



PACO

Patient Advisory Committee

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Patient Centered Outcomes Initiative (PACO)
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PACO Website
www.PACOSTudy.org

"The Health Log is designed to help patients manage their health information and to support communication with their rheumatologist."

Updates

New PACO website (www.PACOSTudy.org)

PAC members were given a tour of the new PACO website and people made suggestions. All agreed that we should set up a library in the waiting area of the clinic with copies of the books listed on the PACO and BRASS websites. Patients would then have an opportunity to read and review the books. A suggestion was made to include pamphlets from the Arthritis Foundation in the waiting areas. We will explore the possibility of providing Arthritis Foundation pamphlets so that patients can obtain those that are useful to their particular situation.

Photos of the PAC for the web?

The PACO website has a section about the PAC. We would like to include photos from our PAC meetings and will ask members at our next meeting (January 24, 2008) if they would consent to having photos taken.

Discussion

Wait times to see your doctor

The issue was raised that at times patients come for their appointments on time but find that the doctor has gotten behind schedule, possibly from dealing with an emergency or for another reason. One person suggested that there be a sign in the reception area to let patients know that the doctor is running late. Alternatively, a PAC member suggested calling ahead to check, and if the doctor is late, the patient can shift her/his schedule, do errands or bring a book. Most patients appreciate that the doctor has a full schedule and when it is their turn, the doctor will devote attention to them.

PACO Collaborations

Osher Center collaboration with PACO

PACO is collaborating with Brigham and Women's new Osher Center of complementary and integrated Medical Therapies.

[Sunday Globe 12/16/07

http://www.boston.com/news/health/articles/2007/12/16/sticking_his_neck_out?]

We have three PAC members who have volunteered to try the Center's services and report back to the committee. The Center's mission is to enhance the body's natural ability to heal and to maintain good health. Services they provide include: massage therapies, mindfulness-based stress reduction, acupuncture, integrative medicine, dietary herbs/vitamins/supplements, therapeutic Tai Chi/Yoga and more. The center is located at 850 Boylston Street in Chestnut Hill, MA.



Osher Center

Inflammatory Arthritis Initiative

Dr. Shadick is participating in a national consortium to improve collaboration between family practitioners and rheumatologists to more quickly diagnosis patients with rheumatoid arthritis. Research has found that the sooner a person is treated, the better their outcome. Dr. Shadick asked for a volunteer to attend the next meeting with her sometime in the spring.

PACO Project

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



New Mental Health Service

Research has found that chronic illness affects people's emotional health. This is confirmed by BRASS data from participant questionnaire responses. 50% of BRASS patients have mild to severe depression and 75% describe having much or complete difficulty with sleep and anxiety. During the meeting, PAC members contributed their own observations about depression: *"Depression can cause a downward spiral increasing RA activity, which leads to increased depression."* *"The more things I cannot do, the more I get depressed."* *"It's frustrating not to be able to carry on the life you had before."* *"I didn't know you could be depressed with RA: thought it was just me."* In addition, the findings from the PACO focus groups indicated that social isolation was a major concern and that fatigue and pain can at times seem psychologically overwhelming. Dr. Shadick has investigated different mental health services for patients and found a psychologist who is trained in helping patients tap their own inner resources to help them cope with their disease. The psychologist has worked through her own psoriatic arthritis using the method she will use with RA patients. More information on the psychologist and the new service will be part of the next PAC meeting.

Journaling to Deal with Chronic Illness

The benefits of journaling to deal with chronic illness were also discussed. Dr. Shadick mentioned a recent article in the Journal of American Medical Association, called "Effects of Writing about Stressful Experiences on Symptom Reduction in Patients with Asthma or Rheumatoid Arthritis" If you are interested, you can get a copy of the article from the PACO website library or type this address into your web browser.
(http://www.pacostudy.org/?page_id=11).



"Research has found that chronic illness affects people's emotional health"

"Depression can cause a downward spiral increasing RA activity, which leads to increased depression."

Health Log (formerly the Passport)

PAC members reviewed a new version of the Health Log (formerly the Passport). Everyone agreed that it is a useful companion tool and could help patients during their clinic visit better communicate with their rheumatologist. PAC members made suggestions such as adding more space for lists of specialists and future appointments. Comments included, "*These days it's important to have your health history in your hand whenever you see a doctor.*" Others mentioned a personal need to keep track of test results because medical institutions change computer systems, and then cannot access results. One person commented there is a "*Need to keep track of it yourself, to avoid duplicates and to save time.*" Some commented that the section where patients can record their daily physical functioning, pain, and fatigue, would be more helpful to newly diagnosed patients. We are reworking this section to be more useful for everyone, making it resemble a weekly or monthly calendar where people simply use a code to indicate their condition with additional pages for notes if needed. Once the changes are made, the PACO team will pilot the Health Log with a randomly selected group of BRASS patients. Please feel free to use the Health Log for your own care and bring additional comments to the next PAC meeting January 24, 2008!

Next Seminars

There are two seminars planned for the spring. One in March will introduce our new mental health provider who will be starting in the clinic. The mental health program will incorporate a number of approaches including Mindfulness Stress Reduction and will help patients tap into their inner resources for coping with RA. In June, the seminar topic will be "Nutrition and Rheumatoid Arthritis."



Next PAC Meeting – January 24, 2008