



PACO

Patient Advisory Committee

Newsletter Winter 08
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Patient Centered Outcomes Initiative (PACO)
Principal Investigator Dr. Nancy Shadick
Co-Investigators Dr. Michael Weinblatt and Dr. Jonathan Coblyn
Brigham and Women's Hospital, Rheumatology, Immunology, Allergy

Dr. Patricia Duquette Foundation Director at Bristol-Myers Squibb

We were fortunate to have Dr. Patti Duquette - Bristol-Myers Squibb Foundation Director - join us for the January 24, 2008 Patient Advisory Committee meeting. Dr. Shadick thanked Dr. Duquette for the funding without which all the visionary work in PACO wouldn't happen. Dr. Shadick commented, *"The patients, doctors, and nurses in the Arthritis Center have expressed great enthusiasm for this project. We have learned much from the patients through focus groups and the Advisory Board and have implemented their suggestions in the form of educational seminars, the Health Log, and now a new self-management program."*

Patti Duquette, in turn, thanked everyone and said that it was the Foundation's privilege to find partners who are improving patient care, spending their time and expertise so that other people can live better with rheumatoid arthritis. She described the approach at the Foundation as looking at what patients need outside of the clinic - i.e., managing your disease at home and in your community. Dr. Duquette stated,

"You can inform clinicians about what is happening when you are not at the clinic. What is your life like? What are things that become challenges? What are things that become easier? What is changing so physicians can respond appropriately? Patients and physician working together to co-manage their disease - all aspects of living with the disease so that patients do as well as they can."



Patricia Duquette, Director of the Bristol-Myers Squibb Foundation (right) and Judith Mullen of the BWH Development Office

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[PACO Website
www.PACOstudy.org](http://www.PACOstudy.org)

"Patients and physician working together to co-manage their disease - all aspects of living with the disease so that patients do as well as they can."

Discussion

Highlights from the discussion between the Patient Advisory Committee members, the PACO team, Nurses Pat Green and Fran Griffin, and Dr. Weinblatt and Dr. Coblyn.

How do we help patients become proactive about seeking information related to their RA and asking questions during the clinic visit?

The first step is to prepare for the clinic visit and come with more information about disease activity between visits, which helps the doctor focus questions and treatments. Another step is to prepare questions and concerns to make sure that the visit addresses what is on your mind. Lastly, mention concerns and questions early in the visit, if possible, so that the doctor will be sure to cover them. All of these steps can lead to a more satisfying visit for both the patient and the doctor.

Suggestions about materials that would be helpful to patients

1. A new patient brochure. This would be sent to new patients before their first visit and would tell them what to expect, what to bring, e.g., blood work, and a brief description of what it will be like to work with a rheumatologist at the Brigham.
2. A list of resources. This would contain a list of resources at the Brigham such as the nurses (their location, contact information, hours available, and the types of support they provide) and the Osher Center for Complementary and Integrative Medical Therapies at 850 Boylston, as well as a list of additional resources that are of value to RA patients, such as where to go for occupational therapy, physical therapy, and sleep assessment.
3. Online resources. Dr. Coblyn suggested that we might have a "Ask your Doctor" feature on the PACO website where patients could post questions and a rheumatologist would respond.

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PACO Initiative

A collaborative effort between patients and researchers at the Brigham and Women's Hospital, funded by the Bristol-Myers Squibb Foundation





Photographs from the meeting



Discussion (cont.)

Patients taking ownership of their health

Overall, patients commented that they must take ownership of their own health information and mentioned that the Health Log will be useful for this. The topic came up in light of a discussion of the difficulty of transporting a patient's medical information between doctors in different organizations. For example, one member commented about the lack of communication between her primary care doctor and her rheumatologist. One of the rheumatologists said that he makes a point to send reports to his patients' primary care doctors but finds communication from the primary care often doesn't happen. Members also expressed interest in getting access to their records, particularly medical procedures and tests results. The PACO team will look into what might be accessible.

Meeting and talking with other patients

Several people talked about how helpful support groups are as a way to allow people to learn from each other, particularly from those who have had RA for a while. One person commented, *"Nothing is like talking to people who have the same thing. People can give support through bad times, and share joy when things are good."* This support is beyond what doctors can provide through the clinic visit.

Dr. Shadick posed the idea of group rheumatologist visits, which would also function as a type of support group. She mentioned a rheumatologist in Palo Alto who sees 5-7 patients at once and no longer does individual patient visits. Nurse Pat Green mentioned that patients were encouraged to pair up and share problem-solving strategies as part of the self-help course she conducted. The PACO seminars are potential places where patients can meet and talk, so including time to have patients talk together before or after the seminars is one possible way to provide a support group setting. The new self-management program with Nancy Sowell will also include group meetings. Plans are also underway to establish a buddy system that would match patients one on one for support.

New Patient Orientation

PAC members have a strong interest in making sure that there is as much support as possible for those who are newly diagnosed. In addition to the New Patient Brochure and the buddy system, they suggested that the BWH Arthritis Center establish a new patient orientation program. Sessions would run 3 or 4 times a year, with sessions in the evening for people who cannot attend during the day. The importance of these orientations is highlighted in a PAC member's comment, *"When patients are first diagnosed, they are very overwhelmed and anxious. It is crucial to hear from someone that most people with RA live very productive lives."*

"Patients must take ownership of their own health information"

"Nothing is like talking to people who have the same thing."

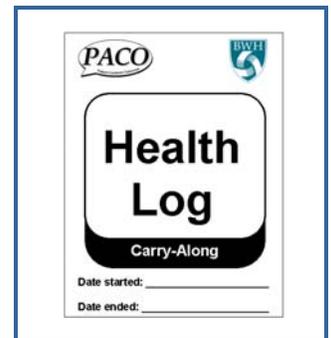
Updates

Osher Center collaboration with PACO

Comments from PAC members who have volunteered to try the Osher Center services have had only positive things to say about their experience so far. They have commented that the consult with Dr. Donald Levy, the Director of the Center, was very informative, that the people there are kind and that they are already noticing the benefits.

Health Log

The Health Log has been distributed to a randomly selected set of twenty-five patients in the Arthritis Center. They have volunteered to use the Health Log over a period of time encompassing two clinic visits. We will contact them in the fall to obtain their feedback.



Seminars

On March 12th, Nancy Sowell gave an informative talk on how patients can draw on their inner resources to cope with their disease. Ms. Sowell is initiating a new self-management program in the clinic. She herself has inflammatory arthritis and brings her direct experience in self-management to the program. Her personal experience gives her a deeper understanding of what it's like to have the disease, and what would help others regain a sense of hope and self-efficacy. She covered a number of approaches including mindfulness-based stress reduction and biofeedback. At the end of the session, she guided members of the audience through a relaxation exercise. Participants' comments about the session included: *"This was an informative and empowering seminar, very exciting."* *"The Relaxation took out the kink that had been in my shoulders all day."*

Our next seminar will be on June 5th, 2008, starting at 6:00, and will feature Dr. Ronenn Roubenoff, who will talk about nutrition and rheumatoid arthritis.

Next PAC Meeting - April 16, 2008

Wednesday from 12:00 - 2:00pm

Location - Bayles Conference Room

(see enclosed map)