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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

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What is a family health history?



- A family's combination of shared genes, environment, behaviors, and culture

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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

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Risk factors

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





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Risk factors

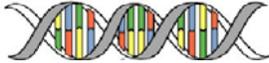
- Behaviors and lifestyle
 - Poor diet
 - Lack of physical activity
 - Weight
 - Smoking
 - Not getting the recommended screening tests





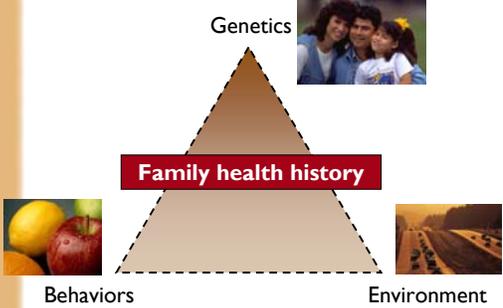
Risk factors

- **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



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Why is it important?



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We all have a family history of something!



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

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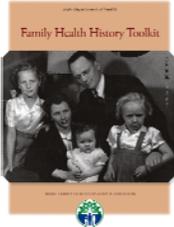
Why is it important?

- **“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

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How to collect one

- **Easy as 1, 2, 3!**
 - Talk about it
 - Write it down
 - Share it
- **Use the Family Health History Toolkit**
www.health.utah.gov/genomics



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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!**



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HEALTH FAMILY TREE

Coming online soon! Visit www.health.utah.gov/genomics

My Family Health Portrait

Welcome to My Family Health Portrait

The Family Health Portrait allows you to create a personalized family health history report from any computer with an Internet connection and an up-to-date Web browser. Information you provide creates a family tree and lists the names and dates of your family health history. Both the tree and the listing can be printed and shared with your family members or your health care professional. Consult your doctor with your health care professional, your family health history can help you receive your family health history and identify disease prevention strategies that are right for you.

Now you can click on **Create a Family History** to begin creating a personalized family health history. Returning users can click on **Load a Saved Family History** to edit an existing personalized family health history.

[Create a Family History](#) [Load a Saved Family History](#)

Additional Information

How the Family Health Portrait is made based on additional software needs to be downloaded or installed. The health information you provide is stored only on your computer and not on a U.S. Government server. You own the file and you choose what to do with it at any time.

With the Family Health Portrait, you can:

- Edit or update your health information at anytime.
- Save your health information to a file and take it with you if you are using a public machine (e.g., at the library).
- Email web pages you want to share your health information.
- Decide how to share your health information (e.g., mail it to yourself).

If you do not know all the details about members in your family, the health information you do enter into the tool will be sufficient and useful. When used in conjunction with a doctor or health care professional, the Family Health Portrait can be a valuable tool in assessing your risk for disease and identifying strategies to prevent disease.

The Family Health Portrait is part of the U.S. Surgeon General's Family History Initiative. For more information about the U.S. Surgeon General's Family History Initiative, please go to:

- [U.S. Surgeon General's Family History Initiative](#)
- [Surgeon General's Initiative on Family History](#)

CREATING YOUR FAMILY MEDICAL HISTORY

Instructions: You may have a greater risk for colorectal cancer if you have a personal or family history of certain kinds of cancer or of polyps in the colon. To help you determine your risk, complete this family medical history. For each blood relation, mark in the box if they have had any of the following medical problems and their age at diagnosis: colorectal cancer, inflammatory bowel disease (Crohn's or colitis) or stomach or bowel problems, breast, uterine or endometrial cancer, or colorectal polyps (adenomas).

Share this information with your health care provider to see when you should begin colorectal cancer screenings.

COLORECTAL CANCER AWARENESS MONTH

March is National Colorectal Cancer Awareness Month, founded by the Cancer Research Foundation of America in collaboration with many partner organizations. Talk with your health care provider about colorectal cancer. Colorectal cancer is preventable, and is easy to treat and often curable when detected early. Ask your health care provider what kind of screening test you should have and when.

Preventable. Treatable. Beatable!
Funded by the Cancer Research Foundation of America

To learn more, call 1-877-35-COLON or visit our Web site at www.preventcancer.org/colorectal

THE RISK CHANNEL

Your Disease Risk

THE SOURCE ON PREVENTION

What to watch out for

9 out of 10 preventable diseases

What's your cancer risk?

What's your diabetes risk?

What's your heart disease risk?

What's your osteoporosis risk?

What's your stroke risk?

Generational Health

Welcome to Generational Health

Understanding how your family's health history can help you make informed decisions about your health.

Please Select

Family Health History

Create a New Family Tree

Return to Saved Tree

How to collect one

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- 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)

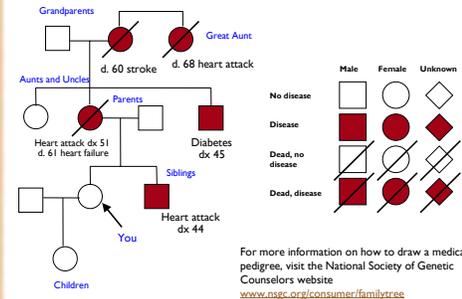
How to collect one



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

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Medical pedigree



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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

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Death certificates

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

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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

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Assessing your family health history



- **Step 2a: Review your family health history**
 - Summarize what you learned
- **Step 2b: Apply risk categories**

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Step 2a

Condition	No. 1 st degree affected relatives (parents, siblings, children)	No. 2 nd degree affected relatives (grandparents, aunts and uncles)	Age of onset	Age and cause of death
Cancer (specify type)	0	1 (breast)	62	70, stroke
Diabetes	1	0	45	Living
Heart Disease	1 (high cholesterol)	3 (cong. heart failure, HCOM, arrhythmia)	60's 50's 47	Living 70, stroke Living
High Blood Pressure		2	unk	Living
Stroke		1	69	70, stroke
Other	2 (depression)	2 (depression)	40's, 16, 30's 30's	All living

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Assessing your family health 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)

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Step 2b: Risk categories

High Risk

1. Early disease in a 1st degree relative.
2. Early disease in a 2nd degree relative (coronary artery disease).
3. Two affected 1st degree relatives.
4. One 1st degree relative with late or unknown disease onset and an affected 2nd degree relative with early disease from the same side of the family.
5. Two affected 2nd degree relatives with at least one having early onset disease.
6. Three or more affected family members.
7. Presence of a "moderate risk" family history on both sides of the family.

Moderate Risk

1. One 1st degree relative with late or unknown onset of disease.
2. Two 2nd degree relatives from the same side of the family with late or unknown disease onset.

Average Risk

1. No affected family members.
2. Only one affected 2nd degree relative from one or both sides of the family.
3. No known family history of disease.
4. Adopted person with unknown family history.

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Scheuner, et al. Am J Med Genet (1997), 71:315-324

What is "early onset"?



Disease	Age
Breast cancer	<50
Colon/colorectal cancer	<50
Coronary heart disease	<55-65
Diabetes	<20
Endometrial cancer	<50
High Blood Pressure	<40
Dementia	<60
Ovarian cancer	<50
Prostate cancer	<60
Stroke or mini-stroke	<60
Sudden unexpected death	<40
Thyroid cancer	<50

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Step 2b: Risk categories

Condition	Risk Level	What risk criteria are met?
Cancer (breast)	Average	#2 Only one affected grandparent from one or both sides of family.
Diabetes	Moderate	#2 One parent with late or unknown onset of disease. (Overweight)
Heart Disease	Moderate - High	#1 Early disease (cholesterol) in parent. #2 Two grandparents from the same side of the family with late or unknown disease onset. #6 Three or more affected relatives. (Grandpa smoked heavily)
High Blood Pressure	Moderate	#2 Two uncles from the same side of the family with late or unknown disease onset.
Stroke	Average	#2 Only one affected grandparent from one or both sides of family.
Other (depression)	High (depression)	#3 Two affected parents, children, or siblings. #1 Early disease in a parent, child, or sibling. #5 Two affected grandparents, aunts/uncles with at least one having early disease onset.

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Assessing your family health history

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

Courtesy K. Oahika, Minnesota Genomics Program

Assessing your family health history

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




Assessing your family health history

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Scheuner, et al. Am J Med Genet (1997), 71:315-324

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

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- **Quality of information**
- **Privacy issues**
 - What if you have a genetic predisposition? Do you tell your family? Do they want to know?

Ethical issues

- **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
- **Geneweaver software**
 - www.geneweaveronline.com
- **CDC Family History**
 - www.cdc.gov/genomics/public/famhistMain.htm
- **U.S. Surgeon General Family History Initiative**
 - www.hhs.gov/familyhistory/
- **Genetic Alliance**
 - www.geneticalliance.org

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Resources – books

- Shawker, Thomas H. *Unlocking your genetic history: A step-by-step guide to discovering your family's medical and genetic heritage.* Rutledge Hill Press, 2004.
- Daus, Carol. *Past Imperfect: How tracing your family medical history can save your life.* Santa Monica Press, 1999.
- Bennett, Robin L. *The practical guide to the genetic family history.* Wiley-Liss, Inc., 1999.
- Milunsky, Aubrey. *Your genetic destiny.* Perseus Publishing, 2001.
- *Genealogical Journal* Vol. 28 No. 3 (2000).
- *Genealogical Journal* Vol. 30 No. 2 (2002).

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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)**
- **More information at** www.health.utah.gov/genomics

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