Appendix

Ground Rules

**GROUND RULES**

- What do you need to be more effective?
- Focus on Action Opportunities
- Creative, half-baked ideas too!
- Specific / Immediate & Longer-term
- Actionable

**GROUND RULES**

- All participate, no-one dominate
- Questions OK at all levels.
- Toggle = big/small hat
- We can agree to disagree... without being disagreeable.
- Strong opinions... openly held
- No attribution w/o consent.
- G-gnomes awards!
Morning Panel

**Nicholas Dracopoli Ph.D.**
VP, Clinical Discovery, Technologies, Genomics
Bristol-Myers Squibb

**Francis Collins M.D. Ph.D.**
Dir Human Genome Project
Nat’l Institutes of Health

**Janet Warrington Ph.D.**
VP Clinical Applications
Affymetrix

- How can we sit next to you?
  - Being willing to do your homework.

- Support large studies.
  - Anti-trust laws impede
  - Consortia in drug development.
  - Enroll patients in clinical studies help.

- Concern in advocacy to be too closely tied to a particular trial.
  - Traits - Have advocates involved in design & review.

- Snapshot of tumor - thru whole disease.
  - Every disease is different.
  - Monitoring important - Longitudinal studies required.
  - Statistical argument necessary - Data & outcome necessary.
  - Need to look at data as well as RNA.
Afternoon Discussion Panel

Questions...
- What areas are we thinking about to stretch...
- Discussion

- What's available now? How do you find it? What's coming short-term?
- How to reprioritize bureaucracies?
- Transparency, regular reports
- Biomarkers for BC - why so difficult?
- Drug metabolism - how does this relate to NMD?

- How can we learn from other diseases like diabetes?
- Reporting & responsibility
- How to create a new generation of advocates?
- Are we looking in the right place? Genes in relation to environment: stem cells...
- How to get people into cohorts - policy & coalition building
- WHO else?
- NCI - what they did as a result of budget doubling (program like DOD to report out)
- To the public - qualitative involvement in genomic copy
- Advocacy groups stop focusing on study parts
- Identify our advocacy outcomes - reward researchers etc with our participation
- How do we facilitate effective research not be an impediment?
- How long until markers are meaningful?

PANEL - Afternoon:
- DAN HAYES MD, go to 2B1733
  Clinical Dir Breast Oncology Program
  U of Michigan Comprehensive Cancer Ctr.
  Gene clinical science & technology

- KATHY HUDSON Ph.D
  Dir Genetics & Public Policy
  Review state laws, promote tests
  Enroll private sector to talk to members of Congress, at person level
  SHARON TERRY
  Pres ICD Genetic Alliance
  Web event, worrying in April, more
  Erase cartels
  Define disaster & health - out of control, whole area broken
  Share best advocacy practices
  "Knew" on Congress
  Non-discrimination
Discussion Panel

Questions...
What areas are we thinking about to stretch...

Trio discussion

- What's available now? How do you find it? What's coming short-term?
- How to reprioritize bureaucracies?
- Transparency. Regular reports.
- Biomarkers for BC. Why so difficult?
- Drug metabolism: How does cancer metabolism differ?

- How can we learn from other diseases in diabetes?
- Reporting & responsibility
- How to create a new generation of advocates?
- Are we looking in the right place? Genes in relation to environment. Stem cells...
- How to get people into cohorts - policy & coalition building
- WHO else?

- NCI. What they did as a result of budget doubling. Program like DOD to report out
- to the public... galvanize involvement in genomic opty.
- Advocacy groups stop floundering body parts.
- Identify our advocacy outcomes - reward researchers etc. with our participation
- How do we facilitate effective research not be an impediment? How long until markers are meaningful?

DOD is effective because:
- Out budget yearly
- "search & destroy attitude"
Discussion Panel

**PANEL - Afternoon.**

- **DAN HAYES, M.D.**
  - Go see *Gallina*
  - Clinical Dir. Breast Oncology Program
  - U. of Michigan Comprehensive Cancer Ctr.
  - Merge clinical science with technology.

- **KATHY HUDSON, Ph.D.**
  - Dir. Genetics & Public Policy
  - Review state laws on Genetic tests
  - Enroll private sector to talk to Chamber of Commerce re privacy bill

- **SHARON TERRY**
  - Pres & CEO Genetic Alliance
  - Create cartels.
  - Define disease with health... out of silos.
  - Hold researchers feet to outcomes.
  - Share "best advocacy practices"... non-discrimination.
  - April 1, 2004 "Kapow!" on Congress.
  - Multi fronts.
Actions

Target audiences
1. Patients - language, raise awareness
2. Advocacy Community - media training, critical thinking skills
3. Genomic Knowledge – identify, advocate

Scientific funding - pancreatic cancer model mapping published data, prioritize areas, develop

Create a map of gaps in genomic knowledge

Collaboration - Best Practice - Action

Website - Summary, meeting follow-up, emailing list, jump start a conversation, priority survey, establishing guidelines

We all motivate our constituencies

1. If they love - what is available?
2. Standards - calls for action,出台 - for a proposed benefit, write a white paper for genomics SPHERE is model

Deborah Collyar

1. Educ. Bailey

2. Concept of SCIENCE - genomics - partnerships, integrate genomics into medical care & professional commitment