Strategies for Genomic Integration into the Curriculum

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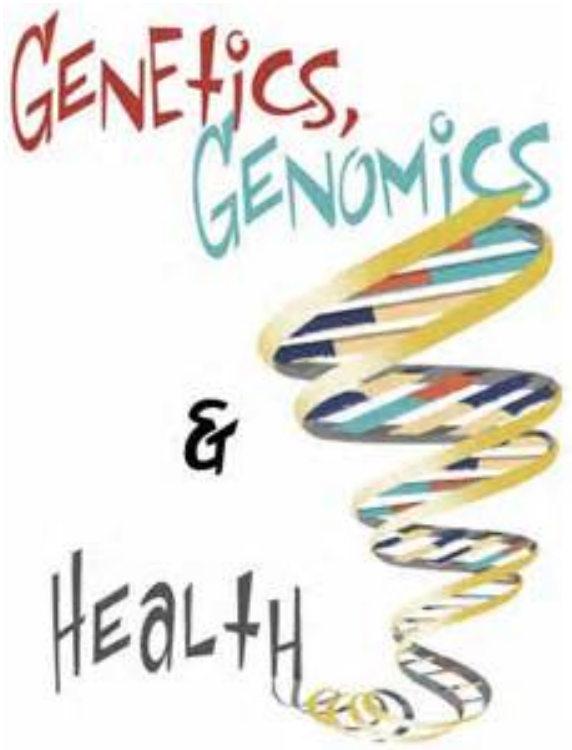
Models for Genomics Education



- Content integrated throughout the curriculum
- Standalone course
  - Required course
  - Elective course

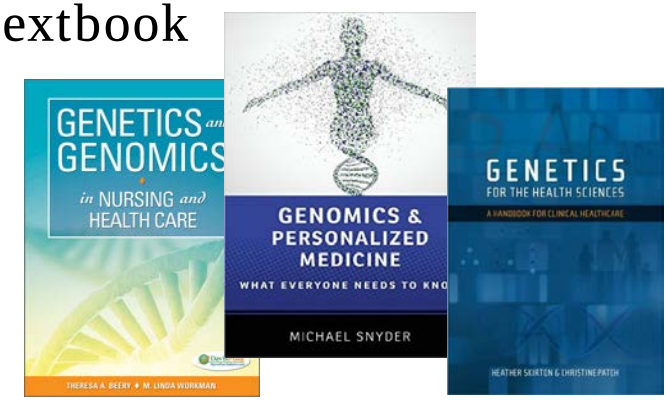
Integrated Approach

- Benefits
  - Greater chance of students linking the genomic content they learned in one course to genetic content learned in future courses
  - More opportunities to reinforce genomic content

- Challenges
  - Some faculty may not be willing or feel comfortable with, integrating genomic content into “their” course
  - Greater chance of inconsistency in the quality of genomic content being taught – also greater chance of redundancy

Standalone Course

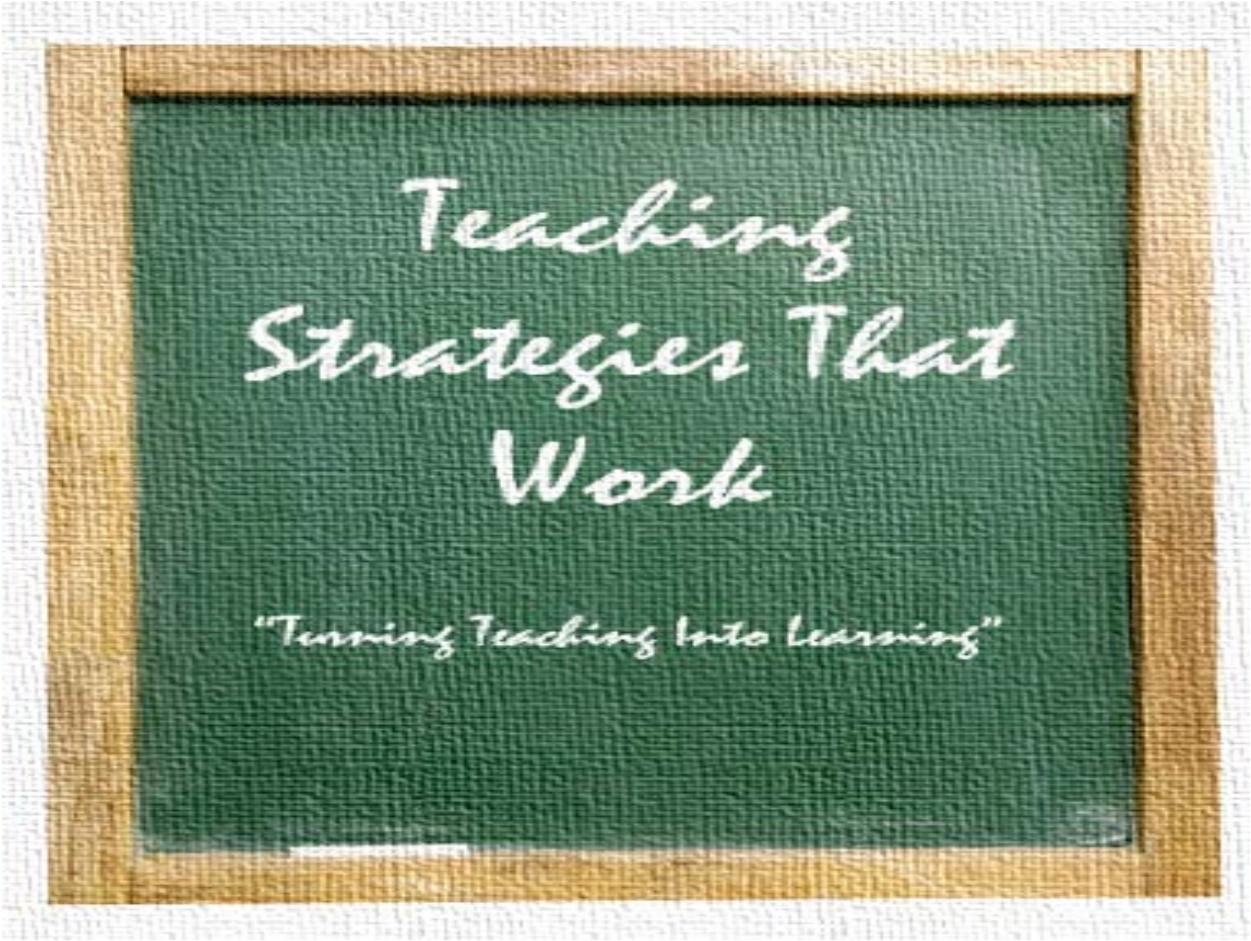
- Benefits
  - Easier to track genomic content being taught
  - Quality of teaching more likely to be consistent/ less chance of redundancy
  - May be easier to justify having students purchase a genetics/genomics textbook



- Challenges
  - Finding room in the curriculum for another standalone course may be difficult
  - Overreliance on a single faculty member /some schools may not have faculty with the necessary expertise
  - Students may find it difficult to link what they learned in the standalone course into other courses

Integration of Content Throughout the Curriculum

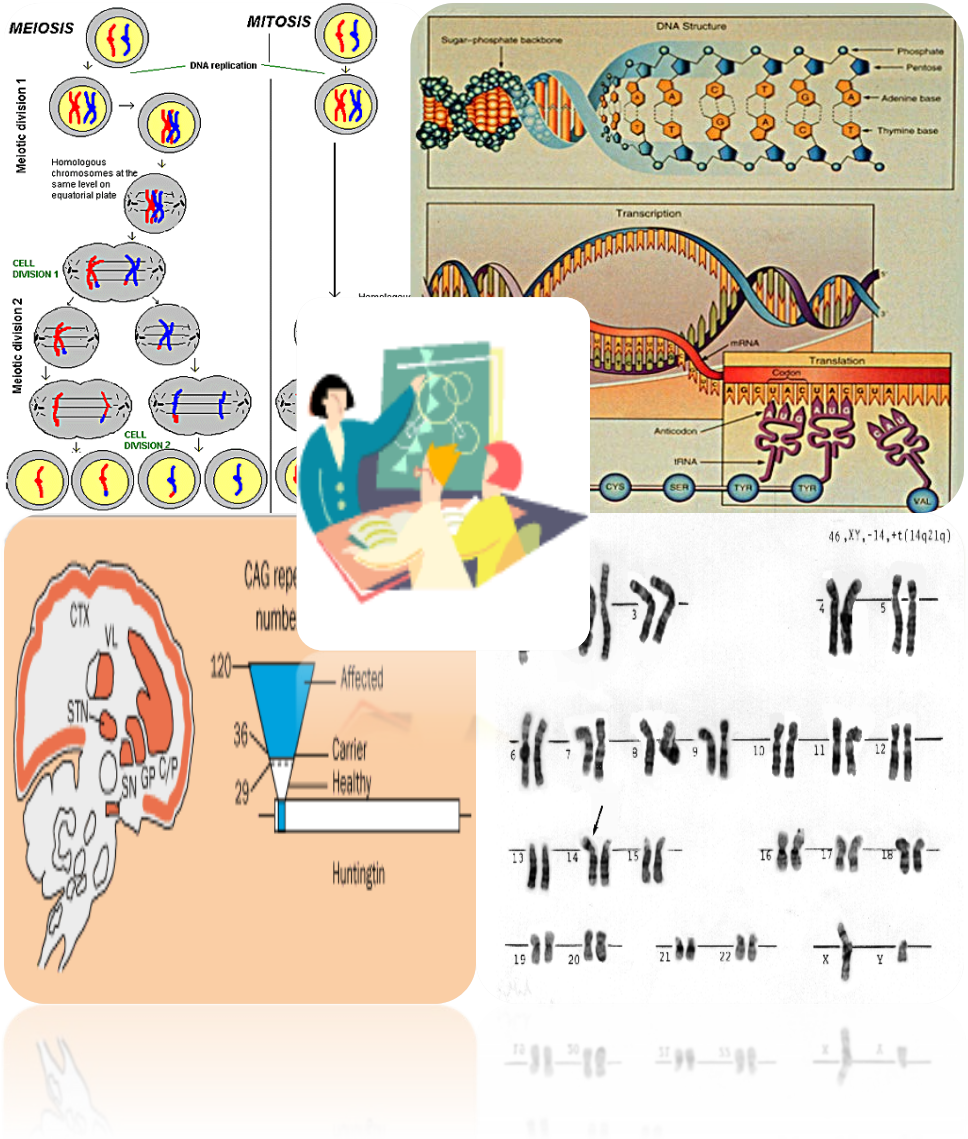
- Pathophysiology
  - *Basic genetic concepts*
  - *Patterns of inheritance*
- Health Assessment
  - *Dysmorphology*
  - *Family history/Pedigree*
- Discipline Course
  - *Nursing/PA roles in genomic healthcare*
  - *Ethnic, Racial & Cultural Considerations*
- Nursing Research
  - *Human Genome Project*
  - *Genetics/Genomics research & methodologies*
- Pharmacology
  - *Pharmacogenomics*
- Medical-Surgical Courses
  - *Care of patients with adult onset conditions & their families*
  - *Genomics and Cancer*
- Maternity
  - *Prenatal & newborn screening*
- Pediatrics
  - *Care of children with genetic conditions & their families*
- Ethics
  - *Ethical, legal, and social implications of advances in genomics*



Creative strategies for getting students and clinicians interested in & excited about learning genomics

Examples of Strategies I have used in the following courses:

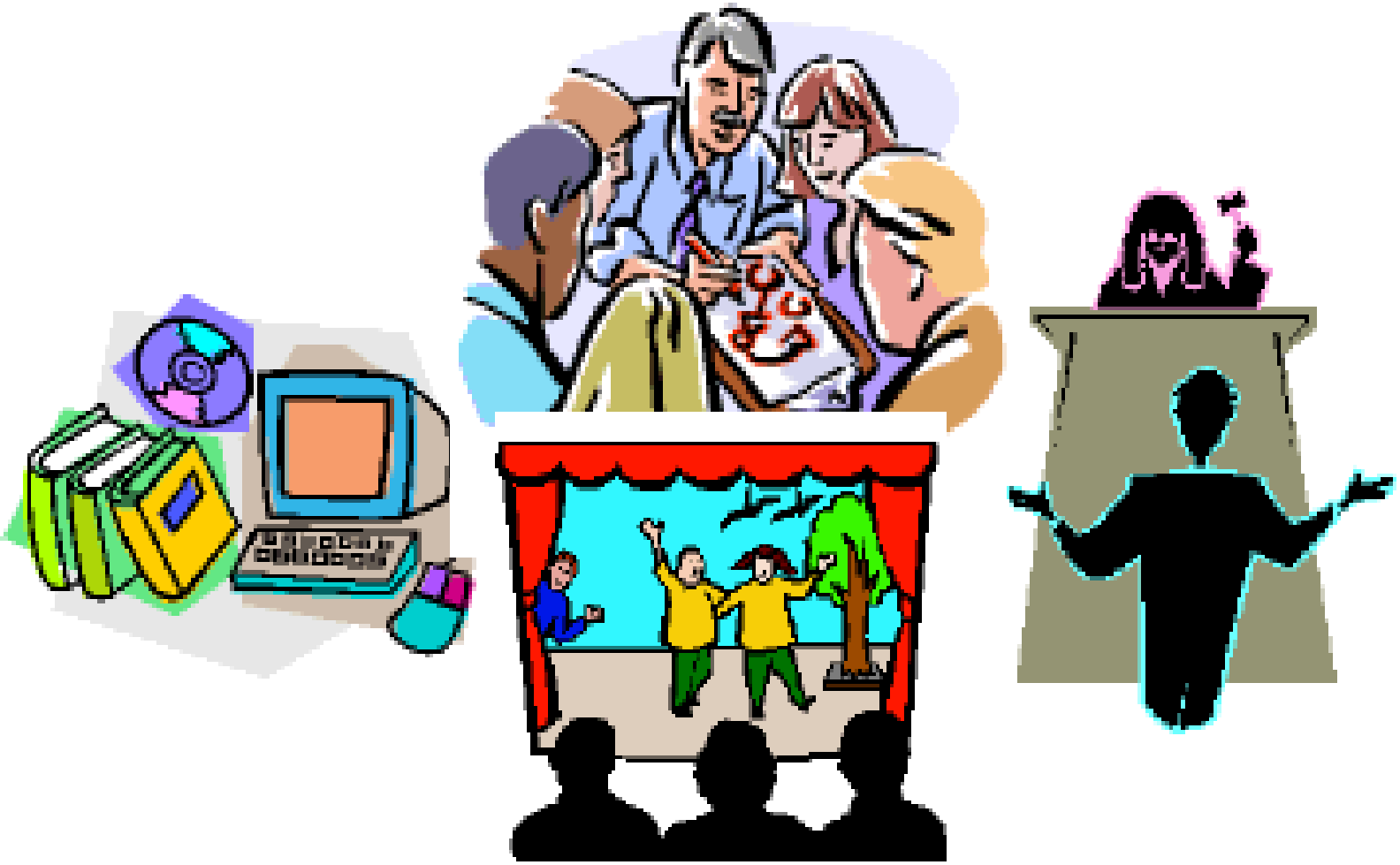
- *Family Centered Genomic Health*
  - Required course for all undergraduate nursing students at the University of North Carolina at Chapel Hill - School of Nursing
- *Clinical Genetics*
  - Required course for Nurse Midwifery DNP students at the Louise Herrington School of Nursing, Baylor University
- *Genomics and Society*
  - Elective course for graduate students at UNC-CH
- *Continuing Education Courses for nurses and other providers*



Lectures

- For certain topics, the lecture format probably works best

Other Topics Work Better in Different Formats



- In-class activities
  - Family history exercise
  - Dysmorphology exercise
  - Family assessment exercise
  - Genomics and Ethics in the media exercise
  - Case studies
- Enrichment activities
- Family and Genetics Project
- Reflection Paper
- Unfolding Case Study

In-Class Activity: Family History

- Divide students into groups of two
  - Have them take turns taking their teammate's family history and constructing a family pedigree
    - https://familyhistory.hhs.gov/fhh-web/home.action

- *"Family History: The most valuable and least expensive genetic test"*

Make them aware of Family Medical History tools/resources

- NHGRI
  - Family Medical History and Tool Resources
    - https://www.genome.gov/11510372/family-medical-history-and-tools-resources-online/
  - NHGRI Family History Tool Conference 2016
    - https://www.genome.gov/27565264/the-nih-family-health-history-tool-conference-2016/

National Human Genome Research Institute

- Progeny
- Me Tree
- Family Healthware from Sanitas
- Proband
- CancerGeneConnect
- VICKY
- Cancer IQ
- CRA Health

In-Class Activity: Dysmorphology

- Divide students into groups of 3-4
- Give each group an envelope filled with pictures of individuals who have genetic conditions with noticeable dysmorphic features
- Ask the students to identify
  - Specific dysmorphic features
  - Genetic conditions
- After students are finished
  - Discuss the correct answers
  - Make them aware of resources such as Face2Gene

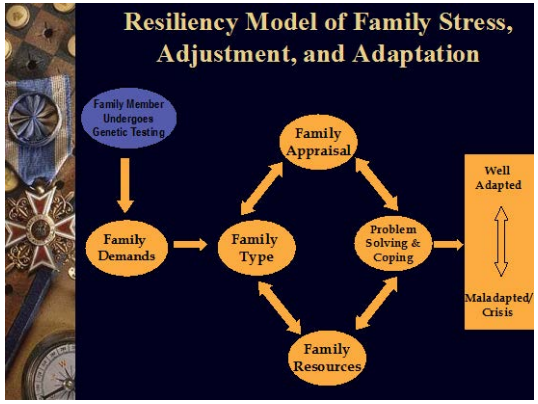
FDNA
Accessible Genetics

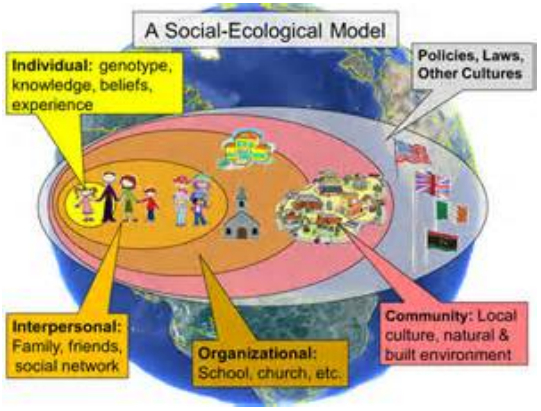
Face2Gene

http://www.fdna.com/face2gene/

In-Class Activity: Family Assessment Exercise

- Show a video clip of a family living with a genetic condition
- Have the students assess the family using a family framework
- You Tube is a great resource
  - http://www.youtube.com/watch?v=xCSzysu_flY





Genomics and Ethics in the Media Activity

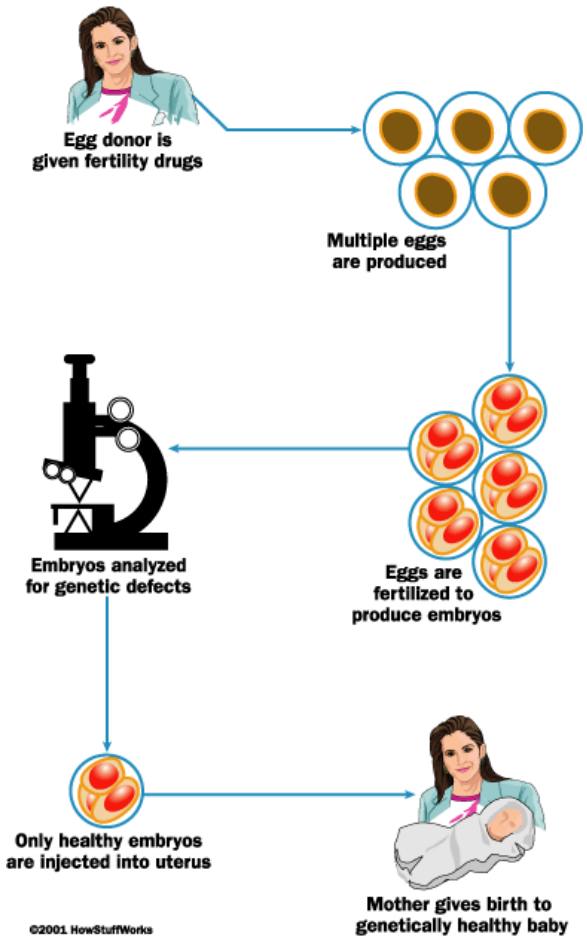
- Have students find an example of ethical, legal, or social implications of genetics/genomics being discussed in the popular media (e.g., a cartoon, an article, a commercial, a video clip, a movie etc.) & have them come to class prepared to discuss it

Structured Controversy

- Students are randomly assigned to groups of 4 students (2 advocacy teams per group)
  - One team is given a position on an argument
  - The other group is given a different position on the same argument
- Students review materials that support both positions.
- Each Advocacy teams has 10 minutes to advocate for their position
- Then, the positions are reversed and each group has 10 minutes to advocate for the other position.
- Finally there is general discussion in which they seek to reach the best decision possible.

Structured Controversy

- *The role of regulation in pre-implantation genetic diagnosis*
  - One team is given the position that more regulations are needed
  - The other team is given the position that fewer regulations are needed



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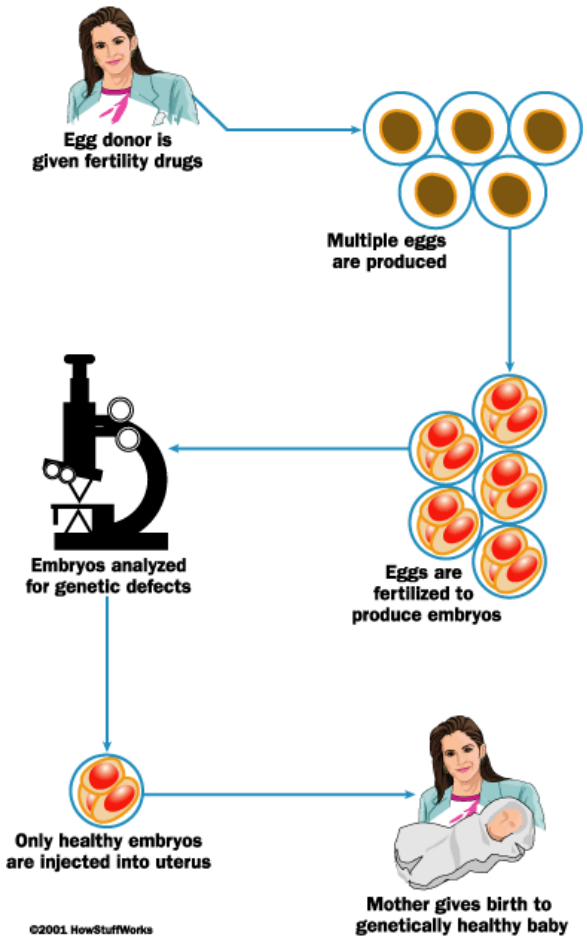
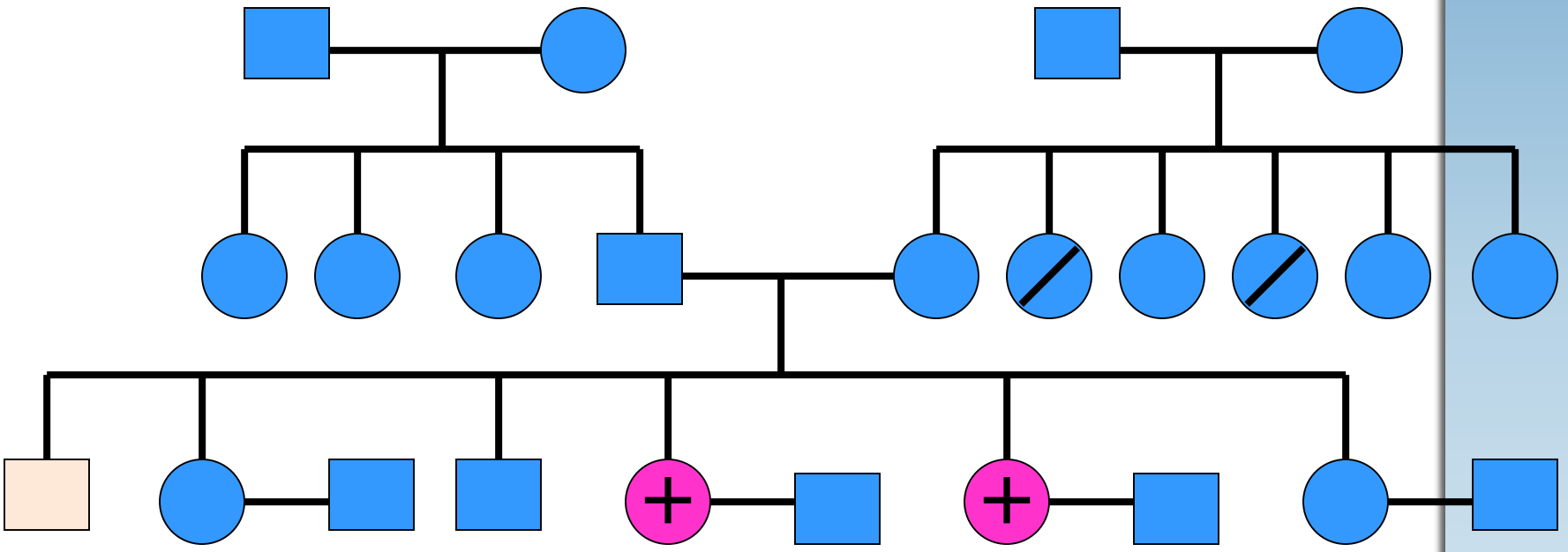


Case Studies

- Using a video clip
  - http://www.pbs.org/pov/inthefamily/video_classroom3.php
- Using data from a research study
  - I used data collected during my *K01 Family Experience of Genetic Testing: Ethical Dimensions* funded by NINR

- Family Experience of Genetic Testing (Van Riper, 2005)
  - BRAC 1&2 Testing for Hereditary Breast and Ovarian Cancer



BrCa 30, 36

BrCa 41

Key:

Breast Cancer

Mental Retardation

Sisters went as a group to a genetic counseling session– but their response was not a “group response”

- *“We learned in that session and shortly thereafter that even though we are blood sisters, raised together in the same household, in a very close family, with the same parents; we had totally different responses to this. Totally different! “*

4 Sisters: 4 Responses

1st Sister BrCa X 2 BRCA testing+	Bilateral Mastectomy, Bilateral oophorectomy, No breast reconstruction
2nd Sister Hx BrCa x1 BRCA testing+	Bilateral Mastectomy, Bilateral oophorectomy, Br reconstruction
3rd Sister No Hx of BrCa	Increased Surveillance – Starting to "rethink" her decision
4th Sister No Hx of BrCa	Minimal Surveillance

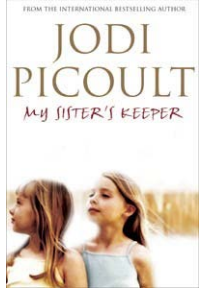
Sisters agreed that it was "okay" to disagree

- *"We respected each other's opinions, but I will probably never totally understand her decision and she'll never understand my decision. And we found that's okay. These decisions are so highly personal that even a sibling can't relate to what you are going through."*

In contrast, in another family, they did not agree to disagree

- *"My sister said that because I didn't use genetic testing to terminate a pregnancy affected by Down syndrome and make life better for the world, she wouldn't use genetic testing to help me find out if we had a family thing... Personally for me there is a difference between a baby and a breast, but everybody sees the world differently. She just could never get past that. She could just never, to her dying day, believe that we brought this person (the child with Down syndrome) into the world. She said no woman on the planet would do what I did, refuse to have an amnio. She said that nobody who was sane would do what I did, nobody who was sane would bring a retarded person into the world."*

Enrichment Activities

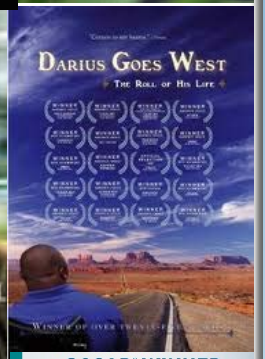


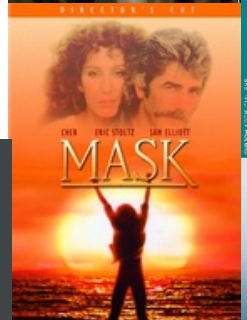
- Movies
- TV Shows
- Books
- CDs
- Web-based activities
- Seminars
- Interview a genetic specialist

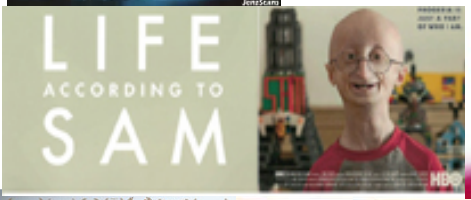
- Have students spend one hour outside of class doing something related to genomics
- Have them write a paper in which they answer the following questions
  - **What did you do?**
  - **What were the key messages you learned?**
  - **How will you use what you learned in practice?**

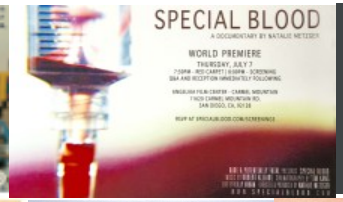
Examples of Movies/Documentaries

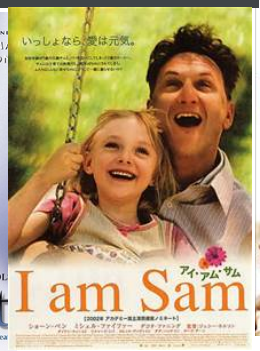
- ESPN 360 videos
  - Perfect (DS)
  - Flip of a Coin (HD)
  - Catching Kayla (MS)
  - Backup Catcher (HLH)

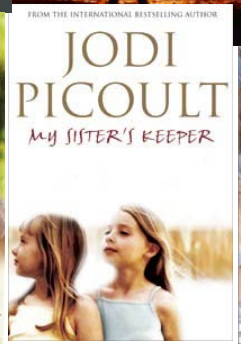




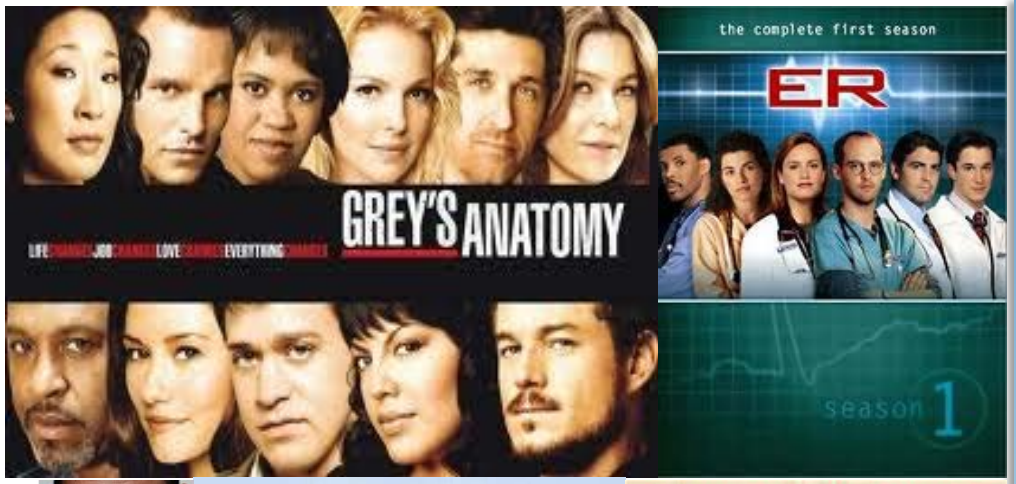








TV Shows


GREY'S ANATOMY
the complete first season
ER
season 1


BORN·THIS·WAY


TLC
the little COUPLE

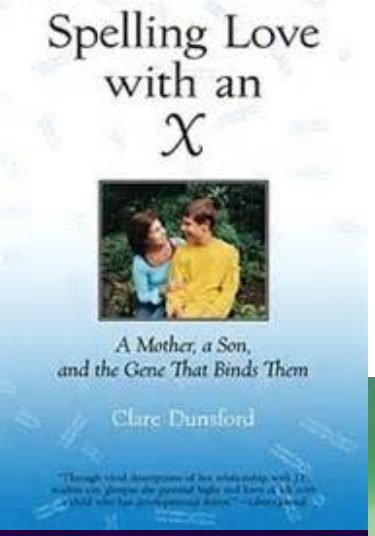

CALL THE MIDWIFE
THE ALBUM
MUSIC FROM SERIES 1, 2 AND THE CHRISTMAS SPECIAL
2CD COLLECTION INCLUDING ORIGINAL '50s RECORDINGS,
CAST PERFORMANCES AND MUSICAL INTERLUDES
BBC

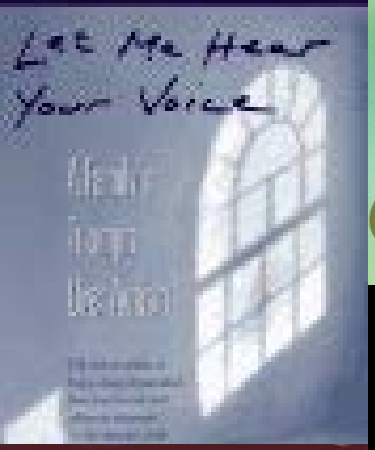

HOUSE
M.D.

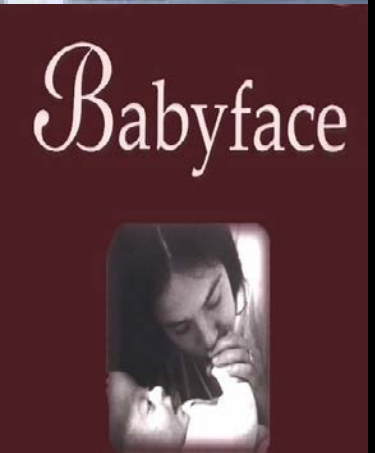

TWO
IN A
MILLION

Sites Where Students Can Search for ONLINE Activities

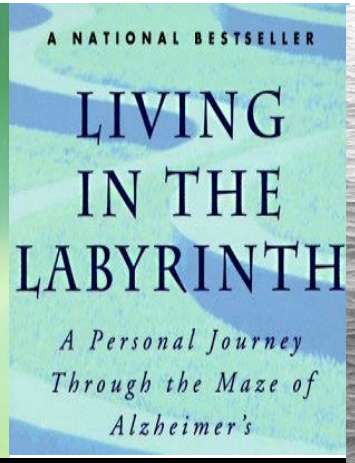
- Genome TV
  - http://www.genome.gov/genometv/
- CDC- Office of Genetics and Disease Prevention
  - http://www.cdc.gov/genomics/default.htm
- Learn Genetics http://learn.genetics.utah.edu/
- TED Talk on Genetics
  - https://www.ted.com/topics/genetics
- Telling Stories Website
  - http://www.tellingstories.nhs.uk/
- Genetic Alliance Website
  - http://www.geneticalliance.org/
- Global Genes
  - https://globalgenes.org/rare-documentaries-and-films/

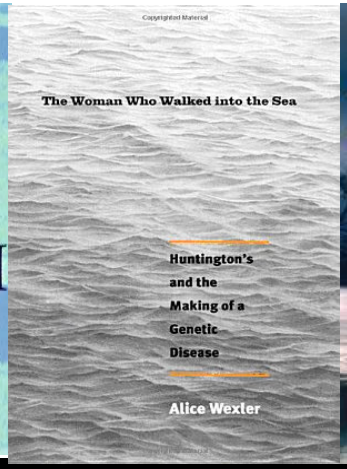


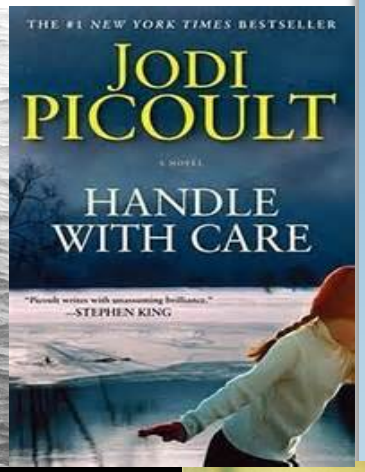




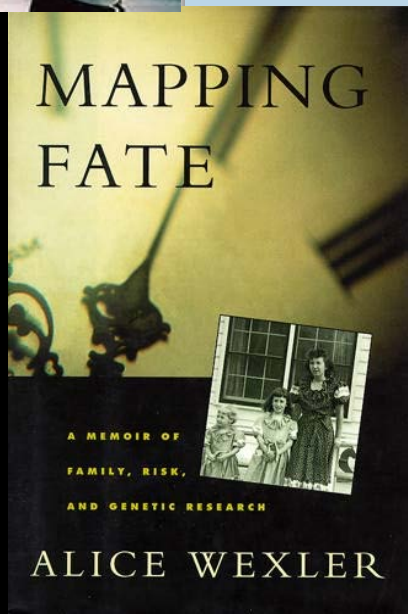
Family and Genetics Project







- The purpose of this project is to explore the family experience of living with a genetic condition.



Family & Genetics Project

- Family Composition/Pedigree
- Genetic Condition
  - Incidence /Variation in factors such as risk and expression related to gender, ethnicity and/or religion
  - Genetic Basis of Condition
  - Typical Pattern of Inheritance
  - Pathophysiology
  - Symptoms/Clinical Features
  - Nursing Priorities
- Family Assessment using Resiliency Model of Stress, Adjustment and Adaptation
- References

	A few examples from past classes
Achondroplasia	Real Family on TV Show (*Little People*)
Alpha Antitrypsin Deficiency	Real Family
Adrenoleukodystrophy	Movie (*Lorenzo's Oil*)
Alzheimer's Disease	Real Family /Book/Movie (*Iris)*
Aspergers	Real Family
Autism	Real Family/Book (*Just this side of normal*)/Movie (*I am Sam)*
BiPolar Disorder	Real Family/Book (*An Unquiet Mind)*
Cystic Fibrosis	Real Family/Book (*Alex-Life of a Child*)
Diabetes	Real Family/Movie (*Steel Magnolias)*
Factor V Leidan	Real Family
Fragile X	Real Family/Book (*Spelling Love with an X)*
Huntington Disease	Real Family/Book *(Mapping Fate)*
Osteogenesis Imperfecta	Real Family /Book (*Handle with Care)*
Parkinson's Disease	Real Family/Book *(Lucky Man)*
Schizophrenia	Real Family/Movie *(A Beautiful Mind)*
Sickle Cell Disease	Real Family
Wilson's Disease	Real Family

Spring 2016: **Most groups chose to focus on a group member's family or a family known by a group member**

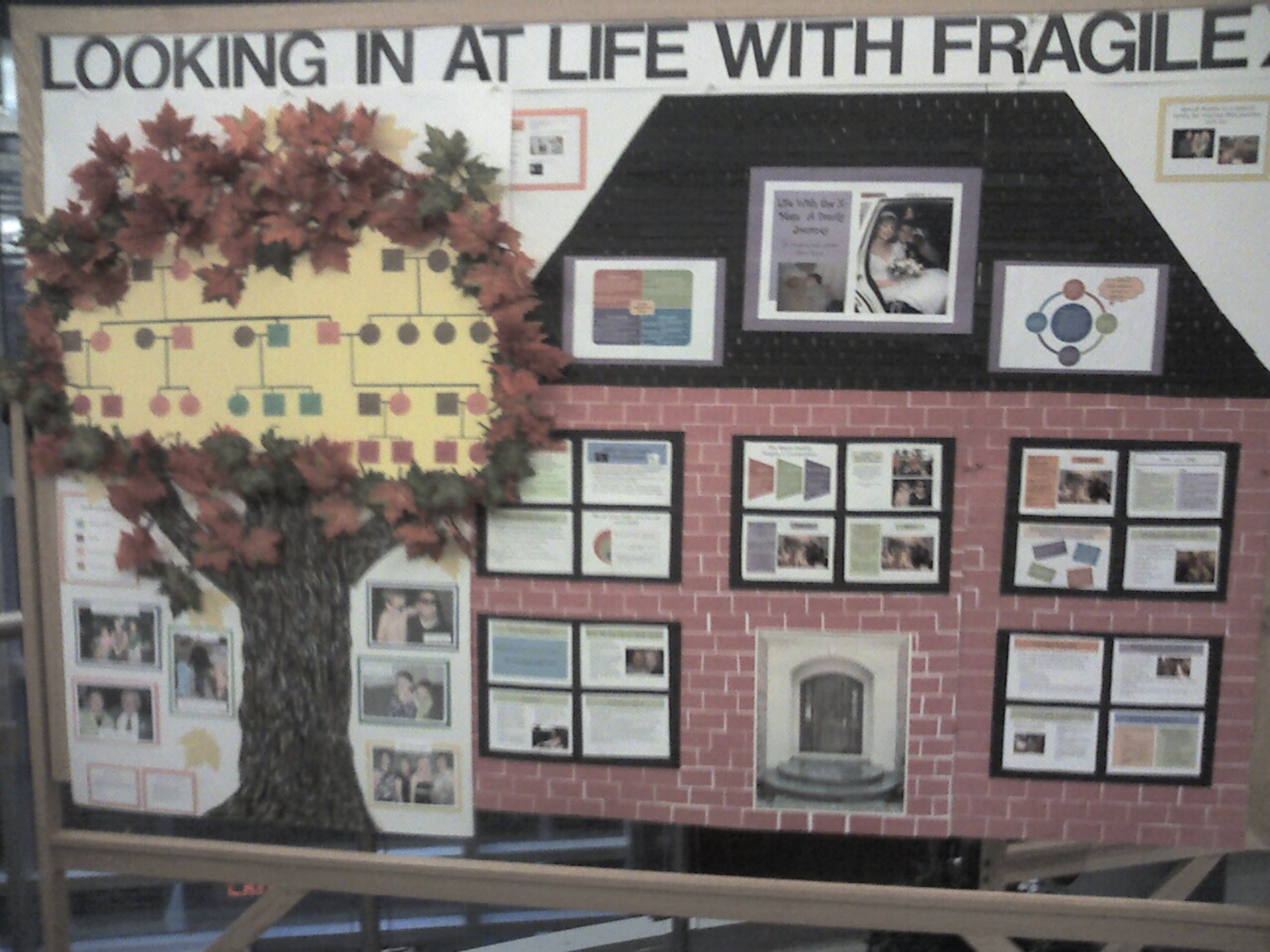
Alzheimer's Disease (Still Alice)	Hemaachromatosis
Asperger's	Hemophilia
BiPolar Disorder	Huntington Disease (Twitch)
Chromosomal Deletion (rare)	Lupus
Chronic Mucotaneous Candidiasis	Mitochondrial Disease
Cystic Fibrosis	Muscular Distrophy
Cleft Palate	Oromandibular Limb Hypogenesis
Congenital Adrenal Hyperplasia	PCOS (Reality TV Show)
Congenital Glaucoma	Polycystic Kidney Disease
Cri-Du-Chat	Phenylketonuria
Crohn's Disease	Schizophrena
Dense Deposit Disease	Spherocytosis
Down Syndrome	Spinal Muscular Atrophy
Fibrodysplasia Ossificans Progressive	Type 1 Diabetes
Fragile X	Turner Syndrome
	William Syndrome

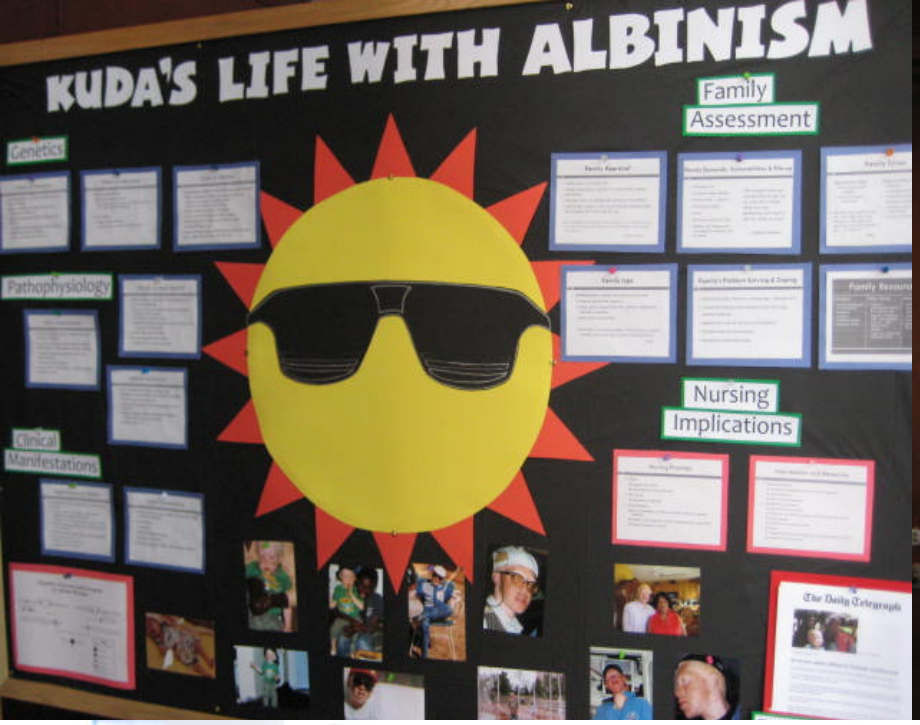
Opportunities to Share Their Work with Others

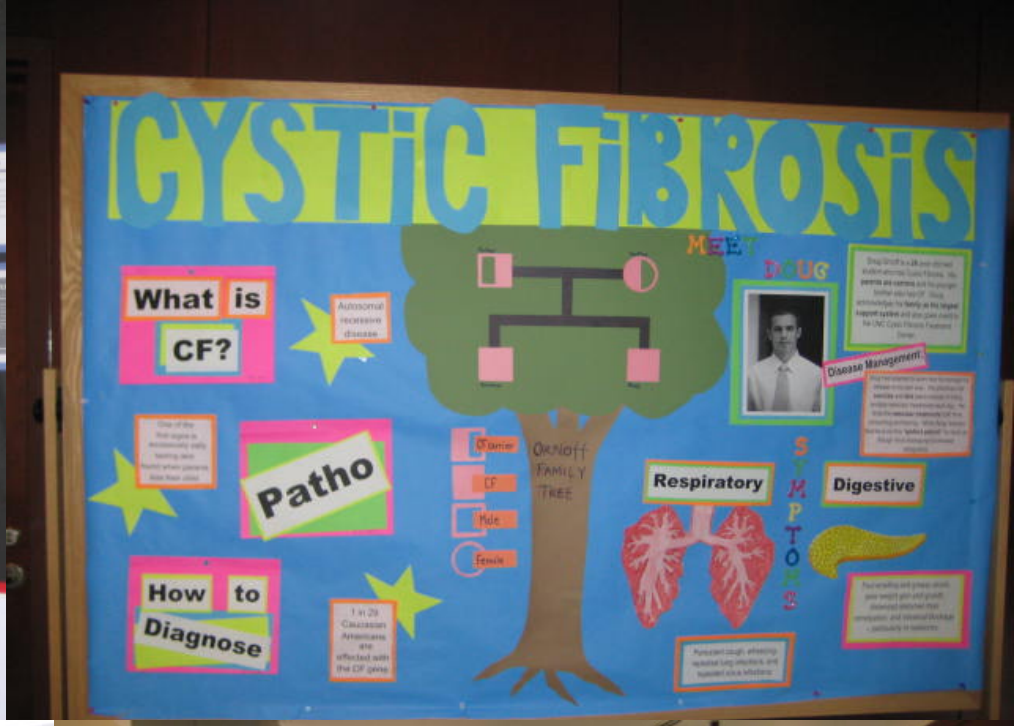
- In-Class Group Presentations
  - 5 minute presentations
- Poster Presentation on display during Nursing in the Genomic Era Conference
  - Creativity is encouraged
  - Chance for students to teach others about "their condition"
- Handout/Powerpoint presentation


HUNTINGTON'S DISEASE
FAMILY PEDIGREE

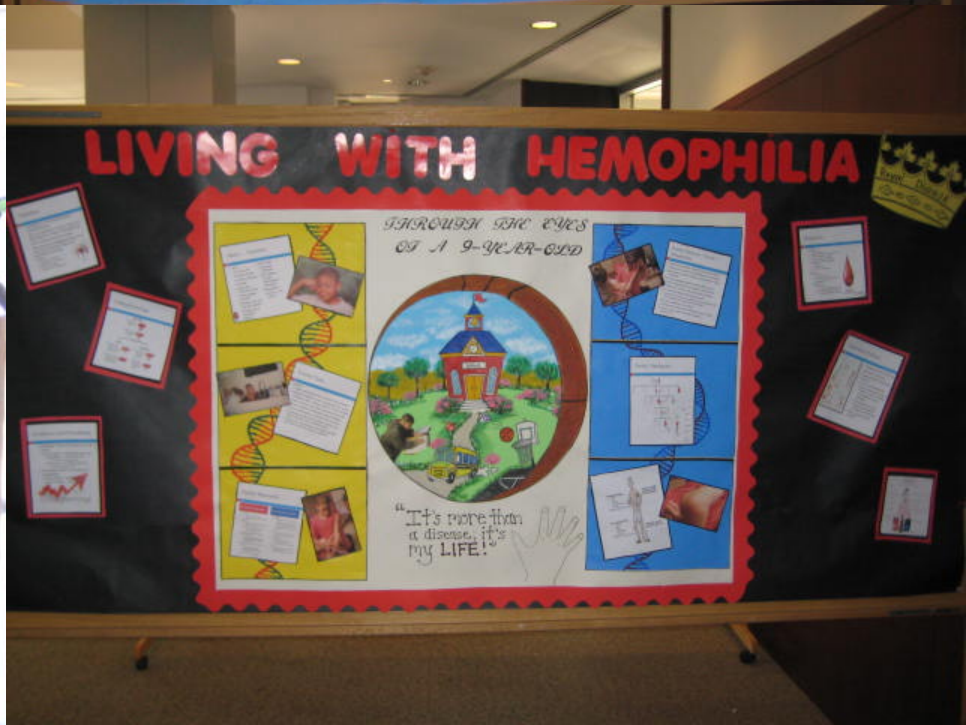

T O R
V
LEIDEN
COALITION TO PREVENT


LOOKING IN AT LIFE WITH FRAGILE


KUDA'S LIFE WITH ALBINISM
Genetics
Family Assessment
Pathophysiology
Nursing Implications
Clinical Manifestations


CYSTIC FIBROSIS
What is CF?
Autosomal recessive disease
MEET DOUG
Disease Management
Patho
OKNOFF FAMILY TREE
Respiratory
Digestive
SYMPTOMS
How to Diagnose
1 in 29 Caucasian Americans are affected with the CF gene


Spina bifida
FAMILY ASSESSMENT


LIVING WITH HEMOPHILIA
THROUGH THE EYES OF A 9-YEAR-OLD
"It's more than a disease, it's my LIFE!"

Reflection Paper

- Chance for students to reflect on what it was like doing the family and genetic project (1-2 pages)
  - Was it a worthwhile activity?
  - If so, what made it a worthwhile activity?
  - What did you learn from doing it?
  - How will it influence the way you practice?
  - Or, how has it already influenced the way you practice?

Unfolding Case Study

Opportunity for students to apply what they have learned during the course/workshop

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Anna, 32 year old woman -annual physical appointment

- While you are in the process of updating her family history, Anna says, ***"I have decided to get tested for Huntington's disease and Alzheimer's disease. "***

- Slides for the remainder of the case study will be available after the case study has been presented.

Questions?