Stronger NSAIDs are available by prescription. DMARDs are useful in slowing or stopping the progression of RA by modifying the immune system response. Common DMARDs used to treat RA includes Methotrexate®, Plaquenil®, and Arava®. Biologics and JAK inhibitors fall under the newer class of DMARDs.



Biologics, such as Enbrel® and Humira®, target specific steps in the inflammatory process that causes joint and tissue damage. JAK inhibitors, such as Xeljanz®, prevent inflammation by blocking a specific pathway involved in the body's immune response.

Sarilumab (Kevzara®) is the newest drug on the market to treat RA. The FDA approved the medication in May 2017. Sarilumab is used to treat adult patients with moderately to severely active RA after at least one other DMARD has been used that did not work well or could not be tolerated. It can be used alone or in combination with methotrexate or other DMARDs. In a clinical trial, it was shown to reduce RA signs and symptoms, improve physical function, and slow progression of structural damage. Sarilumab is available in a prefilled syringe, which can be self-administered, every two weeks or as prescribed by your physician.



*Do you have swollen joints?*

*Has your rheumatologist talked about adding treatments to better control your rheumatoid arthritis (RA)?*

### **You could be eligible for the LiiRA study!**

We are looking for patients with RA over the age of 35 to join our study about cholesterol and heart disease in RA.

Everyone in this study will receive an FDA approved drug for RA, certolizumab (Cimzia) free. As part of the study you will also receive a free cardiac stress test.

To participate you must have active RA and cannot already be on a biologic therapy such as Enbrel or Humira, or a statin.

The study covers parking, eligible travel expenses, and up to a \$350 stipend.

If interested, please contact us for more information:

**Gabrielle Cremone**, 617-525-7495,

gcremone@bwh.harvard.edu

**Ethan Lam**, 617-732-8169, elam3@bwh.harvard.edu

<http://www.liira.org/>

*"For more information visit  
<http://www.liira.org>*