



**National Committee on
Vital and Health Statistics
ad hoc Work Group on Secondary Uses
of Health Data**

August 2, 2007

**Sharon F. Terry
President & CEO
Genetic Alliance**

Perspective

- Parent of 2 affected children
- Founder of Genetic Alliance BioBank
- Manager of 33 lab research consortium
- Chair of the Coalition for Genetic Fairness
- Member of Genetic Association Identification Network Steering Committee
- Founder of WikiAdvocacy & WikiGenetics
- Member of Google Health Advisory Board

Individuals do not know about the use of their data (they consider it information, not data)

Physicians often do not know, and are either clueless or worried about these uses

Transparency would lead to investment

Logistics for Achieving Transparency

Revolution in how we perceive healthcare

Continuum

Not a 'done deal' - iterative

Not education, experience

- Admit uncertainty
- Reveal iterative nature
- Engage a la Facebook and Webkinz
- Build communities - Angie's List, CD Baby
- Employ robust IT
- Continually feedback improvements that include conveniences for the person and their community

Potential Harms

Distrust

Lack of involvement and engagement

Lost chance for improving healthcare

Oversight/stewardship for each use of the data?

Communities: Advisors

Individuals: Opt in mechanisms

'Results': GPPC GWAS town halls -
consent me, give me choices, respect
my desire to know

Quality vs. Research

Create a system where the difference
doesn't matter

HIPAA and the Common Rule?

Creating a hybrid system would require elements of HIPAA and the Common Rule to be merged - issues of privacy and protection overlap, but also have nuances that may be mitigated in a system that correctly configures new methods for research and quality advancement.