

**DEPARTMENT OF HEALTH AND HUMAN SERVICES  
NATIONAL INSTITUTES OF HEALTH  
NATIONAL CANCER INSTITUTE**

**MINUTES OF THE 57<sup>th</sup> DIRECTOR'S CONSUMER LIAISON GROUP MEETING  
Chapel Hill, North Carolina**

**May 18-20, 2011**

**Members Present**

Ms. Gwen Darien, Chair  
Mr. Everett Dodson,  
Vice Chair  
Dr. Jeff Allen  
Ms. Susan Braun

Ms. Joyce Wilcox Graff  
Ms. Cheryl Jernigan  
Ms. Phyllis Pettit Nassi  
Mr. Jon Retzlaff

Ms. Wendy Selig  
Mr. Josh Sommer  
Ms. Arlene Wahwasuck  
Mr. Max Wallace

**Speakers**

Dr. Robert Harrington, Duke Clinical Research Institute  
Dr. Nancy Sung, Burroughs Wellcome Fund  
Mr. Philip Porter, Hogan Lovells  
Mr. Troy Livingston, Museum of Life and Science  
Dr. Shelley Earp, UNC Lineberger Comprehensive Cancer Center  
Dr. Laura Linnan, UNC Gillings School of Global Public Health  
Dr. Anissa Vines, UNC Gillings School of Global Public Health  
Dr. Paul Godley, UNC Lineberger Comprehensive Cancer Center  
Dr. Cathy Melvin, UNC Lineberger Comprehensive Cancer Center  
Dr. Jennifer Leeman, UNC School of Nursing  
Dr. Nadine Barrett, Susan G. Komen for the Cure, NC Triangle  
Dr. Monair Hamilton McGregor, Susan G. Komen for the Cure, NC Triangle  
Dr. Marlyn Allicock, UNC Gillings School of Global Public Health  
Dr. Kurt Ribisl, UNC Gillings School of Global Public Health  
Dr. Michael O'Malley, UNC Lineberger Comprehensive Cancer Center  
Mr. John Czajkowski, National Cancer Institute  
Mr. Robert Mittman, facilitator

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## May 18, 2011 – Opening Remarks

Introductory and welcome remarks from Everett Dodson, Gwen Darien and Shannon Bell

### Meeting Objectives

- Explore innovative partnerships
- Examine how partnerships enhance translation
- Identify opportunities for DCLG members to develop partnerships that enhance translation

### Translational Research: A Review of the Clinical and Translational Research Continuum

*Dr. Robert Harrington, Director of the Duke Clinical Research Institute*

### *Dialogue with the DCLG*

In your research group, do various disciplines work together to address co-morbidity issues in clinical trials?

- Yes, trans-university institute (ex: chronic kidney and cardiovascular disease; depression after heart attacks)
- Physically put faculty close to each other, mix disciplines

How are people rewarded to move into team science?

- Creating an ethos that team science should be rewarded; changed criteria for promotion; need to make the case to incentivize; typically academic rewards rather than financial rewards

Example was about collaboration within Duke; what about how people work together across the country/various organizations?

- How to partner with like minded individuals trying to solve the same problems; group working with approx 30 academic research organizations, who also reach out into the community
- Predicts clinical trials being done an order of magnitude larger but need more collaboration
- Barriers – admin burdens around clinical trials (contracts, IRBs, elaborate steps to get protocols improved); engaging patients more directly to encourage increased participation – need to also reach out to physicians, can be barrier to getting patients into trials

At the rare disease level, if you have a trial only in one center must get self to that center (time, finances, and separation from family)?

- Every state does not have board-certified childhood rheumatologist; try to link community together, treat where located
- Need statement out of consumer advocacy network about wanting this

Wendy Selig: Cancer trials becoming more personalized/specialized vs. growing numbers of magnitude for one trial

- From a population perspective, how do you move the ball? Need to make it easier for people to do

Susan Braun: Where on the earlier end do you see community/patient input in hypothesis and trial development?

- HIV way ahead on that area; what do patients think about X becoming increasingly important, adding patients to committees. Very little research done on impact of patient involvement.

### **Major Barriers to Translating Research into Practice and Policy**

*Dr. Nancy Sung*, Senior Program Officer, Burroughs Wellcome Fund, Health Research Alliance member

#### ***Dialogue with the DCLG***

Your paper from 2003 (Sung et al. *JAMA*. 2003) highlights big problems in translational research. These problems are still around now. What has changed in the past eight years?

- Fragmentation of infrastructure is decreasing. We are slowly moving in right direction. Also, the clinical trials process in the US is in trouble. Trials are moving outside US for a number of reasons. The culture of American medical schools needs to change. The US needs new scientists and scientific leadership.

In that same paper, did you discuss the balance between R01 grants and RFPs in translational research portfolios? Were you able to discern what a good balance would be?

- We did not study that factor exactly

What can we do (as funders) to accelerate translational research?

- Bring increased numbers of physical scientists into the field to discern patterns in huge data sets
- Change the cultural perception that translational science is “poison to the basic science enterprise”
- The most critical time in a researcher’s career is between their post doc position and their associate professor position (5-6 years), particularly for MD PIs. We need to create and support levers to get the researchers through this professional period in their career
- Reward collaboration, particularly for MD PIs

### **Roundtable Dialogue on Partnerships and Policy**

*Dr. Robert Harrington, Mr. Philip Porter, Mr. Josh Sommer, Dr. Nancy Sung, Mr. Max Wallace*

Research Triangle, NC is the birthplace of the clinical research organization (CRO). Prior to CROs (mid-1980s), the attitude was that the pharmaceutical industry would never outsource clinical research. This was the core of what they did. Dennis Gillings disagreed and created Quintiles. Paula Ehrlich, guest attendee, is a veterinarian with global public health experience.

Philip Porter is a partner at Hogan Lovells, a law firm with over 2,500 lawyers worldwide. He works on commercial law and intellectual property. He has specialized in life science contracts for a while.

- CEO Roundtable on Cancer: Started by Bob Ingram and George HW Bush with the idea to get companies to work together to fight cancer. There are two problems with this goal:
  - A successful company is selfish—it needs to keep its confidential information confidential. It needs to keep its intellectual property in its circle of wagons
  - Government takes a dim view of companies talking with one another (antitrust issues).
- The CEO Roundtable on Cancer is addressing the challenge but has not overcome the challenge. The Roundtable is a group of CEOs of 30 companies in the pharmaceutical, medical device, and other industries. The goal of the Roundtable meetings is to see what has been done to improve the treatment of cancer and what has been done in the past year.
- The CEO Roundtable on Cancer has four initiatives and two working groups.
  - CEO Roundtable on Cancer Gold Standard: Certifies companies as a smoke-free workplace. This includes not only a smoke-free building but also around the perimeter of the building. The company also has to hold wellness and health programs.
  - Life Sciences Consortium: George HW Bush formed it with three goals.
    - 1) START Clauses: Helped to create a standard research trial agreement. The CEO Roundtable on Cancer looked at beginning and agreed on contracts to see where there were overlaps. A survey found that START clauses have accelerated research.
    - 2) When a drug is being approved for a new indication by the pharmaceutical industry, there are reams of safety data. When NCI does it, less data is collected. The CEO Roundtable on Cancer wanted to see if the data collection by industry is necessary.
    - 3) Biomarkers: Some pharmaceutical companies are working on the same things, duplicating efforts. To avoid this, the NCI works as a safe harbor to review anything individual companies send. They can tell the company that it's a bad idea, it's a good idea, or it's such a good idea NCI would like to partner with them.

Josh Sommer is founder of the Chordoma Foundation. The Foundation works at the early end of the research to care continuum. Not much work done on the disease and not many people know what it is either. In addition to providing funding for research and convening research, it works on making available the reagents needed for research (tissue, cell lines, and animal models). The Foundation contacts anyone involved in chordoma or tangentially involved.

- It didn't take much to get people excited about chordoma. The obstacle is once people agree to research it, they ask, "Where are the tissue, cell lines, and animal models?"
- Partnerships: The Chordoma Foundation works with a number of universities. It has funded labs to create cell lines. It has a prize mechanism to incentivize researchers to develop new chordoma cell lines. This has been very successful. It offers a \$10,000 prize for new cell lines. Anyone that develops a cell line and signs a material transfer agreement to the Chordoma Foundation to use it gets the money. Five cell line candidates (one from Tulane University, two from Germany, two from China) have been submitted and 160 have shown interest.

- The Foundation partnered with InnoCentive (a spinoff of Eli Lilly), which offers a platform applicable to many diseases. They announced a public good program to partner with nonprofits to offer their services at no cost.
- Before the Chordoma Foundation, there were seven cell lines in the literature. Only one was valid. Josh worked to publish a paper that invalidated the six others. By the end of 2011 there will be five or six cell lines. It's difficult to create treatments without any material to study with.

Nancy Sung: Convened a group of other organizations to see how they are addressing early-career scientists. See what are the early-career bells and whistles needed to get an early career scientist off the ground. This led organizations to relaunch or retool their early careers scientist programs just based on sharing information.

- Burroughs Wellcome Fund (BWF) is looking at the nuts and bolts. How do you do peer review? There are working groups with organizations in venture philanthropy. This helps to shorten the learning curve with these organizations. This shows the benefits of sharing information.
- BWF is now looking at open access and public access. It is looking at ways to urge progress in that direction.
- Opening a dialogue with FDA to bring lectures into FDA or resident scholars program to work inside FDA.
- IOM Forum—Speakers to talk about these issues. There are sessions coming up (Dr. Rob Califf of DTMI is speaking at one). There's a workshop on public engagement to see how we can use social networking to better engage. There's a workshop later this year to spur more innovation in regulatory science.
- The Reagan-Udall foundation at FDA is another place and venue to partner in this collaboration process.

The Duke Clinical Research Institute (DCRI) model: It's a step forward. It's not all about the money, it's about reputation and what people are getting credit for.

- Duke must balance what he wants to do with academic interests
- Quintiles was not a nimble tool; it had become hulking, overpowering. Sandra Silberman was asked to create a disruptive, orthogonal network. This became Quintiles Innovation—a special forces CRO.
  - Max Wallace met Sandra Silberman (through Josh Sommer), and she offered to be a Chief Medical Officer with ABC<sup>2</sup>. She'd be the one to hold the CROs feet to the fire. She could pick and choose the resources within Quintiles she wanted to use. Quintiles also offered to invest in the ABC<sup>2</sup> project (either by not billing or investing).
- Disruptive Innovation—Harold Varmus addressed disruptive innovation in Provocative Questions. The whole exercise was 10 hours, and the group spent the first hour talking about what “provocative” means.
  - Looking at metastatic cancer and see if how we treat it is right. Should more research be done? Where is the evidence?
  - Glioblastoma—Is cytomegalovirus a cause of glioblastoma? Look at antiviral drugs to combat CMV in early life to preempt GBM later in life.

- Clayton Christiansen wrote *The Innovator's Prescription: A Disruptive Solution for Healthcare*.
- Is the impenetrable nature of academia incompatible with disruptive innovation?
- There is success when taking small steps, but there has to be a balance between the two. How do we reward the people who are a bit rogue and creative and at the same time recognize a majority of researchers are going to be doing a little at a time?
- Sung: Foundations are the risk capital. The recipe is having a combination of insightful people at the table and evaluating what they've done. For a scientific advisory board, those closest to the field are harshest. People a little further away give more leeway.

Porter: The pharmaceutical industry is engaging in activities to be the most successful and bring wealth to their shareholders. Let's look at these activities and see what parts are not competitive. Maybe cooperation at the "A" or "B" level can help everyone at the "E" level. Pick activities in the pre-competitive realm to collaborate on so that you can be more competitive in the end.

Harrington: DCRI can do things commercial groups cannot do because DCRI is academic. DCRI does most its work in the cardiovascular field, second most in hematology, then adolescent depression. Being part of a university allows DCRI to take more risk because there are no shareholders. It can do "sideline" things.

- External partners—DCRI works with anyone with interesting ideas that needs the expertise of DCRI. It works with foundations, NCI, and the pharmaceutical industry. It has more success with smaller companies than larger companies. Smaller companies allow more leeway and are less set in their ways.
- Duke is creating a cancer institute for training, care, and research under one roof. This is creating major discussions. Most hospitals look back to the Flexner Report from the early 1900s. Departmental structures do not allow for this type of overlap.
- Comorbidities—Who takes care of the patient in the medical home? Managing a group of patients with comorbidities is a challenge, but it's better in a place that views it in overlapping ways.
  - CMS Innovation Center – how do we create an accountable care organization?
  - Joyce Graff: Multisystem disorders are difficult to care for. No one coordinates the care
  - Harrington: Camden project (Atul Gawande in the 1/24/2011 issue of *New Yorker*).

Sung: Foundations can be a catalyst by inducing behaviors that you'd like to see done rather than forcing them to be done.

- K99 to R00 mechanism—BWF helped to fund early investigators. They studied it and brought it to the National Academies of Science; it helped create the K99 grant mechanism.
- Howard Hughes Medical Institute (HHMI) is collaborating with NIH by funding the first few years and then National Institute of Biomedical Imaging and Bioengineering (NIBIB) picks it up after then.
- BWF collaborated with HHMI to create materials on how to run a lab for their grantees. Conducted a train the trainer program with investigators all over the country.

Gwen Darien: Many organizations have put together tissue banks recently. Josh, how have you added a dimension to that, and how is it a model for other groups?

- Sommer: The Chordoma Foundation is still working on setting it up. It submitted for IRB approval last week. Ohio State University is the contractor for the tissue bank. The Chordoma Foundation owns the samples. Providing tissue gives more leverage than funding to promote collaboration and release of data in timely manner. To use the samples the data must be released to public before publication.
- A pharmaceutical company wanted to test its compounds against chordoma cell lines. The material transfer agreement with the university wouldn't allow cell lines to be used by private for-profits. The Chordoma Foundation worked with the university and paid \$10,000 to allow those cell lines to be used for nonprofit and for-profit.

Sommer: The Chordoma Foundation has worked to get Duke and UNC to collaborate on a project. The investigators are incredibly eager to collaborate. They have complimentary interest and expertise. The Chordoma Foundation was the catalyst for the collaboration. It wasn't money; it was focus that brought that together.

Harrington: Collaboration between Duke and UNC means more success with NIH grants. Look at those players in the space and use money to bring them together. Advocacy groups have the ability to bring funders together who are usually rivals—they can make collaboration a requirement. “One-sixth of something is better than 100 percent of nothing.”

- HHMI is a behemoth. Medical students take a year off from studies to work at NIH. BWF felt that a great audience to bring in would be veterinary students so they could learn research. HHMI would run it and BWF would invite veterinary students to apply and also fund the program. BWF is using a mechanism that is already in place. This way it increases the funding without increased the administrative cost. Funders are looking to lower administrative costs.

What are the keys to partnerships?

- Porter: Honesty and transparency is needed in partnerships.
- Harrington: Someone has to convince groups why partnerships are needed.
- Wallace: Fairness, honesty, trust and respect.
- Sung: Must deliver value beyond what you can do alone
- Sommer: Offering logistical support. Mundane things like following up or organizing things; a conference call number can mean a lot.

### **Day One – Review and Reflections**

Yesterday the Group got a clear sense of the continuum of research, beginning of conversation about how partnerships can be of value

- Fantastic speakers, opened my eyes, starting to think about how to work with different organizations such as Burroughs Wellcome Fund



- Often the research community underestimates the power of the advocacy community; good chance to discuss best practices, make easier, use as successes and models that work to bring more orgs into practices that are making an impact
- Liked discussion about having companies work together in non competitive space and expanding that space; concerned about lack of progress over years; need not just meetings, but someone to take ownership
- Interesting that the Melanoma Research Foundation has done joint funding with four different organizations; can be hard to do because nonprofits can be competitive as well
- Health Research Alliance's last meeting was all about partnerships; nonprofits may not be aware of resources available to them
- How to achieve partnerships in the academic environment, how to change culture/rewards in the near future; losing promising researchers to pharmaceuticals because they are more flexible
- Academic health centers are setting up innovation centers; centers are running into the academic culture which makes it more difficult; not sure how to change; smaller organizations are more apt to step out of the box, might have to be grassroots up but would be faster if could do top-down; had speed dating for venture capitalist event recently; grants are difficult because things are moving too fast ; not getting to institutions that are training new researchers – R01 grants seen as gold standard
- In 1980 China recognized that huge organizations were not serving the interest of quickly changing economy; public investment went to smaller, more innovative companies; there are negative effects to large existing companies; is this beginning to happen in research? Where are the cutting-edge programs coming from, and who is investing?
- How to access money if not a grant process set up; organizations are afraid to change and try new models
- Organizations that don't have to follow grant making process still do, could try different ways to approach, ex: Ashoka has very different grant making model
- President's Cancer Panel this year was devoted to looking at the cancer research process, how to be more nimble, speed up the research process (Canary Fund – early funding of diagnostics, will go out of business intentionally when funded the goal items, Gates Foundation, idea funds, etc); report should be available within the next few months; proceedings are available online
- Need to be pushing for more advocates at all tables, push back on advocates not knowing as much or confusing the process; is this b/c calling for accountability, need well trained advocates but need more, not tokens

### **Public Engagement with Science: An Emerging Paradigm**

*Mr. Troy Livingston, Vice President for Innovation and Learning, Museum of Life and Science*

#### ***Dialogue with the DCLG***

Focused on urban areas, how do you move these projects out to rural areas? The accessibility gap is getting wider; new innovation stays in populated areas

- Huge problem; work closely with colleagues in museums located in more rural areas; takes a lot of money to get to people

- Enormous gap even within urban audience; Maslow's hierarchy

Parents had to make decision to take through door of the building; now marketers coming to individuals based on tracking, more of a pull society but first step of engagement needs to come from audience – how to address that and bring people in? How use new technology to create generation that you don't have to wait for them to walk in?

- Expensive to create- thinking about how games could change science education, yet to find the "Angry Birds" of science; is it cost effective?

An app does not involve engagement with researcher or policymaker; public engagement says expectation that both parties will have change; is there research on apps making more involved when older?

- Technology should be equalizer

What happened to museums being part of the curriculum?

- Museums related to standard course of study; however, low numbers of student attendees; test-based learning

Any evidence for appetite on the part of scientists, management, policy, funding for engagement that would change behavior or would prefer status quo?

- Science museum can be trusted broker; participants in their programs came away with different perspective about public's level of knowledge, interest, and concerns
- Need more work to test experiences; tend to avoid circumstances that make uncomfortable – no prep to deal with public; identify the researchers that are interested and don't waste time with researchers who aren't interested because they won't have as much of an impact

Part of small organization; public engagement is secondary because they are not looking to be household name; forcing incremental change in research community – primarily live in that world; how do you describe what you do to general public?

- Public engagement is critical; workshopped hands-on way to explain, ability to explain to 10-yr old important; other scientists don't understand items outside of their field either

Great to have scientists ingrained in functioning system and be able to explain. Where does that get us with constantly moving topic? If you can't access information and how future generations are engaging (data available to be collected) and researchers design programs for those areas, what is accomplishment?

- Meet people where they are; have to be able to speak to a more general audience but doesn't mean eliminate specifics; have to use different ways of knowing

In rural populations, games are a way but also webinars and interactive broadcasting that could allow to engage without travel

Concerned about distinction between educating children and how to engage/goal of public engagement at this level; changing conversation about cancer. How engage museums/science centers that make conversation between people setting agenda for research and people that are or may be predisposed to funding research? How to recruit new advocates? Advocate groups as evidence that researchers are open to hearing other perspectives. How do create models to engage people/advocates with scientists, etc in ways that are mutually transgressive?

- Parents can be reached through their kids because that's the reason they go to places
- What purpose are we engaging the public in science for? Want to educate advocates, but then where do we send them off to? Limited options to get engaged. Require advocates on grants but has been education process for both sides
  - Possibly contact community organizers, reach out to others who may have been involved
  - Advocates as creators of ways to engage/collaborate; creating these opportunities as part of this meeting's goal
- Irrespective of audience/specific roles of advocates, is it about understanding or engaging? Is an advocate's role to really engage? Part of how advocates got involved was that advocates got engaged and scientists began to realize they could be helpful in process. Engaging increases number of seats available. Funding lever – If organizations won't give funding without advocates on review panels and clearly states that, there are levers
- Building up knowledge base in scientific literacy important, engagement can be committed to gaining that knowledge as critical to your life. Engagement is at multiple levels; public dialogue is important
- Look after molehills, mountains will look after themselves. Think about who you are going to engage, workshop for own board would be good idea, extension arms in the community; tie science and non-science staff together more fully; example is allegory vs. direct transfer

### **Facilitated Board Dialogue**

The DCLG engaged in an exercise to identify where members were and their affiliated organizations were operating across the cancer research continuum.

Cheryl Jernigan: Komen, NCI Community Cancer Centers Program (NCCCP), KU Medical Center

- Komen spans across the continuum; affiliates partnerships in community health centers
- NCCCP community partnerships
- University of Kansas (KU) Medical Center is working with community, later discussed how KU is working with Cancer on CTs

Josh Sommer: Chordoma Foundation

- Levers: Access to biospecimens and molecules; speed of information flow (decrease time data is shared between labs)

Jeff Allen: Friends of Cancer Research works in clinical research

- Lever: Pre-market science and new collaborations with NCI/FDA/industry around reviews, drug combinations, novel trial design, etc.; area between approval and wide-scale use; third area, legislative policy

Susan Braun: Commonweal

- California Breast Cancer Research Program – disparities, so dissemination side; org testing novel cell lines for testing clinical chemicals
- Smith Center for the Healing Arts – patient navigators and training of navigators for low income pops

- Creating Research Infrastructure to Better Science (CRIBS ) project – grant from NIEHS to train pairs of community based orgs to compete better for participatory research
- Breast Health Global Initiative – system to look for guidelines that are stratified based on income
- Commonweal – lots of work (mostly cancer) to look at mechanisms of cancer causation

John Retzlaff: AACR

- Covers entire continuum, mostly focused on funding now
- Hill Day with 150 congressional meetings; goal of combines scientist and advocate in every meeting
- Cancer Progress Report
- FDA Regulatory Science Report, how can AACR be more helpful in preparing FDA with science

Gwen Darien: Samuel Waxman Cancer Research Foudnation

- Works in discovery and translation, but is really a catalyst for a lot of work that benefits patients (ie, lung cancer work that now appears fruitful)
- Trying to expands the notion of collaboration (Webcast/podcasts/education)

Everett Dodson: Lombardi Cancer Center, Office of Health Disparities

- Program to engage those in public housing units (underserved) and guide them in their care and potential to participate in research,

Wendy Selig: Melanoma Research Alliance

- Discovery into preclinical, through translation, and little in clinical development and FDA approval, funds translational research, not basic
- Levers: collaboration is the way MRA works (NCI, FDA, other foundations, industry)
- Barriers: Funding, our area has been under funded; getting industry to take risk in this area even those there's a small payoff

Phyllis Petit Nassi: Huntsman Cancer Institute

- All levels but mostly clinical trials; program at Huntsman is about access, increasing accrual to cooperative group clinical trials
- Lever: Willingness; you give me the problem and we will figure it out, Huntsman provides funding, which could be a barrier, but not in this case
- Lever: Reverse capacity building, getting researchers out in the community to meet community, learn how to deal, provide perspective, and energize
- Barrier: Community consent

Joyce Graff: VHL Family Alliance

- Deals with diagnosis, treatment, and QOL; works with coordination of care because lots docs involved
- Collaborations with lots of foundations in other cancers (brain, kidney)
- Creates education tools related to management of this condition, like Web site and handbook
- Tries to work with the pharmaceutical industry but it's difficult because the population is small, so they want to do research at a single center

Max Wallace: Accelerate Brain Cancer Cure (ABC<sup>2</sup>)

- Focused solely on discovery and early translation
- A bio matchmaker; a special forces team; measure everything we do by impact, leadership, and collaboration (how do you build a big clubhouse and invite people in)

### **Board brainstorming session**

Identify potential barriers DCLG member may be interested in collaborating around to address.

Susan Braun: Commonweal

- Program that brings scientists out into different community venues (two-way dialogue)
- Tissue banking and tissue sampling (disease and normal) lends itself to collaboration; overall view of economics and how fits into biomedical research, and how accessible interventions are

Gwen Darien: Samuel Waxman Cancer Research Foundation

- Underlying issue is commitment to collaboration, rather than duplication/ replication; let leaders

Shannon Bell: NCI Office of Advocacy Relations

- Working with AACR on idea of creating mechanisms to keep policy makers informed on ROI of science on the lay audience level

Rick Borchelt: NCI Office of the Director

- Working on ways to engage Cancer Centers and grantees to communicate about ROI of cancer research. How do we change messaging from competitive to more collaborative?
  - Give out collaborative grants
  - NCI should advertise collaborative projects; NCI's role as the convener and catalyst; over ride cancer centers
  - Larger issue is congressional people encourage finding other ways to find money

Cheryl Jernigan: Komen, NCI Community Cancer Centers Program (NCCCP), KU Medical Center

- Communicate bang for your buck of science and impact on patients

John Retzlaff: AACR

- Struck by number of organizations focusing on the young PI; how can we collaborate around that because there are lots of players?
- Accountability for those members of Congress who vote against legislation that will support biomedical research

Max Wallace: Accelerate Brain Cancer Cure (ABC<sup>2</sup>)

- Lack of leadership on our side. We need to spend some time thinking about leadership cultivation and development. People listen to those in Congress; they only get information from the orgs.

Sage Bionetworks – turning data into usable information; how to get better partners in research community? Provide tools to grantees to use as collecting data so that it is consistent, and does require scrubbing later

**Welcome and Overview of UNC Lineberger Comprehensive Cancer Center**

*Dr. Shelley Earp, Director Lineberger Comprehensive Cancer Center*

**Community Partnerships to Promote Health and Reduce Cancer Burden (Panel 1)**

*Dr. Laura Linman, Dr. Anissa Vines, Dr. Paul Godley, Dr. Cathy Melvin, Dr. Michael O'Malley*

**WAY to Health: A Worksite Partnership**

*Dr. Laura Linman, Program Director and Associate Professor, Dept of Health Behavior & Health Education, School of Public Health, UNC Chapel Hill*

**Carolina Community Network Center to Reduce Cancer Health Disparities**

*Dr. Anissa Vines, Associate Director, UNC Program on Ethnicity, Culture and Health Outcomes, Chapel Hill, NC*

**High Point Colorectal Cancer Project**

*Dr. Cathy Melvin, Research Associate Professor, Department of Maternal and Child Health, School of Public Health, UNC-Chapel Hill*

***Dialogue with the DCLG***

Have changes in the recommendations for various procedures, specifically mammograms been difficult to convey to the community?

- Have held workshops among multiple partners about changing recommendations/results
- Have had community oncologists go out in person to speak to community groups about what changes are occurring and what they mean

How do partnerships impact care?

- There is more exchange of information between partners than ever before
- Creation of learning clusters
- Ongoing information exchange and converting that exchange to action
- Allow to address specific community issues (ex: lack of mammography in rural low-income areas)
- Allow for follow-up care when a screening is positive – partnership with local colonoscopy clinics

**Community Partnerships to Promote Health and Reduce Cancer Burden (Panel 2)**

*Dr. Jennifer Leeman, Dr. Nadine Barrett, Dr. Monair Hamilton McGregory, Dr. Marlyn Allcock, Dr. Kurt Ribisl, Dr. Michael O'Malley*

**Using Policy Training and Technical Assistance to Promote Adoption of Evidence-based Practice. A Community-Academic Partnership Between the Susan G. Komen for the Cure Triangle Affiliate and UNC Lineberger/UNC Chapel Hill**

*Dr. Jennifer Leeman*, Assistant Professor, School of Nursing, UNC Chapel Hill

*Dr. Nadine Barrett*, Director of Community Programs, Susan G. Komen, NC Triangle

*Dr. Monair Hamilton McGregory*, Director of Community Programs, Susan G. Komen, NC Triangle

**MOVE\* Vets!**

*Dr. Marilyn Allicock*, Research Assistant Professor, Department of Nutrition, UNC Chapel Hill

**Health e NC: Healthy Stores, Health Communities—Transitioning Tobacco Product Retailers toward Healthier Options**

*Dr. Kurt Ribisl*, Associate Professor, Health Behavior and Health Education, UNC Chapel Hill

***Dialogue with the DCLG***

What kind of work has Health e NC done with the Native American population

- Highest rate of smoking of all ethnic groups
- Cigarettes are a big source of income on reservations
- Health e NC looking to work with native populations

Is Health e NC collaborating with other disease groups?

- There is very heavy interdisciplinary work between smoking, healthy food and built environment
  - UNC houses the cancer and health promotion departments near to each other, so they work together a lot

How do you offset the profit for the corner stores?

- Looking for alternative items to sell
- Looking for caps on retailers selling cigarettes
  - Similar to the Baltimore Healthy Stores initiative with Johns Hopkins

How can Komen cover all the territory in Eastern North Carolina?

- They are looking at other regional approaches and tiered approaches

Is the Komen program being shared with the Komen Affiliate Network?

- National Komen is being trained on it now

Make sure the Komen program is referred to the multicultural advisory committee for Komen

**National Cancer Institute Update**

*Mr. John Czajkowski*, Executive Officer, National Cancer Institute

- Shrinking resources at NIH has been the theme of the first five months at NCI. NCI leadership is addressing problems thoughtfully. The NCI Director is keenly aware of how enlightened we need to be to avoid long-term consequences.

- caHUB: Our interest is around standards and knowledge. Lots of people to provide specimens. NCI needed to move away from retail concept. Carolyn Compton has embraced the research model; standards and research model are what the community looks to NCI for; that is core to NCI's mission. This is more about staying true to our mission and less about budget.
- caBIG: Rapid evolution over the past couple of month, in light of the BSA recommendations. Working to create an executive snapshot of what caBIG looks like and what it does. Leadership is meeting regularly about this with Dr. Ken Buetow. caBIG is not about growing software in house; we are not a service provider. Others do that. It is not our business.
- We also are looking at NCI DOCs in an effort to identify efficiencies. We are being thoughtful about where a contraction can happen, without producing a disruption.
- We have been targeted, deliberate, and thoughtful, rather than doing everything completely across the board. We tried to squeeze in places where we could without breaking anything.
- The Institute is looking for advocates to be our voice in helping others understand that the good news you hear or read about cancer is probably directly or indirectly related to NCI. That connection is not always as clear as it should be.

Can you talk about open positions and the impact of the economy on hiring?

- The Federal hiring process is a difficulty. It struggles. It is broken. Hiring high-level talent is particularly tricky. Fortunately, lots of people want to work for or with Harold Varmus. There are three big open positions: Director for Genomics, Clinical Deputy Director, and Director of Global Health. We also need to hire a director for the Division of Cancer Prevention.

Having a physical biobank never made sense, but a virtual one did. Is that still in the works?

- Yes

What is the role of caBIG?

- caBIG will get back to focusing on creating standards, rather than products.
- The job of NCI is to be facilitators of discovery, not be over directive on a day-to-day basis on how researchers do things. It is not that NCI is in charge and everyone else follows. It is a true community.

There was a discussion of the lack of awareness of who NCI is and what NCI does, including the need for grantees to acknowledge relationship with NCI. This is unacceptable to the Board and it will explore further a way to support this acknowledgement occurring.

Josh Sommer: Big, bold projects that solve big problems seem more meritorious. Things like caHUB and caBIG seemed like things to get behind. Given we are moving away from that, what are our flagships that we can get people to get behind?

- Group discussed TCGA and how to communicate about other programs, paying particular attention to not over selling. The doubling of the budget was used as an example.

Results are not everything, particularly in cancer research. Example is VHL.



## Facilitated Board Dialogue

The DCLG discussed partnerships to pursue in addressing barriers to translation

- Barriers and leverage points discussed on Thursday
  - Lack of advocate participation
  - Bringing scientists into community for engagement
  - Collaboration vs. replication – find where good things are already working and collaborate
  - Increasing policymaker awareness of ROI of science and that science is happening
  - Cancer center-specific messaging: competitive vs. supportive
  - Role of NCI as counter advertiser to talk about quality cancer care in general
  - Increasing availability of tissue samples
  - NCI working better with other institutes and centers
  - Overview of economics to end user
  - Information collection and standards
  - Funding and facilitating younger investigators
  - Cultivating leadership
  - Advocating on the Hill
  - Comfort with construction vs. deconstruction; stopping doing things and starting doing things

## Potential Areas for Engagement

- NCI Director as political appointee – should this be changed?
  - Consider models of leadership (surgeon general, organizations with a board and CEO)
  - Look at the pros and cons and analyze if the Board wants to make some alternative recommendation
    - Talk to an organizational specialists, such as David Price (NC-4 Representative) who has a background in government structure and is a champion of NIH/NCI
- Op-eds in local papers by DCLG members
  - Get at the understanding of what NCI is
  - Don't underestimate the personal story—it's what people remember
  - There must be some level of coordination
  - The War on Cancer – no longer works as a metaphor
    - Scientific advances over the last decades have truly changes our understanding of cancer and the experience of patients
    - Cancer is not a single disease, but a set of complex ones
    - Every step takes us closer to better outcomes for patients
    - AACR Cancer Progress Report (coming in September 2011)
  - Scientists in each area
    - Giving op-ed material
    - Pairing advocates with the scientists
- Look at who's doing what at each Cancer Center and advocacy groups in terms of communications people
- Ratchet our level of collaboration among DCLG group and with NCI

- This meeting led to AACR getting Rep. Price to work with NCI, NIEHS
- Collaboration across NCI advisory board
  - Ex-officio members of other boards – in order to keep DCLG abreast of issues
  - Ex-officio members of other boards on the DCLG?
- OCE Cancer Maps program
  - Shows what’s going on in each state - impact of NCI and NIH funding
  - AACR uses these charts in each visit to policymakers
    - American Heart Association does this already on their own
- Make sure we involve international partners
  - Take diagnostics and treatments into third-world locales domestically and internationally
- Increased advocate involvement
  - Knowing where and how as well as what people to engage
  - Advocates in Research Working Group
    - Guide NCI in-house
    - Act as a promising practices document for external organizations
    - Gotten calls from SPOREs, cancer centers about how to engage advocates
- Go into the community as a group (DCLG)
  - Meet more researchers and advocates; make connections
  - Spread the good word of NCI
  - Act as a magnet to representatives and advocates in the community
- Change the name of the DCLG
  - “Consumer” is such an old term
  - Language is critical
  - What we call ourselves is a long discussion
- Change our self-image
  - We are NCI – there is power in that
  - Have confidence that we represent something important
- Utilize the DCLG alumni network

### *Next Steps*

- Op-eds in local papers
  - Contact Shannon Bell to coordinate the stories
- Appropriations meeting
  - Make sure the room is full with the right people to build political will
- Let NCI leadership know what that DCLG members can do for NCI
  - Collective inventory of what each member can bring to the table
    - Three to five assets
    - OAR to do a call out to members
  - Contact list for membership (phone and email)
- Send the OCE Maps to DCLG members to get feedback on maps
- AACR Cancer progress report
  - Collaboration and partnerships section
- OAR Website about collaboration – best practices

- Collection of partnership success stories
- Workshop on social media for the DCLG
  - Social media, open source, peer to peer, PatientsLikeMe—how do we harness these tools?
  - These groups don't have the staff for it, but what if it got easy, what if they got money for it?

### Closing Thoughts

- We hope to get some direct asks from the Director or the Institute in general
- The DCLG would like to have a more active role in doing the follow-up
  - Track the progress made by the board
  - Continue dialogue between meetings
  - Track the progress of what has gotten done in previous meetings
- This meeting felt like people were speaking with the group rather than speaking to the group
- The DCLG needs a good definition of NCI
  - Maybe it means different things to different people
  - Show the faces of cancer and the diversity of NCI
- Follow-up about cancer centers
  - Set up a phone call about how cancer centers can incorporate NCI
  - Work with Association of American Cancer Institutes (AACI)?

The meeting adjourned Friday, May 20, 2011 at 11:48 a.m.

### Certification

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