



PACO

Patient Advisory Committee

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Reflections from Patti Doykos, PhD Bristol-Myers Squibb Foundation

Dr. Patti Doykos joined us for our July 31st, Patient Advisory meeting. She commended the efforts of the Advisory Committee and mentioned that their work would benefit other patients. She also envisioned the tools developed through the PACO project - the Health Log, the coaching manual for other mental health professionals, the scholarly articles - as having potential to make a "huge impact on patient care." We, in turn, expressed our appreciation for her support and for the opportunity to pioneer programs that extend support to patients beyond the clinic visit.

New monthly support group starting with Nancy Sowell, PAC social worker

Many of you know Nancy Sowell as the person who has designed and is facilitating our new "Living Well with RA" mental health research program (see <http://www.pacostudy.org/>). She has a master's degree in social work, and is a licensed psychotherapist with 15 years experience in behavioral medicine. Nancy announced plans for a new, monthly drop-in support group open to everyone. She described the support group as "Providing a safe place for people to discuss the more personal impact of RA." "While there are other resources to help patients deal with RA," she said, "This is a group that will really help people with the more private aspects of living with the disease. A goal is to create a sense of community and connection to reduce the social isolation that can happen with the disease." Meeting topics would arise from the suggestions from the patients in the group. A whole list of potential topics were discussed - RA and family life, self image and self esteem, Intimacy, relationships, fear of the future, dealing with RA socially, in the work place, dealing with RA and family members, traveling, how to balance family/social life and self.

"We need to think about ambulatory processes that put patients first."



Dr. Patti Doykos (center) and PAC members comment on the Health Log and the eHealthLog

Monthly support group (Cont.)

The group would meet once a month, always at the same time so that people could plan ahead. Whoever shows up whether it is for just one meeting or more would be part of the group. Members felt by having the group meet monthly, rather than less frequently, those who were unable to attend one month would not have to wait too long to attend the next month. They felt that this also helped to maintain the bond within the group and helped to reaffirm the confidentiality and sensitivity of some discussions that may arise. Nancy ended by saying, "We will start, see how it goes, and let it grow from there."

Flyers and posters will be posted in the clinic to let patients know when the support groups will start.



Nancy Sowell (left) and the PAC members provide input about the monthly support group.

PACO Initiative

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

Updates

Health Log

Evaluation interviews were conducted with the 26 patients who participated in the pilot study of the PACO Health Log which were distributed winter 2008.

Dr. Shadick summarized comments from the evaluations. One popular idea was to make the health log available electronically through the PACO website (www.pacostudy.org) which would be downloaded and encrypted for security purposes. The patient can then printout the eHealthLog and bring it to their clinic visit or email it if their rheumatologist prefers. For some patients typing is easier than writing in the log, and so having a downloadable version may make the log accessible to a wider audience. Additionally, having the option to email the log prior to an appointment, or print it out to bring to the doctor's appointment may make the log more useful. For those patients who are not as comfortable on the computer, there is the paper version that has been designed and pilot tested. We envision that having information concerning medications, adverse events, quality of life, functional assessment, and questions for the rheumatologist readily accessible, less time will be required to go over medications, prior hospitalizations, and other key information and more time will be available to discuss patient concerns.

Regarding the list of medications, Dr Weinblatt emphasized that it is important to have patients include the start and end dates of medications so this has been added to the newly revised version.



Upcoming Seminar – January 8, 2009

Have you ever had difficulty opening a jar or a car door, looked for ways to make it easier to button buttons? This session is an opportunity to learn about devices that can make daily activities easier.

At 6:00 pm on January 8, 2009 in Carrie Hall - Brigham and Women's Occupational Therapist Marie-Jose Benjamin will talk about and demonstrate some useful devices as well as provide tips that will help you manage better in your home.

Recent Seminar

On October 16, 2008, The Patient-Centered Outcomes Initiative (PACO) and the Lupus Center hosted a seminar and discussion for more than 40 rheumatoid arthritis (RA) and lupus patients, friends, and family members. Serving as the keynote speaker, Janet Austin, Ph.D. gave a presentation entitled "Living with Rheumatic Disease: A Patient Perspective" and answered questions from audience members. Dr. Austin is the Director of Office of Communications and Public Liaison, for the National Institute of Arthritis and Musculoskeletal and Skin Diseases, within the National Institutes of Health.

Dr. Austin presented background information about many rheumatic diseases before focusing on rheumatoid arthritis. She spoke about patient advocacy and the resources available for RA patients through NIAMS. Additionally Dr. Austin led the audience in a discussion about ways to treat arthritis and the lifestyle changes that accompany an RA diagnosis. Diet, weight control, exercise, drug and non-drug pain relief, alternative therapies, and surgery were just some of the topics covered in this seminar.

To obtain a copy of Dr. Austin's presentation slides, go to: http://www.pacostudy.org/?page_id=6



Dr. Janet Austin during her October 16th presentation

PAC Meeting - November 14, 2008
Friday from 12:00 - 2:00pm
Location - Bayles Conference Room