



PACO

Patient Advisory
Committee

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*Patient Centered Outcomes Initiative (PACO)
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Summary of December 5, 2012 meeting

Thank you to everyone who attended the PAC meeting on December 5th and we hope to see those who could not make it at the next meeting in the near future. I also want to thank those who used the call-in option to participate. We are currently recruiting new members of the PAC so please let Brett Pantera (617-525-6608 or bpantera@partners.org) know if you have any suggestions for ways to recruit or know someone who you think would be a great addition to the PAC.

The majority of the meeting was spent on the Patient-Doctor Communication Project. Dr. Shadick asked the PAC members to think of ways they would like to be spoken to by their doctor. One such suggestion was for the doctor to project a sense of hope to their patients. The PAC agreed that it was important for them to have a sense that RA does not have to be debilitating and that they could return to normalcy. Another suggestion was for doctors to lay out some of the expected limitations their patients may have. If patients know what may be coming they could be better able to cope and react when an issue arises. Many members also felt it was a good idea for doctors to engage their patients in a more personalized conversation, the idea being patients would feel more comfortable and more receptive to their doctor. Finally, the PAC offered that doctors should never be dismissive towards their patients. A sense of encouragement and support from a doctor can go a long way in supporting a patient both physically and emotionally.

The suggestions above will be presented by Dr. Shadick to Dr. Helfgott, who is charge of the fellowship program in the rheumatology department. The PAC members will then sit down with the fellows at the next PAC meeting to discuss their suggestions in person.

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Summary of December 5, 2012 meeting (Continued)

Rachel Miller and Taysir Mahmoud, Research Assistants for Brigham and Women's Hospital, attended the meeting as well. They talked about a new pilot study at the hospital called the PRE-RA Family Study. The study consists of interviewing and a blood draw for biologic markers of 1st degree family members of patients with RA. The goal is to obtain enough information to create an online risk estimator for RA. After estimating such risk, one can click through and see how lifestyle changes, including modifying one's diet and exercise can reduce the risk of developing rheumatoid arthritis. Similar studies have been done in the past resulting in websites like this <http://www.yourdiseaserisk.wustl.edu/>. Currently the team is working on their website, as well as adding an education component to the study. If anyone has family members who would be interested in participating or has any questions about the study please contact Rachel (617-264-5885 or rmiller11@partners.org) and Taysir (617-732-8964 or tmahmoud@partners.org).

Dr. Shadick also distributed information cards on Volunteer Services. As representatives of the PAC all members should be official Brigham and Women's Hospital volunteers. Applicants to become volunteers are required to attend New Volunteer Orientation (NVO), complete application materials, submit to a CORI check, be cleared through BWH Occupational Health Services, provide two professional references and interview with the OSSVS Program and Training Coordinator prior to receiving a volunteer placement in the hospital. A representative for Volunteer Services will be at the next PAC meeting to further explain the process. In the meantime anyone interesting in starting the process can contact Volunteer Services at 617-732-5998 or see their website http://www.brighamandwomens.org/about_bwh/volunteer/default.aspx

Once again we want to say thank you to everyone who attended the December 5th meeting and we look forward to seeing you in the future. We are also in the process of planning our next seminar and PAC meeting. Any questions, comments, or concerns can be presented to Brett Pantera (617-525-6608 or bpanter@partners.org).

Updates from BRASS, PARASS, and PACO

The BRASS study is currently in its ninth year and with a new sponsor, Bristol Myers Squibb, and has begun enrolling 300 new patients. Enrollment is off to a blistering pace with over a 160 new patients already participating in the new study. This brings the BRASS participation numbers to 1315 since the study began. The information from the BRASS study has been used for such varying things as evaluating rheumatoid arthritis remission criteria and new statistical methods for analyzing radiographic progression of RA to helping with research on exercise and widespread pain. The PARASS Peer Support Program continues to help patients with RA by matching them with a peer coach. We are always looking for new participants in this program. There have been 82 unique matches of coaches and partners so far and 35 trained coaches. A poster was recently presented in November at the annual ACR Conference in Washington DC with many showing interest. The researchers are close to starting publication of their findings, with the hope of the program becoming institutionalized by the hospital. The monthly support group, led by Pat Green RN, MS and Frances Griffin, RN, BSN is a part of the PACO Initiative and meets the second Wednesday of every month from 12:15-1:15 at the 4th floor, room BC-009 of One Brigham Circle. In each session the challenges of living with RA are discussed allowing patients to connect with others and brainstorm solutions as well as learn helpful information.

