

Sharon F. Terry
President & CEO, Genetic Alliance



# High Interest

Not Yet

Diagonal Dia



## The Information Age:

## Business models, informed decisions, based on new economic constructs

#### Industrial Age (old)

**Control** means of production

Based on **scarcity** 

Hierarchical / Command & Control

**Linear** / Sequential

Win / Lose

Material/Object

#### Information Age (new)

**Open** means of production

Based on abundance

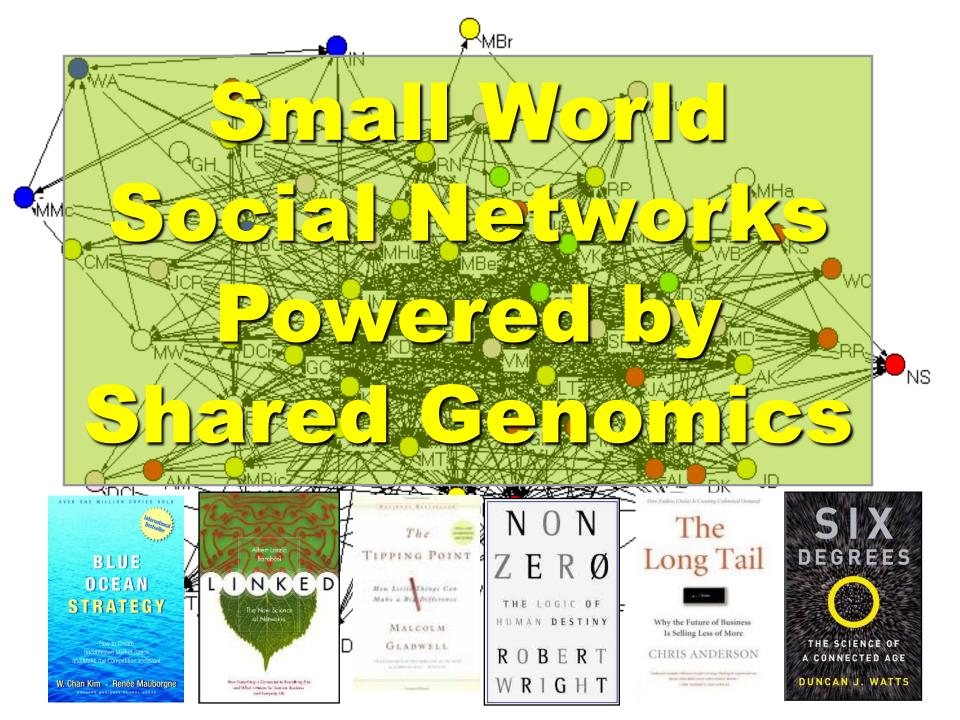
**Network** / Collaboration

**Organic / Dynamic** 

Win / Win

**Information** 





## Privacy Misuse Confidentiality Stignesse Accesson















Detecting single person's SNP profile:

Craig, PLoS Genet. 2008 August; 4(8)



#### **Drinking Freely:**

Better living through genomics?

Accelerates research-practice translation?

Promotes innovation?

Transforms medicine?

Introduces prevention?



#### Moderated intake:

Higher quality of information?

Greater relevance?

Strengthens the role of providers?

Safer?

More targeted, actionable?





### Should I trust this information?

(Trust it or trash it?)

Cooperative agreement #525036-02 with the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (CDC)



Who said it?
When did they say it?
How did they know?



#### LINKS

TOOLS HOME

**Content Scale** 

**Quality Scale** 

**Usability Scale** 

#### How do I use the Quality Scale?

The Quality Scale has 6 elements to help you judge the quality of information in a booklet, website, or other educational materials. There are definitions and examples to help you ?score? the information. The purpose is not to determine the overall score, but, instead, to help you think about how you should use the information in decision making. Please use your own good judgment!

The scores for each element range from 1 to 5, where a score of 1 should be given to the lowest quality material while 5 should be given to the highest quality material.

**Print** the Quality Scale to use to assess materials.

Click on each element below to learn more and see examples.

Element	Low Mid High					
Source of Information	1	2	3	4	5	
Depth/nature of expertise	1	2	3	4	5	
Consistency among materials	1	2	3	4	5	No other
Basis for information	1	2	3	4	5	
Type of sponsoring or funding group	1	2	3	4	5	
<u>Date</u>	1	2	3	4	5	



Even if it is accurate, credible, quality information –

Beyond clinical interpretations
Beyond clinical utility

How is it clinically useful?



### Take away:

- There are no scientific standards
- There are no industry standards (yet)

## There is no agreement among consumers

