

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

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# Overview

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- **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?

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

# Why is it important?

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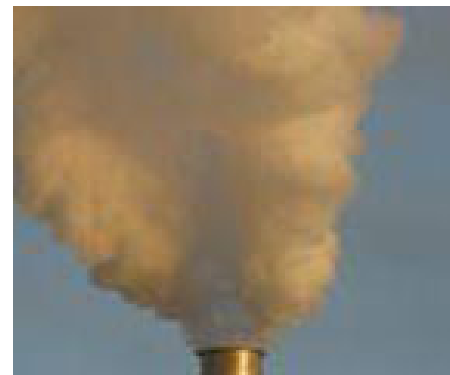
- **Health problems run in families**
- **Helps you know what your risk may be**
  - Guides screening tests and behavior change
- **Family history may be a “risk factor” in all stages of life**
  - “Risk factors” are things that can increase your chance of getting a health problem
  - Environment
  -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

# Risk factors

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- **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

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## ■ 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?

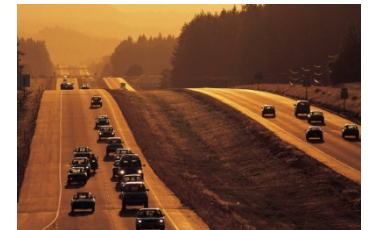
Genetics



**Family health history**



Behaviors



Environment



# We all have a family history of something!

diabetes    allergies    high blood pressure    blue eyes

autism

high  
cholesterol

red hair

obesity

stroke



leanness

osteoporosis

pre-term birth

curly hair

birth defects

Alzheimer's

asthma

arthritis

cancer

kidney disease

height

emphysema

# Why is it important?

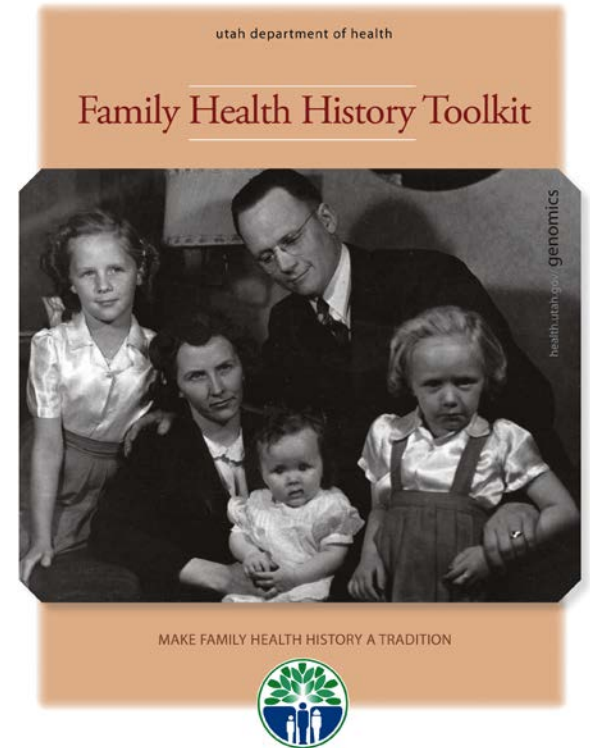
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- **“Knowing your family history can save your life. The earlier you know which health conditions run in your family, the easier it is to develop prevention plans with your doctor.”**
  - Dr. Richard H. Carmona, past U.S. Surgeon General

# How to collect one

- **Easy as 1, 2, 3!**
  - Talk about it
  - Write it down
  - Share it
- **Use the Family Health History Toolkit**

[www.health.utah.gov/genomics](http://www.health.utah.gov/genomics)



# How to collect one

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- **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!**



# HEALTH FAMILY TREE

## DIRECTIONS

TALK TO YOUR PARENTS AND RELATIVES TO GATHER THE INFORMATION NEEDED TO COMPLETE YOUR TREE. IF YOU CANNOT FIND THE ANSWER TO A QUESTION ABOUT A RELATIVE, PLEASE MARK "NOT SURE."  
AGE AT DIAGNOSIS IS VERY IMPORTANT, EVEN A GUESS IS BETTER THAN NO INFORMATION.

IF YOUR MOTHER OR BROTHER HAS MORE THAN FOUR SIBLINGS, USE EXTRA SLICES ON BACK.

IF YOUR FATHER OR BROTHER HAS MORE THAN FOUR SIBLINGS AND YOU'VE USED THE EXTRA SLICES ON BACK.



Coming online soon! Visit [www.health.utah.gov/genomics](http://www.health.utah.gov/genomics)



Help with this page



## Welcome to My Family Health Portrait

**My 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 drawing of your family tree and a chart of your family health history. Both the chart and the drawing can be printed and shared with your family members or your healthcare professional. Used in consultation with your healthcare professional, your family health history can help you review your family's health history and develop disease prevention strategies that are right for you.

New users 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 or update an existing personalized family health history.

[Create a Family History](#)

[Load a Saved Family History](#)

**My Family Health Portrait** is compatible with most browsers and operating systems. Please see our [compatibility statement](#) for more information. For users who prefer to use a downloadable software version of My Family Health Portrait, please visit the [My Family Health Portrait Download](#) page on the U.S. Surgeon General's Family History Initiative Web site.

### Additional Information

Since **My Family Health Portrait** is Web-based, no 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 can choose what to do with it at any time.

With My Family Health Portrait, you can:

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

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

My 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](#)
- [Frequently Asked Questions: Family History Initiative](#)

# 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).**

YOUR FATHER'S FATHER      YOUR FATHER'S MOTHER      YOUR MOTHER'S FATHER      YOUR MOTHER'S MOTHER

YOUR AUNTS/UNCLES      YOUR FATHER      YOUR MOTHER      YOUR AUNTS/UNCLES

YOUR BROTHER/SISTER      YOUR BROTHER/SISTER      YOUR BROTHER/SISTER      YOUR BROTHER/SISTER

YOU

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



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

*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.*

**To learn more, call 1-877-35-COLON or visit our Web site at [www.preventcancer.org/colorectal](http://www.preventcancer.org/colorectal)**





# Your Disease Risk

THE SOURCE ON PREVENTION

my results: No Results Yet

Tome el cuestionario en Español

- Cancer
- Diabetes
- Heart disease
- Osteoporosis
- Stroke

9 ways to prevent disease

### What is...?

- Prevention
- Risk
- A Screening Test

### How to...

- Estimate Risk

### Community Action

- Disclaimer
- Privacy Policy
- About This Site
- Link to Us
- Glossary

Welcome to *Your Disease Risk*, the source on prevention. Here, you can find out your risk of developing five of the most important diseases in the United States and get personalized tips for preventing them.

Developed over the past ten years by the Harvard Center for Cancer Prevention, *Your Disease Risk* collects the latest scientific evidence on disease risk factors into one easy-to-use tool.

To get started, choose one of the diseases below.

### What is your risk?

	<b>Cancer: There's much more to it than just smoking and lung cancer.</b>	What's your cancer risk?
	<b>Diabetes: Over 18 million in the U.S. suffer from it. Take steps now to lower your risk.</b>	What's your diabetes risk?
	<b>Heart disease: The #1 killer in the U.S. is also one of the most preventable.</b>	What's your heart disease risk?
	<b>Osteoporosis: Calcium isn't the only way (or even the best way) to protect yourself.</b>	What's your osteoporosis risk?
	<b>Stroke: Most cases of this feared disease can be avoided by lifestyle changes.</b>	What's your stroke risk?



Generational Health

## Welcome to Generational Health

Understanding your family's health history can help you understand your own health.

This Generational Health Web site features an important tool that can help you trace your family's medical history and become better informed about health conditions that may affect your own health and that of your loved ones.

The family health tree you build at this site can go back as far as 2 generations. As you identify some of the medical problems your relatives may have faced, you will have the opportunity to learn more about these diseases and conditions that may be hereditary, including potential causes and the role that heredity may play in their development. Suggestions of what can be done to focus on prevention and early detection are also featured.

You may wish to talk to members of your family and share this information with them. Since this information is also valuable to your physician, you may choose to provide him or her with a copy of your family health tree. You may print out your tree, customized for your doctor, your family, or your personal use.

Learn More About  
Please Select

- Your Family Tree
- Further Information
- Questionnaire
- Pfizer for Women

Ready to begin?

Create a New Family Tree

Already created your tree?

Return to Saved Tree

This Web site was developed as a health information service by Pfizer Women's Health. This site is an anonymous service provided solely for educational purposes. No information about you is collected by this program. You are the only person who can view the results, which are not tracked.



The health information contained herein is for educational purposes only and is not intended to replace individualized medical advice and discussions with a healthcare provider. All decisions regarding patient care must be made by a healthcare provider, who will consider the unique characteristics of the patient. The information on this site is intended for US residents only.

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Generational Health is a resource developed by Pfizer Women's Health.

# How to collect one

- **Focus on “close” family members**
  - Parents, brothers and sisters, children (1<sup>st</sup> degree relatives)
  - Grandparents, aunts and uncles, nieces and nephews, grandchildren, step siblings (2<sup>nd</sup> degree relatives)
  - Cousins and the “greats” (3<sup>rd</sup> degree relatives)



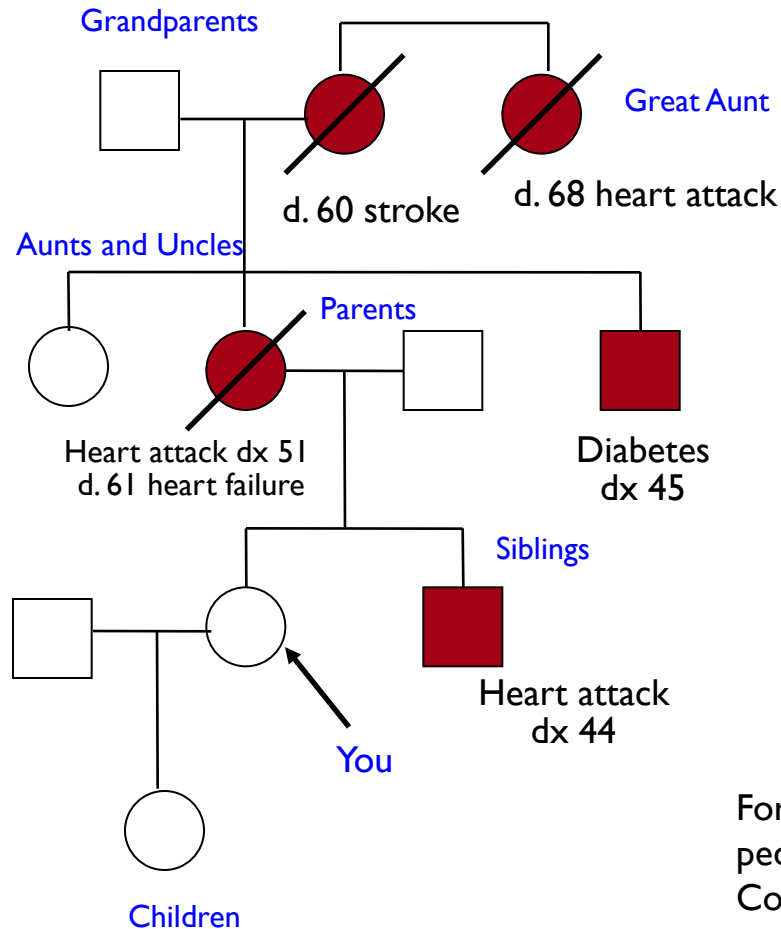
# How to collect one

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

# Medical pedigree



	Male	Female	Unknown
No disease			
Disease			
Dead, no disease			
Dead, disease			

For more information on how to draw a medical pedigree, visit the National Society of Genetic Counselors website

[www.nsgc.org/consumer/familytree](http://www.nsgc.org/consumer/familytree)

# Genealogy records

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- **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

FORM V.S. NO. 1-A REV. 1-56 FEDERAL BUREAU OF INVESTIGATION U. S. PUBLIC HEALTH SERVICE NATIONAL OFFICE, WASHINGTON, D. C.		COMMONWEALTH OF KENTUCKY DEPARTMENT OF HEALTH		66 30889	
1. PLACE OF DEATH a. COUNTY		c. (Last)		4. DATE OF DEATH (Month) (Day) (Year)	
Rutherford		Rutherford		Nov. 16, 1966	
2. FULL NAME OF HOSPITAL OR INSTITUTION (If not in hospital or institution, give street location)		8. DATE OF BIRTH		9. AGE (In years last birthday)	
Logan County Hospital		Dec. 13, 1879		86	
10. CAUSE OF DEATH PART I, DEATH WAS CAUSED BY: IMMEDIATE CAUSE (a)		MEDICAL CERTIFICATION		ONSET AND DEATH	
Cerebral Kewaschke				10 days	
DUE TO (b) Arteriosclerosis cordis vasculosa				10 days	
DUE TO (c)				10 days	
PART II, OTHER SIGNIFICANT CONDITIONS CONTRIBUTING TO DEATH BUT NOT RELATED TO THE TERMINAL DISEASE CONDITION GIVEN IN PART I (a)				19. WAS AUTOPSY PERFORMED? YES <input type="checkbox"/> NO <input checked="" type="checkbox"/>	
Bronchial pneumonia					
20. ACCIDENT <input type="checkbox"/> SUICIDE <input checked="" type="checkbox"/> HOMICIDE <input type="checkbox"/>		21a. DESCRIBE HOW INJURY OCCURRED (Enter nature of injury in Part I or Part II of item 18.)			
21b. TIME OF INJURY Hour a. m. p. m. Month, Day, Year					
21c. INJURY OCCURRED WHILE AT WORK <input type="checkbox"/> NOT WHILE AT WORK <input checked="" type="checkbox"/>		21d. PLACE OF INJURY (e. g., in or about home, farm, factory, street, office bldg., etc.)		21e. CITY, TOWN, OR LOCATION COUNTY STATE	
24a. BURIAL, CREMATION, REMOVAL (Specify)		24b. DATE		24c. NAME OF CEMETERY OR CREMATORY	
Burial		11/19/66		Dripping Springs Cemetery	
25a. DATE REC'D BY LOCAL REG.		25b. REGISTRAR'S SIGNATURE		25c. FUNERAL DIRECTOR	
1-23-67		Maury Hope Henry		Frank J. Mayfield Russellville Ky.	



# Death certificates

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- **The Family History Library 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

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

# Obituaries

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- **Cause of death may not be included**
- **Look for donations and thank you's**
  - “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)

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## ■ 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

Page	Col	Mag	Op	Sp	Age	Sex	W	H	Other
				Wittich	Christie D.	daughter	F	w	10 S
31	31			Jensen	Hans C.	Head	1	0	M M w 65 M
				—	Anna K.	wife	F	w	44 M
				—	Alvira M.	daughter	F	w	9 S
				—	Ellsworth	son	M	w	3 1/2 S
				Hancock	June K.	Niece	F	w	13 S
32	32			Andersen	Soren P.	Head	1	0	F M w 50 M
				—	Stena	wife	F	w	48 M
				—	Cyrill	son	M	w	20 S
				—	Emma	daughter	F	w	18 S
				—	Edna	daughter	F	w	12 S
				—	Alfonso	son	M	w	5 S
				Kendrick	Myrtle	Niece	F	w	11 S
33	33			Christiansen	John Henry	Head	1	0	M w 34 M
				—	Kentred	wife	F	w	29 M
				—	Harry Henry	son	M	w	10 S
				—	Wesley John	son	M	w	6 S
				—	Rushford	son	M	w	4 1/2 S
				—	Alice	daughter	F	w	12 S

# St. Francis Convent, 1880

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Alloysia Lister	W. F.	27	Boarder	at-home	
Eulhtrasia Lister	W. F.	25	Boarder	at-home	
Alphonse Lister	W. F.	25	Boarder	Teacher	✓
Leontine Lister	W. F.	38		Teacher	✓
Sidora Lister	W. F.	22		Teacher	
Henriet Mary	W. F.	27	Servant		
Dougherty Daniel	W. M.	25	Laborer		
Lahder Herman	W. M.	33	Laborer	Consumption	✓
Wittington Thomas	W. M.	22	Laborer		
Ryan Michael	W. M.	70	Boarder		Consumption
Kühoff Henry	W. M.	39		Tailor	
— Catharine					
— Mary					
— Anna	W. F.	3	Daughter		

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

# Old medical terms

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- **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.htm#Diseases>
  - Parker, Jimmy. “Medical Terminology”, *Genealogical Journal* Vol. 28 No. 3 (2000).



# Assessing your family health history

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- **Step 1: Write down your family health history for 1<sup>st</sup> and 2<sup>nd</sup> degree relatives**
  - Use the worksheet, Health Family Tree, or draw a medical pedigree

# Assessing your family health history

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

# Step 2a

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

# 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)

# Step 2b: Risk categories

## **High Risk**

1. Early disease in a 1<sup>st</sup> degree relative.
2. Early disease in a 2<sup>nd</sup> degree relative (coronary artery disease).
3. Two affected 1<sup>st</sup> degree relatives.
4. One 1<sup>st</sup> degree relative with late or unknown disease onset and an affected 2<sup>nd</sup> degree relative with early disease from the same side of the family.
5. Two affected 2<sup>nd</sup> 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 1<sup>st</sup> degree relative with late or unknown onset of disease.
2. Two 2<sup>nd</sup> 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 2<sup>nd</sup> degree relative from one or both sides of the family.
3. No known family history of disease.
4. Adopted person with unknown family history.

# What is “early onset”?

<u>Disease</u>	<u>Age</u>
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

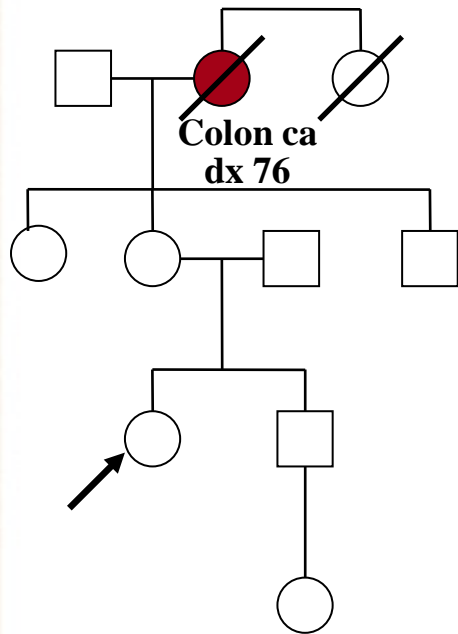


# Step 2b: Risk categories

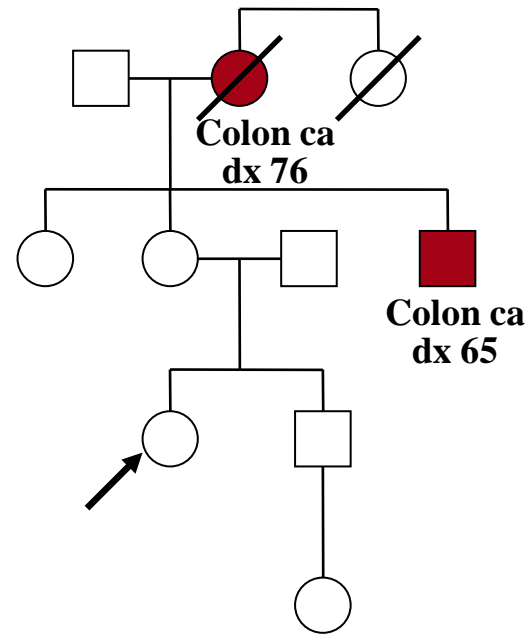
Condition	Risk Level	What risk criteria are met?
Cancer (breast)	Average	#2 Only one affected grandparent from one or both sides of family.
Diabetes	Moderate	#2 One parent with late or unknown onset of disease. (Overweight)
Heart Disease	Moderate – High	#1 Early disease (cholesterol) in parent. #2 Two 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.



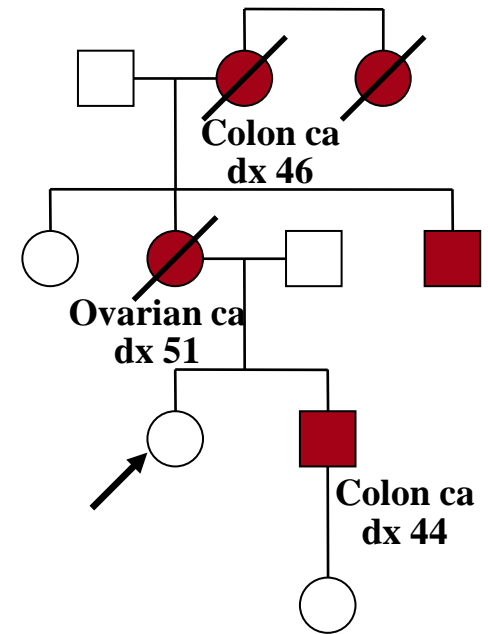
# Assessing your family health history



**Average Risk  
(Sporadic)**



**Moderate Risk  
(Familial)**



**High Risk  
(Hereditary)**

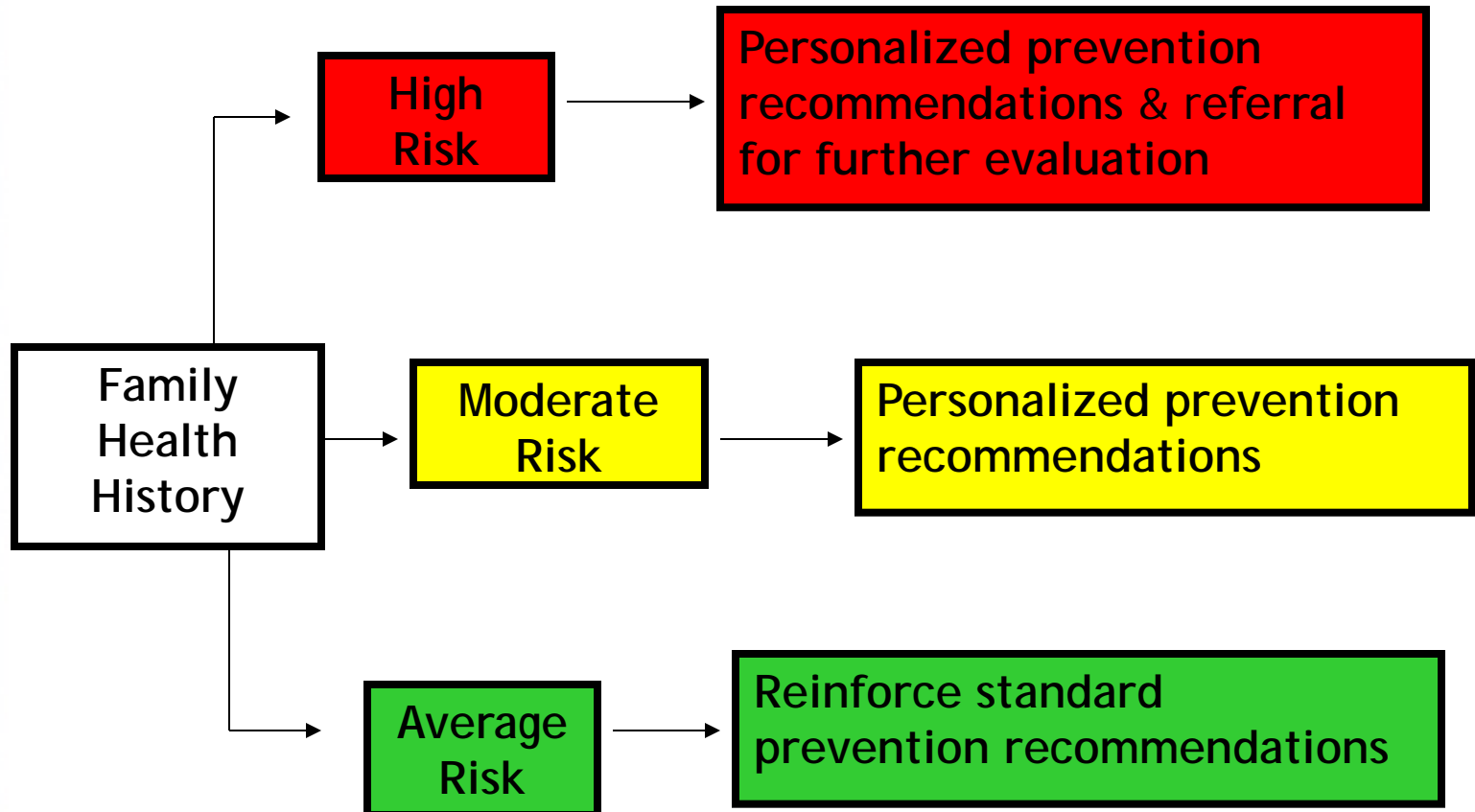
# Assessing your family health history

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

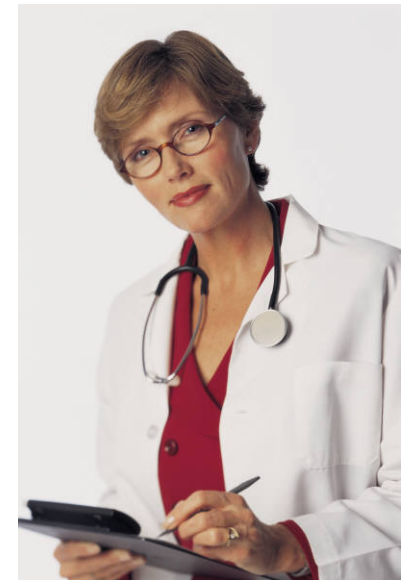
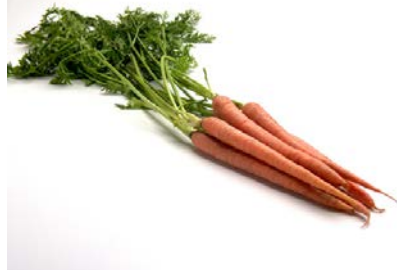


# Assessing your family health history



# 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
  - 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 – websites

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- **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

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- 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).

# Tell us your story!

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- **Contest runs Nov. 1, 2006 – Jan.8, 2007**
- **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)**
- **Entry guidelines available at**  
[www.health.utah.gov/genomics](http://www.health.utah.gov/genomics)