

Making Sense of Your Genes: A Guide to Genetic Counseling. Project Outline.

June 8, 2009

Genetic Alliance
Genetic Alliance

Posted in the Resource Repository at:
<http://www.resourcerepository.org/documents/867/makingsenseofyourgenes:aguidetogeneticcounseling.projectoutline/>



Genetic Alliance

*Transforming Health through Genetics
Promoting an Environment of Openness*

Purposeful Openness

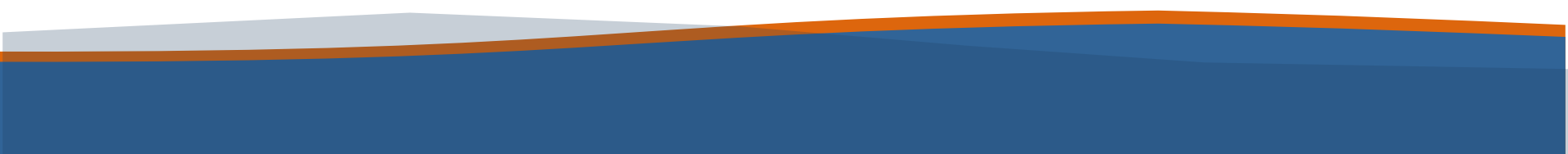
- **Create novel partnerships in advocacy.**
- **Integrate individual, family, and community perspectives to improve health systems.**
- **Revolutionize access to information to enable translation of research into services and individualized decision making.**

Goals & Objectives

- Set up an educational partnership
- Create a product that allows informed decision making
- Engage new stakeholders to transform an existing health system



Project Description

- The class project comprises the development of an article, webpage, booklet, etc., dealing with an issue of interest to genetic counselors and consumers. The project will require thorough research into the topic chosen, but will also necessitate input from advocates, genetic counselors, and other health professionals. Generally the intended audience will be advocates and consumers. The final product will be used by members of the Genetic Alliance network. You are encouraged to work in groups.
- 

Timeline

0/13/2006 - We will submit our project timeline to Holly (and James).

0/20/2006 - We will submit copies of the e-mail we plan to send out as well as the interview guide (guide = a “loose” survey) to Holly and James

0/25/2006 - We hope to have e-mail list of counselor and advocate contacts* complete, and if possible a number of phone calls already placed.

0/27/2006 - We will have initiated contact with all counselor and advocate contacts to arrange dates and times for phone conversations/interviews.

1/23/2006 - We will have completed all interviews and used the information from them to establish (reevaluate) project priorities. We will also have completed our review of existing resources (web-based and otherwise) which will also be factored into project priorities.

2/20/2006 - We will submit a draft of our tool to Holly and James. Once the format has been decided upon (early December), we will address issues involving project details (layout, division of labor, scope, etc.), and use December for assembly. We would like to have the project peer reviewed, and will wait for feedback.

Project Phases

- Partnership arranged with NHGRI/JHU GC program
- Student project developed in class
- Students visited Genetic Alliance offices for project brainstorming
- Request for interviews released by Genetic Alliance and JHU
- Students interviewed genetic counselors and disease-specific advocates
- First draft of guide written by students
- Draft reviewed by interviewees and stakeholders including NSGC
- Content finalized
- Guide was sent out for final copy editing
- Wiki version of guide produced
- Co-branding arranged with NSGC
- Graphic design of print version
- Dissemination plan finalized