Family Health History: Knowing your past can protect your future.

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Overview
- What is a family health history?
- Why is it important?
- How to collect one
- Genealogy records
- Assessing your family health history
- Ethical issues
- Resources

What is a family health history?
- A family’s combination of shared genes, environment, behaviors, and culture

Why is it important?
- Health problems run in families
- Helps you know what your risk may be
  - Guides screening tests and behavior change
- Family history may be a “risk factor” in all stages of life
  - “Risk factors” are things that can increase your chance of getting a health problem
    - Environment
    - Behaviors and lifestyle
    - Genetics

Risk factors
- Environment
  - Exposures to harmful agents in food, air, and water

Risk factors
- Behaviors and lifestyle
  - Poor diet
  - Lack of physical activity
  - Weight
  - Smoking
  - Not getting the recommended screening tests
Risk factors

- **Genetics**
  - Genes give the directions for making proteins in our bodies. Proteins make our bodies function.
  - Genes are passed down from parents to children.
  - Some genes may not work correctly, which can cause disease.

Why is it important?

- **Family health history**

We all have a family history of something!

- diabetes
- allergies
- high blood pressure
- blue eyes
- autism
- high cholesterol
- red hair
- obesity
- stroke
- asthma
- arthritis
- cancer
- emphysema
- height
- cancer
- kidney disease
- Alzheimer's
- leanness
- osteoporosis
- pre-term birth
- curly hair
- birth defects

Why is it important?

- "Knowing your family history can save your life. The earlier you know which health conditions run in your family, the easier it is to develop prevention plans with your doctor."

  - Dr. Richard H. Carmona, past U.S. Surgeon General

How to collect one

- **Easy as 1, 2, 3!**
  - Talk about it
  - Write it down
  - Share it

- **Use the Family Health History Toolkit**


How to collect one

- **You already collect family history but...**
  - Only need a 3 generation pedigree
  - Blood relatives are most important
  - Emphasis on health and behaviors
  - **Lots of tools!**
How to collect one

- Focus on “close” family members
  - Parents, brothers and sisters, children (1st degree relatives)
  - Grandparents, aunts and uncles, nieces and nephews, grandchildren, step siblings (2nd degree relatives)
  - Cousins and the “greats” (3rd degree relatives)
How to collect one

- Health problems of family members
- Age when problem started or was diagnosed
- Age and cause of death
- Lifestyle habits
- Ethnic background

Medical pedigree

For more information on how to draw a medical pedigree, visit the National Society of Genetic Counselors website
www.nsgc.org/consumer/familytree

Genealogy records

- Your family health history may be “hidden” in your genealogy records!
  - Remember, best source is LIVING family members
- Look in...
  - Death and birth certificates
  - Medical examiner records
  - Cemetery and funeral home records
  - Obituaries
  - United States Census records
  - Military records, journals, hospital/insurance forms

Death certificates

- The LDS Family History Library in Salt Lake City has death records
- Some states have death indexes
- To find:
  - Check the Family History Library Catalog or ask the front desk for help
  - Look by state, county, and sometimes city
  - Search death indexes online

Funeral home records

- Required by law to keep records, even if ownership changes
- Funeral homes help in recording death certificates and obituaries
- To find:
  - www.funeralnet.com
  - National Yellow Book of Funeral Directors
  - Call and tell them what you need
Obituaries

- Cause of death may not be included
- Look for donations and thank yous
  - “In lieu of flowers, please make a donation to the Arthritis Foundation”
  - “The family would like to thank the Alzheimer’s Clinic”
- To find:
  - Newspapers in public libraries or state archives
  - Internet search ("obituary index")

United States Census (1850-1930)

- Health clues such as:
  - Gaps between children
  - Occupation (“mad hatter” was someone who worked with chemicals that affected the brain)
  - Different spouse or single parent
  - Nieces, nephews, or grandchildren living with family (possible early death in family)
  - Institutionalized (hospitals, schools)
    - Inmates
    - Wards or patients
*Look in the Family Health History Toolkit for how to find census records

Old medical terms

- You may have to decode old medical terms
- Examples:
  - “dropsy” = congestive heart failure
  - “apoplexy” = stroke
  - “toxemia of pregnancy” = eclampsia
- Resources
  - Cyndi’s List under “Medical and Medicine”
    http://www.cyndislist.com/medical.html/Diseases

St. Francis Convent, 1880

1880—Michael Ryan had “Consumption,” was bedridden.

Assessing your family health history

- Step 1: Write down your family health history for 1st and 2nd degree relatives
  - Use the Health Family Tree or draw a medical pedigree
Assessing your family health history

- **Step 2a:** Review your family health history
  - Summarize what you learned

- **Step 2b:** Apply risk categories

### Condition | No. 1st degree affected relatives | No. 2nd degree affected relatives | Age of onset | Age of death
--- | --- | --- | --- | ---
Cancer (specify type) | 0 | 1 (breast) | 62 | 70, stroke
Diabetes | 1 | 0 | 65 | Living
Heart Disease | 1 (high cholesterol) | 2 (angina, heart failure, HCM, arrhythmia) | 80’s | 87
High Blood Pressure | 2 | | | Living
Stroke | 1 | | 69 | 70, stroke
Other (depression) | 2 (depression) | | 40’s, 16, 30’s | All living

### What is “early onset”?

<table>
<thead>
<tr>
<th>Disease</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast cancer</td>
<td>&lt;50</td>
</tr>
<tr>
<td>Colon/rectal cancer</td>
<td>&lt;50</td>
</tr>
<tr>
<td>Coronary heart disease</td>
<td>55-65</td>
</tr>
<tr>
<td>Diabetes</td>
<td>&lt;30</td>
</tr>
<tr>
<td>Endometrial cancer</td>
<td>&lt;50</td>
</tr>
<tr>
<td>High Blood Pressure</td>
<td>&lt;40</td>
</tr>
<tr>
<td>Dementia</td>
<td>&lt;60</td>
</tr>
<tr>
<td>Ovarian cancer</td>
<td>&lt;50</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>&lt;60</td>
</tr>
<tr>
<td>Stroke or mini-stroke</td>
<td>&lt;60</td>
</tr>
<tr>
<td>Sudden unexpected death</td>
<td>&lt;40</td>
</tr>
<tr>
<td>Thyroid cancer</td>
<td>&lt;50</td>
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</table>

### Step 2b: Risk categories

**High Risk**
1. Early disease in a 1st degree relative.
2. Early disease in a 2nd degree relative
3. Two affected 2nd degree relatives
4. One 1st degree relative with onset of disease in 50’s or unknown
5. One 1st degree relative with late onset and an affected 1st degree relative
6. One 1st degree relative with late onset and an affected 2nd degree relative
7. Two affected 2nd degree relatives

**Moderate Risk**
1. One 1st degree relative with late onset
2. Two 2nd degree relatives with late onset

**Average Risk**
1. No affected family members.
2. One 1st degree relative with late onset
3. Adopted person with unknown family history.

### You may have a higher risk if...
- Early age of onset
- 2 or more close family members have the same disease
- 2 or more generations with the same disease
- Disease occurs in less often affected sex (breast cancer in males)
- Related conditions (heart disease and diabetes)

### What risk criteria are met?

- **Cancer (breast)** Average
  - No affected family members.
- **Diabetes** Moderate
  - One affected parent, relatives, or siblings.
- **Heart Disease** Moderate – High
  - One or more affected family members.
- **High Blood Pressure** Moderate
  - One affected parent, relatives, or siblings.
- **Stroke** Average
  - No affected family members.
- **Other (depression)** High
  - One or more affected family members.


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<th>What risk criteria are met?</th>
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Assessing your family health history

- Average Risk (Sporadic)
- Moderate Risk (Familial)
- High Risk (Hereditary)

Step 3: Make a plan for better health
- What are your health habits now?
- What can you do better?
- Are there prevention guidelines?

You can’t change your genes…
- But you can change your behaviors!
  - Talk to your doctor or see a specialist
  - Get early or more frequent screening tests
  - Eat healthy foods
  - Physical activity
  - Stop smoking

Ethical issues
- Quality of information
- Privacy issues
  - What if you have a genetic predisposition? Do you tell your family? Do they want to know?
- Fear of discrimination
  - Health insurance
  - Life insurance
  - Employment
- Legislation
  - Utah Genetic Testing Privacy Act
  - HIPAA, ADA
  - No federal law!
- Few documented cases of genetic discrimination
### Resources – Web Sites

- Utah Department of Health
  - [www.health.utah.gov/genomics](http://www.health.utah.gov/genomics)
- Geneweaver software
  - [www.geneweaveronline.com](http://www.geneweaveronline.com)
- CDC Family History
  - [www.cdc.gov/genomics/public/famhistMain.htm](http://www.cdc.gov/genomics/public/famhistMain.htm)
- U.S. Surgeon General Family History Initiative
  - [www.hhs.gov/familyhistory/](http://www.hhs.gov/familyhistory/)
- Genetic Alliance
  - [www.geneticalliance.org](http://www.geneticalliance.org)

### Resources – books


### Tell us your story!

- Help other families understand why family health history is important
- Tell us:
  - How you learned about your family health history
  - What impact this has had on you and your family
- Any format (written, pictures, video, etc)