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The Cancer Genome Atlas Project Moves Ahead

The Cancer Genome Atlas (TCGA) - launched as a joint effort between the National Cancer Institute (NCI) and the National Human Genome Research Institute (NHGRI) - is a comprehensive and coordinated effort to learn from the principles of gene sequencing and apply that knowledge to the clinical cancer setting. By building on the work that the NHGRI achieved through its sequencing of the human genome in 2003, the TCGA initiative aims to accelerate our understanding of the molecular basis of cancer by using genomic analysis technologies to sequence the cancer genome.

Specifically, TCGA will pilot this project by studying the genomic make-up of three tumor types which are yet to be determined. If the pilot efforts to study these three tumor types are successful, TCGA will then go on to systematically study the genome of every tumor type, ultimately exploring the entire spectrum of human cancer.

According to TCGA, the initiative will result in an "atlas" of the many genetic changes and mutations that occur in cancer, providing insight into the molecular pathways that can lead to the uncontrolled growth of cancer cells when their normal patterns are disrupted. TCGA believes that this information will enable significant advances in cancer research and lead to a myriad of new therapeutic targets for scientists to explore. These leaps forward in research have the potential to trigger better disease management by physicians and improved clinical outcomes for patients.

Throughout this project the advocate perspective has been a welcomed voice, due in large part to both Dr. Anna Barker, Deputy Director of NCI and to Dr. Francis Collins, Director of NHGRI. An advocate involved in the TCGA initiative views it as an exciting yet complicated project, because it could be a challenge to make sure that the technology needed to perform the research is accessible and reproducible. Because there is so much scientific and technological complexity with this program,

TCGA has broken it into several components - such as gene sequencing or tumor analysis - so that researchers and institutions can apply for grants to undertake the components that match their areas of expertise.

Because the scope of the TCGA is considered to be quite broad - with the NCI and NHGRI each contributing \$50 million to the project - some within the cancer community are wondering if those dollars could be better spent elsewhere. In light of NCI's major investments in other new areas of research such as nanotechnology and the cancer Biomedical Informatics Grid (caBIG), it will be important that the community keep these agencies accountable for the funds they are spending on these new initiatives, especially if it results in the loss of funding for other established projects such as the Cooperative Groups and the SPORE programs.

And as data from the studies on the first three tumor types begin to come in, it will also be important to build in opportunities for advocate and community oversight. This will help ensure that the genomic information gleaned from patients' biospecimens is handled in a safe and ethical manner that supports scientific advances while still protecting patients' privacy. The sharing of this data among researchers and institutions will be vital in order to maximize its usefulness, but exactly how and when the data will be entered into the public domain - and who will be able to access it - is still to be determined. It is an exciting time as the TCGA project gets off the ground, and advocates should stay apprised of the initiative's progress so that the community can continue to provide its input on the important issues related to these advances in research and patient care.

For more information on the Human Genome Project, please visit <http://cancergenome.nih.gov/index.asp>

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Advocates and Industry Struggle to See Eye-to-Eye on Drug Pricing

In the last few years there has been a significant advance in the treatment of many cancers, as newer therapies and targeted treatments have been developed by industry and then approved by the FDA. As advocates, we recognize the cancer community's need for these treatments, which offer improvements over older therapies by reducing side effects, improving long-term clinical outcomes such as survival, and giving hope to the patients and families affected by cancer.

Because the advocate community recognized the promise that these new therapies held, many of us partnered with industry to support the clinical trial enrollment for these treatments and then pushed FDA for faster approval of these drugs. But as the initial excitement surrounding these new drugs has faded and reality has set in, the community has been left to grapple with the exceedingly high prices that industry is charging for their new treatments. As a community we are supportive of the availability of new treatment options, but as individuals and organizations trying to assist patients through the maze of reimbursement and access to care, the pricing of drugs is an issue we must be able to better understand.

And pricing is clearly a hot topic - it has been the subject of recent editorials in the *New York Times* and has been discussed at advocate conferences. Even industry is beginning to recognize that this issue isn't going to go away on its own, and some companies are attempting to address it with the advocate community. Both pharmaceutical and biotech companies have recently invited a corps of advocates - including the Research Advocacy Network - to their campuses for discussions that include pricing. While these meetings were a step in the right direction, the conversations on how these companies decided to price their drugs was not in sufficient detail to understand the methodology.

The community understands that quality cancer drugs require years of research and can be difficult to manufacture, contributing to a higher price. Most patients do not consider paying for life-saving medicine to be a choice. We all know patients who are mortgaging their homes to pay for these treatments, or who have access to these drugs through their insurance but can't afford the monthly co-pays which often exceed \$1000.

And while the drug companies need to do a better job of answering pricing questions in a straightforward, open manner, we as advocates also need to learn pricing methodologies, ask tougher questions and push for those answers when they are not readily forthcoming. We recognize the importance of our partnerships with these companies - who often underwrite our programs and provide us with unrestricted educational grants - but an important component of true partnership is honesty. As advocates we need our industry partners to be more informative about how drug prices are truly determined, and we need to educate ourselves about the drug development process so that we can engage in productive dialogues on this subject. We must also not be misled by statements made without full knowledge of the situation. For example, the press has reported that the price of a drug is dependent on the type of cancer to be treated. Drugs are priced per unit. What affects price is differences in the dosage needed to effectively treat different cancer types.

In an era of cutbacks throughout the healthcare system, we must urge companies to control costs and look into reducing the prices of prohibitively expensive drugs. We must ask for detailed explanations of their pricing models to understand exactly how these prices are determined. And most of all, we must understand how the healthcare system works, so we can decide whether these prices are appropriate or whether our industry partners are over charging the patients we serve.

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Announcements

ASCO re-launches People Living With Cancer website. The patient information website has been redesigned to offer more user-friendly navigation and comprehensive content about cancer. <http://www.plwc.org/>

The Alamo Breast Cancer Foundation (<http://www.alamobreastcancer.org/>) invites advocates to participate in the archived webcast on HOT TOPICS 2005 from the San Antonio Breast Cancer Symposium <http://www.m3login.com/content/E86EED55-59CB-4880-833B-B76469363981/64.aspx>

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Research Advocacy Network Activities

- May-June - Focus on Research Webconferences
- June 1 - Women Against Lung Cancer Annual Meeting Advocacy Presentation
- June 2 - Focus on Research 2006 dinner at ASCO
- June 3 - TAILORx advocacy briefing at ASCO
- June 4 - RAN (Mary Lou Smith) oral presentation, ASCO Breast Cancer General Session
- June 5 - RAN poster presentation at ASCO
- June 2-6 - American Society of Clinical Oncology (ASCO) Annual Meeting
- June 23-25 - ECOG Spring Meeting
- June 22-25 - RTOG Spring Meeting

Awareness EventsComing up in June

- National Cancer Survivors Day - June 4th
- Sarcoma Awareness Month

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

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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 by sending a donation. RAN is an exempt 501 c 3 organization and dependent on your support to keep going. Our mailing address is: East Rand Rd, Suite 175, Arlington Heights, IL 60004. Thanks!

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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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