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### **Advocates Participate in NCI's caBIG Initiative**

In 2004, the National Cancer Institute's (NCI) Center for Bioinformatics launched an initiative aimed at connecting individuals, researchers, and institutions to promote the sharing of information, tools and resources related to cancer research. Called the cancer Biomedical Informatics Grid – or caBIG – this voluntary virtual network has collaborated to create a “world wide web” of cancer research, with the goal of speeding the delivery of innovative approaches for the prevention and treatment of cancer.

Ultimately, the caBIG initiative will develop a grid that will facilitate the successful sharing of specimens and data, leading to more rapid translation of basic research to improve cancer care. caBIG believes that by linking the scientists and organizations at the forefront of critical research, it will be possible to support the NCI's goal of eliminating death and suffering due to cancer by 2015.

From its inception, caBIG has worked to aid advances in research by breaking down the technical and collaborative barriers within the cancer community that prevent inter-disciplinary communication and partnership. Based on this approach, the initiative has identified the guiding principles of open source, open access, open development, and federation, involving 50 NCI-designated cancer centers, more than 800 individuals, and over 80 volunteer organizations. Patient advocates have been involved in all aspects of the caBIG project since its beginning, and they have focused on ensuring that the initiative's end product, “The Grid,” will ultimately benefit patient treatment and outcomes in the most effective and timely way possible.

To this end, caBIG is working toward implementing common standards and software architecture to promote the delivery of open access and inter-operable tools, thus creating an infrastructure that allows for the sharing of data. The initiative has also focused on developing high-tech solutions to enhance collaboration in five key aspects of cancer research:

- clinical trial management systems,
- integrative cancer research,
- tissue banks and pathology tools,
- vocabularies,
- common data elements.

As a result of this work, the entire caBIG community – along with other cancer and biomedical researchers – is able to share applications, resources, and data sets.

Beyond these tools and data-driven resources, caBIG is also delivering a breadth of products such as:

- OMB (Office of Management and Budget)-derived Race and Ethnicity Standards,
- Candidate caBIG Data Standards,
- caBIG Compatibility Guidelines,
- project-specific white papers,
- development models,
- end user materials for training and documentation.

In addition, the initiative has created educational materials and template agreements relating to open source software licensing, publications, and other proprietary issues. All products, as they are completed, are available on the caBIG web site at <http://caBIG.nci.nih.gov>.

Patient advocates who are interested in caBIG can volunteer to participate in the project, or can check on the progress of the initiative and share their input by contacting the advocates already involved. For more information on the caBIG initiative, please visit <https://cabig.nci.nih.gov/>.

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### **Paying for Physicians' Performance: A New Approach to Healthcare**

As the advocate community is well aware, many patients do not have access to quality healthcare, regardless of whether they are receiving treatment through community physicians, large HMOs, or independent hospitals. The lack of consistency among treating physicians has created a healthcare system with huge variability in the medical care that patients receive, ultimately impacting patient outcomes. And when paired with the skyrocketing costs of healthcare, it is clear that the entire system is in crisis.

In an effort to improve healthcare delivery and patient outcomes across the board, different stakeholders are coming together to discuss strategies for increasing quality. At the heart of these discussions is the concept of paying physicians based on their performance and the quality of care of that their patients receive.

Recent pay-for-performance meetings have included healthcare purchasers who want reduced costs, private and government payers who seek improved value and increased affordability, and non-profit organizations who want accountability among physicians. Some of these key players include the Leapfrog Group, which represents major healthcare purchasers such as AT&T, IBM, Marriott, GM, and many others; payers such as Blue Shield Blue Cross and the Centers for Medicaid and Medicare Services (CMS); and the National Quality Forum, a non-profit organization that was created to develop and implement a strategy to improve the delivery and reporting of quality healthcare.

Each of these stakeholders plays a key role in the discussions, helping to ensure that patient care isn't sacrificed in order to cut healthcare costs. Therefore, the proposed pay-for-performance system is built around disease management principles, in order to identify symptoms more quickly, correctly diagnose and treat patients, so that they move through the system from sick to well and have a better shot at remaining healthy.

But in order to evaluate the system's effectiveness, patient outcomes must be clearly and consistently recorded so that clinical evidence can be gathered on high quality, cost-reducing approaches. These results must also be publicly reported so that patient care isn't short-changed, and so that improved treatment methods can be accepted and routinely used by physicians.

As the pay-for-performance system begins to broadly establish agreed-upon quality indicators for chronic diseases and acute conditions, it is possible that the physician community will resist these changes. Currently, CMS is planning to reduce payment to individual physicians by 1% over the next year, when their patient outcomes fall below accepted quality indicators. And that figure is set to increase to 2% within five years, with CMS re-distributing that 2% of payments to the highest achieving physicians as a reward for providing high-quality care to their patients.

Already it is possible to foresee debates on the merits and drawbacks of a healthcare system that compensates and penalizes physicians based on their performance. However, it also offers hope that patients will begin to receive better care on a consistent basis, regardless of the type of insurance coverage they have. Because of this, it will be a tricky balance to develop a fair system that improves patient outcomes while rewarding physicians and cutting costs. With so much at stake, it is important for patient advocates to have a seat at the table as quality indicators are determined and as the pay-for-performance system is widely implemented.

For more information on the 2006 CMS Oncology Demonstration Program, go to the National Comprehensive Cancer Network at [www.nccn.org](http://www.nccn.org).

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### **FDA Guidance on Patient Reported Outcomes: Discussion, Dissemination, and Operationalization--February 23-25, 2006**

*submitted by guest contributor, Cynthia Chauhan*

This meeting was held as a forum for the FDA and professional stakeholders to discuss the FDA Guidance Document for assessing PROs (Patient Reported Outcomes) in clinical trials. This guidance document is still open to public comment. You are encouraged to review the document at <http://www.fda.gov/cder/guidance/index.htm>, reading closely with a mind to considering whether or not Patient Reported Outcomes are being held to a higher standard than other measures. This document and its implementation are excellent opportunities for patient advocates to engage in appropriate watchdogging to make sure the importance of the label does not supersede the importance of the patient and his/her reporting of experience.

A concern is whether some will read the documents guidance "shoulds" as regulatory "musts." Even though the FDA lays out, in good faith, narrow suggestions, not broad mandates, a relevant question is what steps are being taken to assure that their own staff, much less those answerable to it, will construe it thusly? For those who are committed to hearing and reporting the patient voice in all of its nuances, for making sure that a hallmark of intervention is individualized responsiveness to the whole person, this document and its implementation must be carefully monitored. While I believe the FDA and all of the people engaged in the forum were well-intentioned, I was reminded of Yogi Berra's insightful statement, "In theory, there's no difference between theory and practice; in practice, there is." Here is an opportunity for watchdog advocates to make sure that the theory and practice mesh in the best interest of the patient.

[Click here](#) to link to the commentary "A Patient Reported Observation" by Cynthia Chauhan

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### **ADVOCATE LECTURE SERIES ON GENOMICS, PHARMACOGENETICS AND TISSUE COLLECTION, STORAGE AND ACCESS**

The Indiana University Department of Defense Breast Cancer Center of Excellence and the Research Advocacy Network co-sponsored an Advocate Lecture Series in March. The lecture series informed advocates about the importance of genomics, pharmacogenetics and biospecimen collection and storage in making targeted treatments available to patients.

Playbacks and materials from the sessions are available through the Advocate Institute ([www.researchadvocacy.org/login.php](http://www.researchadvocacy.org/login.php)) Funding for the lecture series was provided by the DOD Breast Cancer Center of Excellence and Eli Lilly and Company.

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### Research Advocacy Network Activities

- April 1-5 AACR Annual Meeting
- April 9 - 11 caBIG Annual Meeting
- April 10-13 NCCTG Spring Meeting
- April 19-23 Tenth Intercultural Cancer Council Biennial Symposium, Washington DC
- April 28 – May 1 NSABP Spring Meeting
- May 23 – Coalition of Cancer Cooperative Groups Scientific Leadership Council on Lung Cancer
- May-June Focus on Research Webconferences
- June 1 Women Against Lung Cancer Annual Meeting, Atlanta, GA
- June 2-6 American Society of Clinical Oncology (ASCO) Annual Meeting, Atlanta, GA

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### April Awareness Events

- Cancer Control Month
- Cancer Detection & Early Awareness Month
- Cancer Fatigue Awareness Month
- Head & Neck Cancer Awareness Month
- Lymphoma Awareness Month
- National Young Adult Cancer Awareness Week - April 3-9
- Oral Cancer Awareness Week - April 11 – 17
- Testicular Cancer Awareness Week - April 1-7

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

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### 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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