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Cooperative Group Patient Representatives See Efforts Pay Off for Multiple Myeloma

Advocates have been working in the Cooperative Groups for more than 10 years. The primary activity of these advocates is providing the patient perspective to the multi-centered research being designed and conducted by these organizations. The Eastern Cooperative Oncology Group (ECOG) Patient Representative Committee recently experienced a surprising and exciting outcome for their efforts. More than three years ago they engaged multiple myeloma patients in a discussion about upcoming research with the leadership of the ECOG Multiple Myeloma Committee. The patients asked for the addition of a low dose dexamethasone (Decodron®) arm to a trial the committee was planning using a regimen of dexamethasone and lenalidomide (Revlimid®) for newly diagnosed patients. The Committee listened to these patient concerns and E4A03 was designed with two treatment arms. In arm one, patients received lenalidomide and dexamethasone at standard doses and arm two received standard-dose lenalidomide and low-dose dexamethasone. The primary objective was to determine if the low-dose arm would have similar response rates and lower toxicity than the standard-dose arm. Preliminary results have shown that use of low doses of dexamethasone, in combination with lenalidomide is associated with improved survival when compared to a treatment regimen with lenalidomide and a higher dose of dexamethasone. According to the National Cancer Institute press release on the results of this trial, "Researchers found that patients in the study who received low-dose dexamethasone and lenalidomide had a one-year survival of 96 percent compared to 86 percent for patients treated with the standard-dose of dexamethasone and lenalidomide. In addition, there were fewer side effects associated with the low-dose dexamethasone and lenalidomide." The trial was closed early by the data monitoring committee overseeing the trial because of the differences observed in survival.

According to Mike Katz, co-chair of the Patient Representative Committee and a member of the ECOG Multiple Myeloma Committee, "It's rare to get this sort of opportunity/result as an advocate. We think the impact on clinical practice could be huge since dexamethasone is currently included in so many

regimens at the higher dose. Hopefully, these results will provide impetus for other trials incorporating dose questions."

E4A03 was presented at the American Society of Clinical Oncology annual meeting held in Chicago, Ill., from June 1 to 5, 2007. To read the National Cancer Institute press release go to <http://www.cancer.gov/newscenter/pressreleases/MultipleMyelomaDexamethasone>. The International Myeloma Foundation press release can be found at <http://tinyurl.com/38x2ep>.

Federal Health Leaders Unveil New Programs to Help Eliminate Disparities in Clinical Trials

On May 7, 2007, Baylor College of Medicine and the Intercultural Cancer Council (ICC), and officials from the U.S. Department of Health and Human Services' Office of Minority Health and Office on Women's Health and the National Institutes of Health's National Center on Minority Health and Health Disparities held a news conference to announce two complementary projects -- CLAS-ACT (Culturally and Linguistically Appropriate Standards And Clinical Trials) and BackPack (a set of tools for researchers) -- that are among the first to apply new ways to reduce the cultural and linguistic barriers keeping many underserved patients from participating in clinical trials. This outgrowth of the Eliminating Disparities in Clinical Trials (EDICT) project will provide new resources, examples and models for those who design clinical trials and for those who work with minority and underserved patients at the community level. News conference participants included George A. Strait Jr., communications director for the National Center on Minority Health and Health Disparities; Garth Graham, deputy assistant secretary for minority health for the U.S. Department of Health and Human Services; and Wanda Kaye Jones, Deputy Assistant Secretary for Women's Health for the U.S. Department of Health and Human Services.

Coming soon!!!

A special edition of Network News to report on highlights from the ASCO Annual Meeting and the Focus on Research participants and Research Advocate Mentors.

Research Advocacy Network Publications

Tissue Donation for Research Education Booklets

Research Advocacy Network has developed booklets for prospective donors and institutional review boards to understand the importance and implications of donating tissue for research purposes. These booklets have been in high demand!!! Thanks to an unrestricted grant from Eli Lilly and Company our stock has been replenished and these are available to be shipped again. Please click here to access the [Tissue Booklets Order Form](#).

Genomics in Cancer: An Advocate's Guide

The Research Advocacy Network has introduced an education module for advocates interested in learning more about genetics and genomics and the role of this emerging field in cancer research. The module covers the science behind genomics, including scientific concepts and examples of how genomic technology is currently being incorporated into clinical research. To help bring this information to life, the module also includes basic definitions, diagrams, and graphics - all in an effort to de-mystify the science and technology. *Genomics in Cancer: An Advocate's Guide* was supported by an educational grant and in-kind contributions from Genomic Health, Inc. Order your copy by completing the [Genomics Module Order Form](#).

**Research Advocacy Network Activities
and
Events of Interest to Research Advocates
May, June 2007**

May 7-8, 2007	EDICT (Eliminating Disparities in Clinical Trials) Opportunity Team Leader Meeting, Houston, TX
May 9-11 2007	Advocate Institute webinars on Understanding Clinical Trial Design for Focus on Research and Indiana University Research Advocate Mentor Program participants
May 12, 2007	Hoosier Oncology Group Annual Meeting, Indianapolis, IN
May 15-17, 2007	Indiana University Breast Cancer Center of Excellence Research Advocate Mentor Program Intensive, Indianapolis, IN
June 1- 5, 2007	American Society of Clinical Oncology Annual Meeting, Chicago, IL www.asco.org
June 8- 10, 2007	Eastern Cooperative Oncology Group Spring Meeting, Washington, DC
June 11-13, 2007	NCCTG Patient Advocate Symposium, Rochester, MN
June 22-24, 2007	Radiation Therapy Oncology Group Spring Meeting, Philadelphia, PA
June 24-26, 2007	NCCN Breast Cancer Treatment Guidelines Committee, Virginia

**Some calendar items listed are by invitation only and listed only for your awareness. If you need information about events listed here without a link to the sponsoring organization, please email info@researchadvocacy.org. Thanks!

We need your help! Your Donation Makes a Difference! If you believe in the hope of research and the power of advocacy, you can help the Research Advocacy Network (RAN) by sending a donation. RAN is an exempt 501 c 3 organization and dependent on your support to keep going.

PLEASE NOTE our new mailing address is: 6505 W. Park Blvd, Suite 305, PMB 220, Plano, TX 75093.
Thanks!

Research Advocacy Network Welcomes New Members!!! Thanks to all of you who have recently joined the Network. For those that have not yet please go to <http://www.researchadvocacy.org/> and click on "Join." There are no dues for Network membership and this will assure that you receive all notices and have access to Network programs.

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Editor: Elda Railey

Network News is currently published 10 times per year and includes articles on advocacy, research results and activities. Please share Network News with your friends with the link above. Research Advocacy Network is an Illinois not-for-profit corporation and is designated as an exempt 501 c 3 organization by the IRS. Your donations are greatly appreciated and tax deductible to the extent allowed by law.

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