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Eliminating Disparities in Clinical Trials (EDICT): Formulating Policies National Roundtable Meeting

The Chronic Disease Prevention and Control Research Center (CDPCRC) at Baylor College of Medicine in Houston and the Intercultural Cancer Council (ICC) have launched the EDICT (Eliminating Disparities in Clinical Trials) Initiative, a four-year research program funded by Genentech, Inc. to address the problems and solutions related to improving participation of minority and underrepresented populations in clinical trials.

EDICT Roundtable

Under the aegis of the EDICT Initiative, on September 6-8, 2006, Baylor College of Medicine and the ICC held a national roundtable meeting to create policy strategies to impact the three R's of clinical trial participation: 1) recruitment, 2) retention, and 3) return (post-trial benefit) for minority and underserved patients. The roundtable was attended by over 150 public health officials, medical researchers, professional organizations, clinicians, pharmaceutical and health care companies, and patient advocates in the areas of oncology and asthma clinical trials - two categories where minority and underserved populations suffer disproportionately from the burden of disease.

Policy Strategies Are Currently Being Developed

Policy suggestions generated at the meeting are currently being reviewed and synthesized. Tapes from the meeting are being transcribed to ensure all participants' contributions are documented from the meeting-wide discussions.

Listed below are the major issue areas into which policy suggestions were categorized:

- Education/Training of Healthcare Professionals
- Regulatory Oversight & Enforcement

- Allocation of Research Funding Proportionate to Disease Burden
- Assuring Healthcare Coverage in Clinical Trials
- Providing Incentives to Pharmaceutical Industry
- Publication-Related Policies
- Fostering Community Involvement, Relationships & Education
- Patient Navigation
- Recognition Program
- Technology/Electronic Medical Records

Next Steps: "Opportunity Teams" To Continue in Each Issues Area

Next steps will include further work on these policy areas listed above by participants who expressed an interest at the meeting. If any other individuals would like to participate in one or more of the groups above, please contact the EDICT project staff.

Postings on the EDICT Website (www.bcm.edu/edict)

Additional meeting information may be found on the EDICT website including the EDICT Reading Room with strategies, thought pieces, personal essays and opinion articles to acquaint the reader with issues and tactics for eliminating disparities in clinical trials. This website will be continuously updated as new information and contributions are received.

For More Information, Please Contact: Armin D. Weinberg, PhD, Principal Investigator, EDICT at Baylor College of Medicine, 1709 Dryden, Suite 10.25, Houston, TX 77030, Phone: 713.798.4614, Fax: 713.798.3990 or email: cdrc@bcm.edu.

Thanks to Cynthia Spiker of the CDPCRC for contributing this article.

**Research Advocates Are Invited To Web Briefing on the FDA Draft
Guidance on Laboratory Developed Tests**

The Food & Drug Administration (FDA) has recently developed draft guidance on the potential regulation and oversight of complex genetic and genomic tests. The Research Advocacy Network is presenting a webconference on November 2, 2006 2pm ET to brief the research advocacy community while this guidance document is in public comment period.

RAN also developed a document to highlight the patient perspective on this issue. Click here to download [Patient Considerations](#).

The speakers will be:

- Steven I. Gutman, MD, Director, Office of In Vitro Diagnostic (OIVD) Device Evaluation and Safety, Center for Devices and Radiological Health, will speak for the Food and Drug Administration Office of In Vitro Diagnostic Device Evaluation and Safety
- Paul Radensky, MD, JD, Partner, McDermott, Will and Emery will give the Legal & Industry Perspective
- Bob Erwin - Patient Advocate, Founder and President, Marti Nelson Cancer Foundation will present thoughts on "What this means for patients and advocates?"

To register for the webconference send an email to info@researchadvocacy.org with your name and email address. There is no charge but we do need your registration information. The one hour session will also be archived and available for playback 36 hours following the live session.

Congratulations to the Inflammatory Breast Cancer (IBC) Research Foundation

The IBC Research Foundation has been awarded one of seven Best Practices In Breast Cancer Advocacy Awards through the National Breast Cancer Coalition Fund. Research Advocacy Network was happy to support this effort and we congratulate the ibcRF. For the ibcRF specific press release go to: www.ibcresearch.org/biobank/bestpracticespressrelease.pdf. For the National Breast Cancer Coalition Fund general press release about all the recipients, go to: <http://www.stopbreastcancer.org/bin/index.asp?strid=876&btnid=2&depid=20>.

Research Advocacy Network Activities

- Oct 15 -16 - Breast Cancer Research Consortium
- Oct 18 - Indiana Cancer Consortium
- Nov 3 - 5 - Eastern Cooperative Oncology Group (ECOG) Meeting
- Nov 7 -8 - Summit on Cancer Clinical Trials
- Nov 14 - PRIM&R Community Member Training
- Nov 15- 17 PRIM&R Annual Meeting
- Nov 28 - 29 caBIG Data Sharing and Intellectual Capital Meeting
- Dec 14-17 San Antonio Breast Cancer Symposium

Coming in the next issue of Network News:
Report from the St. Louis Komen Affiliate Research Advocacy Workshop, October 20, 21 and the National Lymphedema Network Lymph Science Advocacy Program Lecture Series.

[Click here for a full listing of Awareness Months/Events](#)

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 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 306, PMB 200, 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.

Editor: Elda Railey

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