

**62nd Meeting of the National Cancer Institute (NCI)
Director's Consumer Liaison Group (DCLG)**

NIH Campus
Building 31, C Wing, 6th Floor, Room 10
Bethesda, Maryland
March 18–19, 2013

Members Present

Ms. Gwen Darien, Chair
Dr. Jeff Allen
Mr. David Arons
Ms. Susan G. Braun

Dr. Adam Clark
Ms. Andrea Ferris
Ms. Joya Delgado Harris
Ms. Linda House

Mr. Jeff Kaufman
Mr. Jon Retzlaff
Mr. Max Wallace

Speakers

Ms. Kelli Marciel, Director, Office of Advocacy Relations (OAR), NCI

Ms. Gwen Darien, Chair, Director's Consumer Liaison Group

Dr. Lou Staudt, Chief, Lymphoid Malignancies Section; Deputy Chief, Metabolism Branch, Center for Cancer Research, NCI

Dr. Kenneth Offit, Chief, Clinical Genetics Service, Memorial Sloan-Kettering Cancer Center

Dr. Margaret Tucker, Director, Human Genetics Program; Acting Director, Division of Cancer Epidemiology and Genetics, NCI

Ms. Elizabeth Pike, Senior Policy and Research Analyst, Presidential Commission for the Study of Bioethical Issues

Dr. Laura Lyman Rodriguez, Director, Office of Policy, Communications, and Education, National Human Genome Research Institute

Dr. Nikhil Wagle, Medical Oncologist, Dana-Farber Cancer Institute; Associated Researcher, Broad Institute

Mr. John Wilbanks, Chief Commons Officer, Sage Bionetworks; Senior Fellow, Ewing Marion Kauffman Foundation

Dr. S. Percy Ivy, Associate Chief, Investigational Drug Branch, Division of Cancer Treatment and Diagnosis, NCI

Dr. Abby Sandler, Executive Secretary, President's Cancer Panel (PCP), NCI

Facilitator

Mr. Robert Mittman

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Day 1: Monday, March 18, 2013

Opening Remarks

Ms. Kelli Marciel and Ms. Gwen Darien

- Ms. Marciel and Ms. Darien welcomed DCLG members, speakers, NCI representatives, and guests.
- Ms. Marciel noted that progress in genomics research is evolving rapidly, raising questions in the scientific community around the potential benefits and risks of this research, as well as the adequacy of existing rules intended to protect patients' privacy and confidentiality. Several ongoing regulatory and guidance developments, as well as a request from Dr. Harold Varmus, NCI Director, are guiding the DCLG's efforts to focus on informed consent for genomics research.
- The meeting will provide an opportunity to assess progress in this area as well as further explore the balance between advancing research and ensuring privacy and confidentiality for patients.
- Ms. Darien added that there are some federal activities that are of interest to the DCLG, recalling in particular, the DCLG's comments on the proposed changes to the Department of Health and Human Services' (HHS) Advance Notice for Proposed Rulemaking, Human Subjects Research Protections.
- Ms. Darien stressed that DCLG members can help guide the dialogue in the community around the need to provide open, broad access of genetic data for the advancement of research, while at the same time protecting and honoring patients and their interests.

The Future of Genomics Research: NCI and Beyond

Dr. Lou Staudt

- Dr. Staudt began his presentation by noting that genomics can be used to better diagnose cancer and develop cures. He stressed the importance of several projects at NCI, including The Cancer Genome Atlas (TCGA); the Therapeutically Applicable Research to Generate Effective Treatments (TARGET) project, which focuses on genomics in pediatric cancer; and the Cancer Target Discovery and Development (CTD²) Network, a consortium to accelerate the translation of genomic discoveries into new cancer treatments through innovative research.
- The goal of TCGA is to develop a comprehensive characterization of a cancer genome and discover the drivers of the cancer. Manuscripts from TCGA research include seven different types of cancer and have been submitted or published, with varying degrees of success in discovering drivers. Analysis is underway on seven additional cancer types and others are in the sample acquisition phase. TCGA is scheduled to be completed in October 2014 and ultimately will study 10,000 samples across a large number of cancer types.
- Dr. Staudt emphasized that many open questions remain in cancer genomics—this is the beginning of the study of cancer genomics, not the end. Cancer is heterogeneous and the full extent of driver mutations and genetic pathways in cancer is unknown, as is the genetic basis of metastasis. Researchers have faced difficulties in obtaining adequate samples from patients with metastatic disease.

- Scientists also know little about the genetic abnormalities that explain response or resistance to therapy. The cancer field needs to become smarter about treatment and identifying which genetic abnormalities explain and predict response or resistance to therapy.
- An example of targeted therapy from cancer genomics is erlotinib treatment of lung adenocarcinoma with epidermal growth factor receptor (EGFR) deletion mutation in exon 19. Smart drugs that target certain receptors are the goal, but single-agent treatments often do not achieve long-term cures. More often, a strong initial response is followed by relapse, but the responses are cause for optimism.
- A much larger sample size will be required to elucidate “all” causative mutations in lung adenocarcinoma, and it will be necessary to analyze 10,000 tumors to identify all causative mutations that occur in at least 1 percent of tumors. The potential to build a 10,000-tumor study is enhanced by the ability to study samples preserved in paraffin and conduct retrospective studies.
- Four types of studies that contribute to the database are (1) TCGA; (2) completed randomized controlled trials, both NCI and institutional; (3) prospective clinical trials, such as ALChEMIST, the Adjuvant Lung Cancer Enrichment Marker Identification and Sequencing Trial; and (4) epidemiologic cohorts from completed case-control studies and prospective trials, such as the Prostate, Lung, Colorectal and Ovarian (PLCO) cancer screening trial.
- Dr. Staudt concluded that the defining principle in NCI trials in the 21st century is that no biopsy means no trial. He emphasized the importance of making trials the best they can be scientifically.

Dr. Kenneth Offit

- Dr. Offit mentioned that genomics testing for cancer prevention involves predicting the future, and science is not always good at predicting the future.
- Scientists can use human models from mouse cancers to develop prevention methods and target genetic therapies. The identification of BRCA1 and BRCA2 in the late 1990s represents one of the breakthroughs of the genetics era; targeted therapies also could mean breakthroughs.
- While informed consent has been relaxed in some contexts, it is rigorous for germline studies. Investigators must be sure that all rules of consent are discussed.
- Incidental findings in genomic studies, the “incidentalome,” raise questions about the duty to warn a patient’s family members about hereditary disease risk. The duty to warn is important, and ignoring it raises the risks of legal repercussions.
- Consent for genomics can readily be modified to allow next-generation sequencing. Consent also incorporates release of anonymized data to the database of Genotypes and Phenotypes (dbGaP), a database of genomics information coordinated by the National Library of Medicine.

Discussion highlights

- In applying the science, investigators turn to genomics to determine which genes are important and what the essential pathways are. Genes and pathways have been found to be complementary.
- Ultimately, the goal is to find therapies that get to the root cause, the essential cell. Current therapies do not do this and better models are needed.

- Incidental findings and the duty to warn are enormous questions and no longer theoretical. Analysis is improving and money is being invested in finding mechanisms. A patient ultimately should be in the position to drive his or her own care.
- Another question is whether to provide patients with validated information without available treatment to offer. It is very challenging for a physician to decide what to burden a patient with. Information that does not appear to be actionable at the moment *may* be actionable in the future.

Using Informed Consent to Align Patient Needs with Research Goals

Dr. Margaret Tucker

- Issues of informed consent confront not only researchers but also participants in research studies involving genomics. Types of studies include clinical trials (e.g., targeted drug studies), collections of clinical specimens, and epidemiological studies.
- Informed consent is an ongoing process. Researchers and participants are often very open to sharing, but they have different interests and potential tensions still exist.

Tensions can involve:

- Return on investment (of time, energy, and biospecimens) for participants
- Privacy and confidentiality for patients
- Impact of a study on a patient's health care
- An "ideal" consent must be at low-grade-level literacy and must clarify expectations of future requests, contacts, data return, and results notifications for participants.
- Until new data sharing policies are in place, researchers are following genome-wide association studies (GWAS) guidelines. Data are available at an individual level to bona fide investigators if they agree not to identify individuals and to provide institutional certification of data security.
- Difficulties remain in returning personal data to participants.

Ms. Elizabeth Pike

- *Privacy and Progress in Whole Genome Sequencing*, the report of the Presidential Commission for the Study of Bioethical Issues, focuses on the need to reconcile privacy concerns with scientific progress.
- Progress in whole genome sequencing requires that individuals remain willing to share their whole genome sequence data and calls for reconciling individual privacy concerns with the need for large amounts of whole genome sequence data.
- No comprehensive law protects genetic privacy or risks associated with sharing whole genome sequence data. The Genetic Information Nondiscrimination Act (GINA) protects against discrimination in certain circumstances, and the Health Information Portability and Accountability Act (HIPAA) protects against disclosure of "protected health information" in certain circumstances. The Common Rule provides research protections only if data are readily identifiable. No overarching federal or industry privacy guidelines exist for commercial genetic-testing entities.

- The report identifies five areas that require deeper ethical analysis:
 - Strong baseline protections while promoting data access and sharing
 - Data security and access to databases
 - Informed consent
 - Facilitating progress in whole genome sequencing
 - Public benefit
- The first recommendation is that funders of whole genome sequencing research; managers of research, clinical, and commercial databases; and policymakers should maintain or establish clear policies defining acceptable access to and permissible uses of whole genome sequence data.
- The Commission also recommends that federal and state governments ensure a consistent floor of privacy protections covering whole genome sequence data, regardless of how they were obtained.
- Unauthorized whole genome sequencing without the consent of the individual from whom the sample came should be prohibited.
- Informed consent processes should be ongoing and:
 - Allow research participants, patients, and others to understand who has access to their whole genome sequences and to know how these data might be used in the future;
 - Require clear and consistent guidelines for informed consent forms, describing whole genome sequencing, how the data might be used, and individual control over future use;
 - Consider the implications of incidental findings and address them in the consent process (whether these findings will be communicated, the scope of communicated findings, and to whom the findings will be communicated); and
 - Consider the preferences and expectations of individuals contributing samples and data to genomic research
- Ms. Pike stated that privacy is complicated legally and difficult to regulate. The Commission recommends that a group of people be brought to the table to determine what should be done and how it should be done procedurally. An upcoming Commission report on incidental findings will address these issues.

Discussion highlights

- The notion of harms and benefits related to privacy is an important framing issue. Actual harms of privacy have not been demonstrated.
- Healthy people and people dealing with illness might have different interests, but everyone is entitled to have his or her data protected.
- Lowered costs of genomic research might influence consent questions. Social media and the way they influence societal attitudes about privacy are also a consideration.
- Any consent must be informed, but time might not allow explaining all aspects of consent for genomic research. Also, many patients will tune out after the first 5 minutes of an informed consent consultation. Sometimes, learning that one has cancer is all a person can absorb.
- It was reiterated that consent is a process, not a single event. Investigators and clinicians must develop contracts with patients stating that the investigators and clinicians will work with the

patients, take care of them, and provide the information they need. It is often spoken of as a single event, but it is not.

- Explaining the implications of the genome is very time-consuming. Consents will move toward electronic interactive forms, not a document, but a process.
- Some papers have suggested real or perceived harms of informed consent such as blackmail scenarios or placing DNA at a crime scene. Breaching scientific data should be a serious felony, and laws against discrimination because of genetics should be enforced.
- Lack of anonymized data for research potentially could be devastating for the research community.
- Researchers want to be able to steer people to a safe harbor and an understanding that the consent is reasonable. Safeguards also are needed for researchers.
- Information sharing is defined by an interactive collaborative agreement and is not part of the consent process with the patient.
- Genomic and genetic information is intellectual property, and a company may want control over genetic information. The information leads to patents and design of devices such as test kits. But how long does a company have the right to exclusive use?
- Patients should be informed about the specific uses and availability of their tissue and data. Data that is in dbGaP, for example, is completely available for all researchers willing to sign a confidentiality agreement.

Status of Ongoing Guidance and Regulatory Developments

Dr. Laura Lyman Rodriguez

- Policy about data sharing principles and structures must originate in the scientific aims. Different cultures—science and consumer protection—come together and intersect at the point of informed consent.
- Genomics has always been about rapid access to information, as in data for cancer research, so that researchers can take advantage of the data. This is in contrast to the culture of human subjects research, where the focus is on protection, individual autonomy, and distributed burden.
- Genomics through human subject research requires participant choice and participant privacy.
- Trends in science have shifted. Many unforeseen projects involve broader consent than was previously needed, new governance models, and an unbounded timeframe.
- NIH's guiding principle is to try to achieve the greatest public benefit. Its 2003 Data Sharing Policy stated that data sharing is essential for expedited translation of research results into knowledge, products, and procedures to improve human health. It endorsed sharing final research data to serve these and other important scientific goals.

- The guiding principle for genomic data sharing is that the greatest public benefit will be realized if data from genomic studies are made available, under terms and conditions consistent with the informed consent provided by individual participants, in a timely manner to the largest possible number of investigators.
- A new and important NIH policy decision states that shared data would be de-identified but terms and conditions would remain consistent with informed consent.
- Guidance in the area is not clear and both science and informed consent are evolving. Some decisions will be made by local Internal Review Boards (IRBs).
- Considerations for consent forms include:
 - Use (and future use) of samples and information
 - Collection of health information
 - Sharing data and information widely
 - Longevity of data and use
- Potential risks are loss of privacy, stigmatization, and discrimination.
- The NIH is in the process of updating its Data Sharing Policy and seeking to improve the informed consent portion of that document. The new policy is a response to questions about accessibility of whole genome sequencing and other rapidly advancing genomics technologies; a consistent approach for investigators, institutions as secondary users, and participants; the increasing complexity of data and project types; and the need to define appropriate consent expectations. NIH will post changes for public comment.
- New information and updates are available from the GWAS Web site at <http://gwas.nih.gov>. Explanations will be posted about how the policy works and how it will be implemented by NIH.
- Consent would apply prospectively, but there are questions about how to handle existing sample sets and whether exceptions are ever reasonable.
- Informed consent elements for genomic research should include:
 - Purpose of the research project
 - Description of the research procedures
 - Discussion of financial compensation, costs, and commercialization
 - Potential benefits and risks for the participant
 - Confidentiality
 - Returning results to participants
 - Withdrawal
 - Alternatives to participating in the project
 - Voluntary participation
 - Contact information

(More information is available at <http://www.genome.gov/informedconsent>)

- A natural tension exists between values to protect and respect participants and promotion of health advances through research. Systems of trust and systems of oversight must overlap.
- Participants are driving the momentum to be part of research and changing the interactions with participant-centric initiatives.

Discussion highlights

- Specifics of consent and how information will be shared are not yet clear.
- Both public health and individual health approaches to consent are relevant.
- Advocacy groups are participating in the public comment process and bring different perspectives to the table. The NIH has built a solid foundation of involving consumer groups.
- Industry has been very active in data sharing. For example, dbGaP was initially built with Pfizer, and many users of dbGaP are from the business community.
- The advocacy community understands the value of the data it provides but wants to know that the data will be disseminated to qualified researchers to develop drugs. Tiers of interoperable data are needed: publicly available, available to qualified researchers, availability limited, and protected.

Practical Approaches to Informed Consent

Dr. Nikhil Wagle

- Genomics in cancer treatment has moved to the point where it can be used in the clinic. It is possible to identify cancer drivers and possibly a drug to link to them.
- The path for personalized cancer medicine involves the development of targeted therapies for mutated genes.
- CanSeq is a system of prospective whole-exome sequencing on patients at Dana-Farber/Brigham and Women's Cancer Center, with the return of clinically actionable results to the clinical care team.
- CanSeq focuses on four cancers: metastatic lung adenocarcinoma, metastatic colorectal adenocarcinoma, metastatic castrate-resistant prostate cancer, and metastatic breast adenocarcinoma. The goal is to sequence samples from 150 to 200 patients in the first year.
- CanSeq will evaluate:
 - Whether exome sequencing is a usable technique;
 - Impact of exome sequencing on clinical decision making; and
 - Physician and patient understanding of genomic data.
- Patients fill out a detailed 18-page consent form, and genetic counseling is offered at the time of consent and available any time after consent. The informed consent process uses clinical research coordinators who receive extensive training. Privacy and other risks are discussed.
- The CanSeq consent form covers types of information that might be returned, risks of genetic testing, privacy issues, and choices about what genetic information patients would like returned (including multiple classes of somatic and germline alterations).

- CanSeq developed an algorithm—PHIAL: Precision Heuristics for Interpreting the Alteration Landscape—for sorting the data. The highest clinically actionable items go into a database; the goal is to have the database publicly accessible like a wiki.
- Early lessons learned from CanSeq are that the time commitment can be challenging for patients and their baseline understanding of the issues varies. Privacy and confidentiality have not played a prominent role in the discussions.

Mr. John Wilbanks

- Mr. Wilbanks started with an operational hypothesis that sharing by small but coherent groups can create asymmetrically valuable resources. A well-known example of the hypothesis is Wikipedia. This can be applied to genomic and other personal health data.
- Mr. Wilbanks paid for his own genotype from 23andMe and posted it on Synapse, a Sage Web-based collaboration tool for scientists working in disease research. His experiment demonstrated that an emerging group of people with resources available can obtain data about themselves without talking to a doctor.
- For his experiment, Mr. Wilbanks and colleagues built PLC, which stands for Portable Legal Consent. This small IRB-approved group seeks to determine whether patient-driven data sharing works in the health field. Patients read and digitally sign the informed consent, and their doctors upload their data. From that point on, patients are participating in public genomics research. Researchers who access and use the data agree not to try to re-identify or harm the participants and to share their research with the public under open-access laws. But there are no guarantees that users will respect the conditions.
- Powerful computers and good mathematicians make complete de-identification of participants in large datasets almost impossible.
- If individuals are empowered to donate their data, some will, and that could create a valuable data source.

Discussion highlights

- Informed consent is often time-limited. Can it take into account that people change their minds and their values change?
- Once data have been shared in a public database, they cannot be removed.
- Consent forms should be interoperable among systems.
- Remaining consistent with a participant's wishes is complicated and involves the duty to report. The field is evolving.
- Data being posted from citizens is not very useful today, but it will be in 5 years.
- To the extent that a genomic profile says something about an individual, that person will be potentially identifiable.
- Informed consent is basically contract law.

- There is a need for more genetic counselors and genetic counseling programs.
- Many institutions debate the tension between return of results and autonomy. Sometimes tumor board members disagree about what is clinically actionable.
- It is not in the best interest of research to rush to commoditize the genome.
- Despite increasing availability and decreasing costs, most people do not want to know their own genomic sequence.

DCLG Working Session

Dr. S. Percy Ivy

The input of the advocacy community is requested for a consent document, which remains a work in progress. The consent form is for studies in which molecular (including genomics) data will be evaluated and additional information is needed about risks and confidentiality.

- The two consent scenarios for trials in which genomic information will be generated are:
 - ALChEMIST, which screens for lung cancer biomarkers
 - NCI MATCH, a screen for molecular features that could predict response to a drug with a given mechanism of action
- A concise informed consent template for the NCI-supported trials consent form has been developed. It is available online at the NCI Cancer Therapy Evaluation Program (CTEP) under Protocol Development/Informed Consent (http://ctep.cancer.gov/protocolDevelopment/docs/NCI_IC_Template.doc).
- The template includes examples of consent language for specimen studies, including for risks and confidentiality. Draft template language can be developed for patient molecular screening and issues surrounding molecular findings. The template also can be adapted for any disease.
- Specified risks included in the NCI consent include: brief pain or bruising from a blood draw, infection from biopsy (rare), unauthorized access to personal information, re-identification of de-identified information, misuse of information by insurers or others, and distress from learning genetic information.

Discussion highlights

- Further specifications of protections already in place would be useful (e.g., the Genetic Information Nondiscrimination Act).
- The meaning of unusable tissue should be clarified.
- Further information about benefits is included in the consent form.
- The risk of knowing genetic information should be better explained. For some people, knowing what genetics tells them about their future might make them want to reconsider participating.
- All types of data related to genomic expression will be gathered, not only cancer information.

- People often sign forms of informed consent, such as online licensing agreements, without reading them.
- Patient privacy is important to researchers, who will make every effort to protect it.
- Patients in genomic trials might be asked to take risks that can extend beyond health care. If individuals want all of their information, they should be able to get it.
- Returning information that cannot be interpreted for patients is particularly troublesome. The field is at the cusp of an explosion of information, but much has not been validated.
- The language in the document should be examined to ensure that it is empowering to the patient rather than denying, which is the current impression. There will always be inherent risks. The investigator must be sensitive to what is said versus what is heard by the patient.
- Dr. Ivy requested further input from DCLG members for the draft consent.

Day 2: Tuesday, March 19, 2013

President's Cancer Panel Update

Dr. Abby Sandler

- The PCP has held three of four scheduled workshops around the theme of the human papillomavirus (HPV) vaccine.
- The topics of the first three workshops:
 - HPV Vaccination as a Model for Cancer Prevention
 - Achieving Widespread HPV Vaccine Uptake
 - Creating an Integrated HPV Vaccination and Screening Program
- The topic of the fourth workshop, scheduled for April 23–24, 2013, in Miami, Florida, will be Global HPV Vaccination: Opportunities and Challenges.
- Some of the main points of the HPV workshops:
 - Progress is being made with vaccine uptake but efforts to increase uptake, especially among males, need to have a high priority.
 - Studies indicate that changes in administration of the vaccine might be considered.
 - Gaps in knowledge about oral HPV infection must be addressed.
 - Expanded data systems will be needed to support vaccine monitoring and surveillance.
 - Health care providers must be educated about HPV-associated diseases (especially non-cervical cancers) and the effectiveness of the vaccine in preventing these diseases.
 - Vaccine uptake could be improved by allowing additional providers, such as pharmacists, to administer one or more doses of the vaccine.
 - Robust infrastructure (electronic health records, vaccine registries, etc.) could facilitate reminders to enhance completion of the vaccine series.
 - Widespread HPV vaccine uptake will shift the balance of screening risks and benefits. It could enable reductions in screening initiation and intervals and provide a rationale for primary HPV testing.
 - Physicians need tools to facilitate adherence to guidelines and communication with patients about evidence-based screening practices in the HPV era.

- The 2010–2011 annual report of the PCP, *The Future of Cancer Research: Accelerating Scientific Innovation*, has been released. It is available on the PCP Web site (<http://deainfo.nci.nih.gov/advisory/pcp/annualReports/pcp10-11rpt/FullReport.pdf>). Hard copies are also available.

Discussion highlights

- The HPV workshops have not generated controversy, but there is controversy about the HPV vaccine in general and questions about safety.
- Information about surveillance that is currently collected at the state level would be useful if compiled nationally.
- Dr. Doug Lowy, Deputy Director of NCI, noted that the evidence is clear that screening interventions are effective, including health benefits from preventive measures such as smoking cessation, but there can be harms from interventions, especially from colonoscopy. The benefits clearly outweigh the harms. The same is true for HPV vaccination. There are harms, but it is important to understand how much the benefits outweigh the harms.
- Some have overstated the harms of HPV vaccines, leading to increased concerns about safety. Information about positive effects of the vaccine has largely been overlooked.

Day 1 Recap and Next Steps

- When advocates think about using informed consent to align patient needs with research goals, the issue of privacy is raised much less frequently than the importance of data sharing.
- The moral compact between patient and provider is an important point, as is the return of research results to patients.
- As science is changing, so are the ethical frameworks of the health care system.
- DCLG feedback to NCI about informed consent will continue. This is a topic in which the DCLG can provide great value.
 - Dr. Ivy requested written feedback from the DCLG.
- The DCLG has an opportunity to establish model language about informed consent. A task force would be useful to write suggested language. A task force will be discussed in an upcoming teleconference.
- One of the goals is to shorten consent forms.
- Specific areas involved in consent can form a framework for discussion and designing forms. These areas include:
 - Participant choice
 - Privacy
 - Data aggregation and distribution
 - Clinical care options
- Innovative ideas include Portable Legal Consent; interoperable consent, a broader construct than portable; and remixable cohorts, which is not quite at an informed consent level.

- Other advocacy organizations (e.g., the Army of Women) can provide input about consent. Resources of individual DCLG members' organizations also should be considered.
- The group discussed opportunities to enhance its charge to provide guidance to NCI leadership. A working group of the DCLG established to examine consent issues is an excellent example of how this can be done.

OAR Update

Ms. Kelli Marciel

- OAR has provided Ms. Darien, Ms. Braun, and Mr. Mittman with a draft paper on drug shortages and plans to share with the rest of the group once it has been reviewed.
- Recent OAR activities include:
 - A meeting of cancer research funders and NCI to discuss areas of potential funding collaboration
 - The office's evolving scope of responsibility, including increased awareness of the sophistication and scientific rigor of non-profit cancer research funding organizations
 - Increasing interactions with the pediatric cancer advocacy community
 - A new database to support the program that was formerly known as CARRA (Consumer Advocates in Research and Related Activities)
 - Redesign of the OAR Web site
 - Restarting the OAR List Serv
- OAR will contact DCLG members about follow up subjects, including the NCI informed consent document and a new structure to support the development of DCLG working groups.

The meeting adjourned at 11:30 a.m.

Certification

I hereby certify that the foregoing minutes are accurate and complete.