



# NetworkNews

Research Advocacy Network

Advancing Patient-Focused Research

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### Gene Profiling Identifies High-Risk Multiple Myeloma Patients

Researchers have identified a small subset of genes whose activity could predict high-risk cases of multiple myeloma and potentially guide therapy decisions in the future. They presented their data recently at the American Association for Cancer Research's Second International Conference on Molecular Diagnostics in Cancer Therapeutic Development. NCI provided partial funding for the study.

The investigators, from the Myeloma Institute for Research and Therapy at the University of Arkansas for Medical Sciences, followed 532 multiple myeloma patients for 7 years after a blood stem cell transplant to create a genetic profile to chart the severity of the disease. The team determined that the activity of as few as 17 genes could mean the difference between high or low risk for a poor prognosis. About 30 percent of the genes that predict high risk are found on chromosome 1.

Source: [http://www.cancer.gov/ncicancerbulletin/NCI\\_Cancer\\_Bulletin\\_092507/page4#b](http://www.cancer.gov/ncicancerbulletin/NCI_Cancer_Bulletin_092507/page4#b)

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### Multiple Myeloma Trial Halted after Analysis Shows Significant Survival Improvements

A phase III trial dubbed VISTA testing bortezomib (Velcade) plus the combination of two chemotherapy drugs for the first-line treatment of patients with newly diagnosed multiple myeloma has been stopped early based on recommendations of the trial's independent data monitoring committee (IDMC) so patients in the control arm can be switched over to the bortezomib treatment arm.

The 682-patient trial was stopped after a planned interim analysis showed that the combination of bortezomib with melphalan and prednisone demonstrated a highly statistically significant improvement in overall survival and progression-free survival, as well as time-to-disease progression and complete remission rate compared with melphalan and prednisone alone.

According to Dr. Paul Richardson, clinical director of the Jerome Lipper Multiple Myeloma Center at the Dana-Farber Cancer Institute and one of the trial's lead investigators, "These results position [bortezomib]-based therapy as a new standard of care for newly diagnosed multiple myeloma patients.", To read the full article go to:

[http://www.cancer.gov/ncicancerbulletin/NCI\\_Cancer\\_Bulletin\\_092507/page4#b](http://www.cancer.gov/ncicancerbulletin/NCI_Cancer_Bulletin_092507/page4#b)

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### **Latino Cancer Experts Celebrate Redes En Acción Impact**

More than 80 Latino health and cancer authorities gathered from around the country to celebrate the achievements over the past seven years of Redes En Acción, the National Latino Cancer Research Network and hear a variety of panel presentations and guest speakers. The theme of this year's meeting was "Amplifying the Redes Ripple Effect."

"In the same way a raindrop creates a ripple when it hits a still body of water, a Redes ripple is created when our network members conduct research, training or many other activities that help reduce health disparities among Latinos across the nation," said Amelie G. Ramirez, DrPH, Redes En Acción Principal Investigator. "It gives me great satisfaction and pride to observe this Redes ripple effect yield more and more ripples as we continue to shape this program into one of growing influence."

Although the "ripples" created by Redes En Acción are reflected in a variety of innovative strategies addressing cancer disparities in the country's Latino population, perhaps the most dramatic impact has been seen in programs promoting new research. For more information go to:

<http://www.redesenaccion.org/news/item20070801.htm>

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### **Arizona Workshop Series Strengthens Awareness of Tissue Donation for Research**

The availability of tissue and biospecimens for research banking has emerged as a major issue in advancing research. To address the limited understanding of tissue donation's importance, the Arizona Myeloma Network has partnered with the Arizona Dept of Public Health and the state's cancer control plan to develop a workshop series to increase awareness.

The booklet "Why Should I Consider Donating My Tissue for Research" developed by Research Advocacy Network was incorporated as a major component of the educational packet. The first workshop in Phoenix featured Elda Railey of Research Advocacy Network and a panel including Jodi Black, TGen VP Research Administration, John Carpten, TGen Senior Investigator/ MM Project Leader, Bunmi Mfuko, Multiple Myeloma Research Foundation /Clinical Trials, Marybeth Montague, Banner Health Clinical trial analyst, Dr. Michael Trujillo, TGen Exec. Director/Program Development & Community Outreach, and Dr. Daniel Rubin, Naturopathic / Scottsdale Medical Pavillion to discuss the issues with approximately 85 attendees. For more information about the project and upcoming workshops in Arizona go to: <http://azmyelomanetwork.org/eventsTDAP.htm>

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### **ENACCT and CCPH Hosts Conference Series**

The Education Network to Advance Cancer Clinical Trials (ENACCT) and Community Campus

Partnership for Health (CCPH) are hosting a conference series designed to explore the potential of employing CBPR (Community-Based Participatory Research) principles in therapeutic trial design, recruitment and retention and dissemination, and to define an agenda for research, practice and policy. Mary Lou Smith and Elda Railey from Research Advocacy Network attended the first in the three-part invitational series. The conference organizers published a background paper and prepared the participants to involve communities and underrepresented groups as partners in cancer clinical trials. For more information about the series and outcomes visit: <http://www.enacct.org>.

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### **Genetic Testing Summit a Success**

Eyes on the Prize: Truth Telling about Genetic Testing took place on September 20 and 21. The 200 participants engaged in vigorous debate about the entire genetic testing pipeline. As a result, Genetic Alliance will publish a meeting report, submit several journal articles, work with stakeholders on a dozen action items resulting from the meeting and convene several other summits. For more information about the Summit and other issues about genetics, genomics and policy, please visit <http://www.geneticalliance.org>

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### **National Cancer Institute's Office of Advocacy Relations**

Dr. John Niederhuber has announced effective October 29, 2007, Shannon K. Bell, MSW, will become the director of the National Cancer Institute's new Office of Advocacy Relations. Shannon holds a masters degree in social work, has worked in the past as an advocate for children and families, and has gained a wide-array of experience at NCI over the last 8 years.

The Office of Advocacy Relations, currently the [Office of Liaison Activities](#), will be relocated to the Director's office and Anne Lubenow will oversee the new Office and be the ongoing contact with advocacy groups. Lenora Johnson who has served as Acting Director of OLA over the last year was acknowledged for her vision and providing continuity during the transitional time.

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### **Four New Members Appointed to DCLG**

NCI Director Dr. John Niederhuber announced his intention to appoint four new members to the Director's Consumer Liaison Group (DCLG):

- Marie Dahlstrom, of Portland, OR, represents De La Mano Frente AI Cancer: Latino Cancer Coalition
- Everett Dodson, of Silver Spring, MD, represents Prostate NET
- Joyce Wilcox Graff, of Brookline, MA, is the Executive Director of the VHL Family Alliance
- Arlene Wahwasuck, of Horton, KS, represents the Four Tribes Women's Wellness Coalition

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### **Training available for GI Research Advocates**

C3 is pleased to announce the third annual Gastrointestinal (GI) Research Advocate Training which will take place January 25-28, 2008 in Orlando, Florida. The training will take place in conjunction with the ASCO GI Symposium. The goal of the training is to strengthen the advocacy skills of patient representatives who serve on various research groups (cooperative groups, SPORES, DSMBs, IRBs) throughout the country. The deadline for submitting an application is October 15, 2007. For more

information or to apply for the training go to:

[http://www.formspring.com/forms/c3-research\\_advocacy\\_training\\_registration\\_2008](http://www.formspring.com/forms/c3-research_advocacy_training_registration_2008).

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### 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 Education Booklet order form](#).

#### Genomics in Cancer: An Advocate's Guide & Training Manual

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 & Training Manual was supported by an educational grant and in-kind contributions from Genomic Health, Inc. Order your copy by completing the [Genomics Module Order Form](#).

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### Research Advocacy Network Activities and Events of Interest to Research Advocates

09/05/2007 to 09/7/2007	ENACCT - CCPH Conference, College Park, Maryland
09/07/2007 to 09/8/2007	ASCO Breast Cancer Symposium, San Francisco, CA <a href="http://www.asco.org">www.asco.org</a>
09/11/2007 to 9/12/2007	NCCN Breast Cancer in the Older Woman Task Force Philadelphia, Pa, <a href="http://www.nccn.org">www.nccn.org</a>
09/17/2007 to 09/18/2007	EDICT (Eliminating Disparities in Clinical Trials) Meeting, Houston, TX
09/17/2007 to 9/18/2007	Fox Chase Cancer Center DOD Breast Cancer COE, External Advisory Board, Philadelphia, PA
09/25/2007 to 9/27/2007	NCCTG Fall Meeting Rochester, MN <a href="http://www.ncctg.org">www.ncctg.org</a>
10/04/2007 to 10/5/2007	NCI Custodianship of Biospecimens Meeting Rockville, Maryland <a href="http://www.cancer.gov">www.cancer.gov</a>
10/29/2007	USCF Breast Cancer Spore External Advisory Board Mtg, San Francisco, CA
11/01/2007 to 11/02/2007	Collaborative Breast Cancer Research Summit, Landsdowne, VA
11/02/2007 to 11/03/2007	Breast Cancer Symposium Mayo, Scottsdale, AZ
11/09/2007 to 11/11/2007	ECOG Fall Meeting, Ft. Lauderdale, FL, <a href="http://www.ecog.org">www.ecog.org</a>
11/30/2007 to 12/4/2007	PRIMR 2007 Annual HRPP Conference, Boston, MA, <a href="http://www.primr.org">www.primr.org</a>
12/13/2007 to 12/16/2007	San Antonio Breast Cancer Symposium, San Antonio, TX <a href="http://www.sabcs.org">www.sabcs.org</a>

\*\*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](mailto:info@researchadvocacy.org) . Thanks!

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

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**Research Advocacy Network Welcomes New Members!!!** Thanks to all of you who have joined the Network. For those that have not yet joined 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

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