Utah Department of Health

Family Health History Toolkit

MAKE FAMILY HEALTH HISTORY A TRADITION

health.utah.gov/genomics

CONTENTS

Family Health History Toolkit
This toolkit will help you 1) talk about your family health history, 2) write it down, and 3) share it with your doctor and family members.

Inserts
Insert 1: **10 Questions to Ask Your Family**
Insert 2: **Questions and Answers**
Insert 3**: Genealogy Resources**
Insert 4**: When to See a Genetic Counselor**
Insert 5**: Fun Ideas**
Insert 6: **Turkey Talk Health Discussion**

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Make Family Health History a Tradition

Make Family Health History a Family Tradition

Did you know that talking about your family health history could be the most important tradition you make with your family?

Health problems that run in your family can increase your chance of developing the problem. This is because families share their genetics, environment, and habits. These can be passed down in families and affect your health. But by knowing your past you can make choices to protect your future.

The Family Health History Toolkit will help you talk about your family health history, write down what you learn, and then share it with your doctor and family members. Take it to your next family get–together and make family health history a tradition!

TALK ABOUT IT

Family gatherings are a great time to talk about your family health history. Use the toolkit or your own ideas to learn about your family health history. Start by talking to close family members - like parents, brothers and sisters, and children. Then talk to grandparents, aunts and uncles, cousins, and nieces and nephews. Sometimes the senior members of your family know the most about your family history and can be a good person to start with. Things to ask about include:

- Health problems they have had
- Age when their problem started or was diagnosed
- Age and cause of death for family members who have died
- Lifestyle habits
- Ethnic background

Talk to your family

"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.

Start the conversation with your family on National Family History Day – celebrated every Thanksgiving."

– Dr. Richard H. Carmona, MD, MPH, U.S. Surgeon General

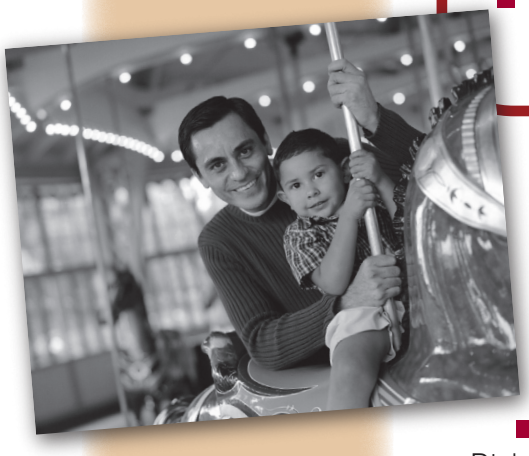
ONE-ON-ONE APPROACH

If some of your family members don't want to talk about your family health history, try talking one–on–one with them. Start with those family members who already have a health problem that runs in your family. Help them make the link between their own health and the rest of your family's health, including younger family members who may not have developed the problem yet. Explain that a family history can increase the chance that other family members may get the same problem. But lifestyle and screening choices can keep you as healthy as possible.

Use the "Talk to your family" box to guide the conversation.

Talk to your family

- I know that you have (for example, diabetes). I learned that diabetes can run in families and that this can increase my risk of getting diabetes, too. Can I ask you some questions about your diabetes?
- When did your diabetes start?
- Do you know if other family members had diabetes? Did they have other health problems?
- How are you managing or treating your diabetes? (For example, medications, lifestyle choices, regular tests, etc.)
- What other choices have you made to stay healthy?



Did you know these health problems run in families?

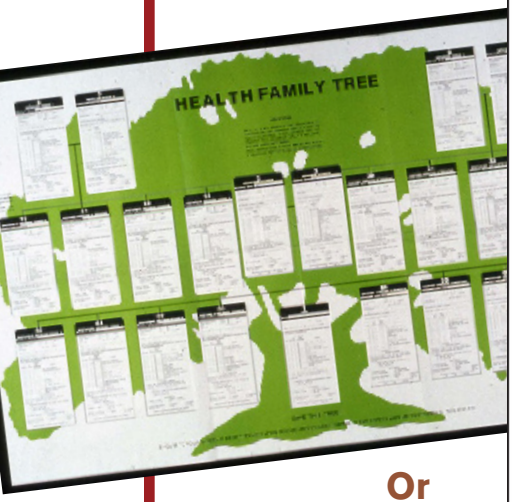
- Alzheimer's disease or dementia
- Arthritis
- Asthma
- Birth defects
- Cancers (breast, colon, lung, prostate, ovarian, and others)
- Diabetes
- Depression
- Heart disease or sudden heart attack
- High blood pressure and high cholesterol
- Pregnancy losses (stillbirths and miscarriages)
- Stroke or blood clots

WRITE IT DOWN

Don't forget what your family talked about – write it down! Use the Health Family Tree to record your family health history. The Health Family Tree was used in high schools for 20 years and helped families learn about their family health history. Or come up your own way of keeping track of what you learn.

There is a box like the one below for each of your family members on the Health Family Tree. Start with the number one box labeled "You" and fill out your health history. Then fill out a box for each of your family members. Try to fill out each box as much as you can. If you don't know if a family member had the health problem, mark "Not Sure". Write down the age when their health problem started; even a guess is better than leaving it blank. And write down any other health problems your family members had even if they aren't listed on the box (for example, depression).

In your toolkit



Or online at health.utah.gov/genomics

1
YOU

Name _____

☐ Male
Year of birth _____ Age _____ ☐ Female

Has he/she ever been told BY A DOCTOR that he/she suffers from any of the following health problems?

YES	NO	NOT SURE	AGE AT FIRST DIAGNOSIS	Condition
☐	☐	☐	_____	Heart Attack (hospitalized)
☐	☐	☐	_____	Coronary bypass surgery
☐	☐	☐	_____	Rheumatic or other heart disease
☐	☐	☐	_____	Stroke
☐	☐	☐	_____	Breast cancer
☐	☐	☐	_____	Colon cancer
☐	☐	☐	_____	Hip fracture
☐	☐	☐	_____	Asthma
☐	☐	☐	_____	Alzheimer's disease
☐	☐	☐	_____	High blood pressure (on medication)
☐	☐	☐	_____	High blood cholesterol
☐	☐	☐	_____	Diabetes

CIGARETTE SMOKING
☐ Smoker: Has smoked cigarettes regularly for at least 1 year
☐ Ex-smoker: Stopped for at least 1 year after smoking regularly
☐ Non-smoker: Never smoked cigarettes regularly
☐ Not Sure

IF SMOKER OR EX-SMOKER mark average amount smoked
☐ Less than 1 pack a day
☐ About 1 pack a day
☐ More than 1 pack a day

USUAL WEIGHT
☐ Slender or average
☐ 50-99 lbs. overweight
☐ 10-49 lbs. overweight
☐ Over 100 lbs. overweight
☐ Not Sure

ALCHOLIC BEVERAGES (beer, wine, liquor)?
☐ Regularly
☐ Never
☐ Sometimes
☐ Former
☐ Not Sure

Vigorous ROUTINE EXERCISE at least 3 times per week?
☐ Yes ☐ No ☐ Not Sure

These other web sites can also help you collect a family health history:

- Health Family Tree www.health.utah.gov/genomics
The online version of the Health Family Tree will give you a report that tells you if you might be at an increased risk for a health problem in your family.

- U.S. Surgeon General Family History Initiative www.hhs.gov/familyhistory

- Centers for Disease Control and Prevention Family History web site www.cdc.gov/genomics/public/famhistMain.htm

- Genetic Alliance www.geneticalliance.org

- National Society of Genetic Counselors www.nsgc.org

SHARE IT WITH YOUR DOCTOR

Now that you have collected your family health history, it's time to share what you learned with your doctor. Use the "Talk to your doctor" box as a guide for sharing your family health history with your doctor.

Talk to your doctor

- Based on my family health history, am I at risk for a health problem?

- What lifestyle changes – like eating a healthy diet, exercising, or not smoking – can I make to lower my risk?

- Are there tests I can take to detect this health problem early?

- Do I need to talk with a genetic counselor or other specialist about my risk or my family members' risk?

You may have an increased risk of getting a health problem if your family has:

- Health problems that occur at an earlier age than expected (10 to 20 years before most people get the problem)

- The same health problem in more than one close family member

- A health problem that does not usually affect a certain gender (For example, breast cancer in a male family member)

- Certain combinations of health problems within a family (For example, breast and ovarian cancer or heart disease and diabetes)

If you are worried about your family health history, talk to your doctor. Your doctor can explain your risk. He or she can also help you make choices about tests to detect problems early. But even for families with an increased risk, steps can be taken to lower the chance of getting the health problem.

Talk to your family

Share your family health history at:

- Family reunions
- Holidays
- Baby blessings or baptisms
- Birthdays
- Family parties and dinners
- Weddings
- Christenings and baptisms

SHARE IT WITH YOUR FAMILY MEMBERS

Share what you learned with your family. Call them or send an email or letter. Help them see how your family's past could affect their future health. But remember to be mindful of family members who may not want to know this information.

Pass on your family health history to future generations by keeping it updated and in a safe place.

LET US KNOW HOW IT WENT

Did your family members enjoy your new tradition? Was this toolkit helpful?

We would love to hear your stories and help other families talk about their family health history.

Send us your family's story by e-mail at genomics@utah.gov or mail it to:
Utah Department of Health Genomics Program
PO Box 142106
Salt Lake City, UT 84114-2106

1

10 Questions to Ask Your Family

1 | What traits seem to run in our family?
(You don't have to ask only about health – start with anything from your family's blue eyes or curly hair to your height and personality – just get your family talking.)

2 | Did my family members have any health problems?

3 | How old were my family members when their health problem started or was diagnosed?

4 | How old were my family members when they died?
(If you don't know exact dates, ask about the approximate age at death.)

5 | What were the reasons they died?
(Note if the cause of death was unknown.)

6 | Were there any pregnancy losses or babies born with birth defects?

7 | Where were my family members born?
(Ethnicity can be a risk factor for some health problems.)

8 | Did any of my family members smoke? If yes, how much and for how long?

9 | What other lifestyle habits did my family members have?
(For example: Did they exercise regularly? Were any overweight or extremely thin? Did any have addictive behaviors?)

10 | What types of allergies did my family members have?
(For example: hay fever, food or medication allergies)

References:
•Daus, Carol. Past Imperfect: How tracing your family medical history can save your life. California: Santa Monica Press, 1999.

•MayoClinic.com. How to compile your family medical history

Questions and Answers

Below are answers to common questions you may have about your family health history.

WHY IS MY FAMILY HEALTH HISTORY IMPORTANT?

Health problems that run in your family can increase your chance of developing the problem. This is because families share their genetics, environment, lifestyles, and habits. But the good news is by knowing your family health history you can make screening and lifestyle choices to lower your risk.

WHAT INFORMATION SHOULD I COLLECT?

Collect information on close family members, like parents, brothers and sisters, and children. Then collect information on your grandparents, aunts and uncles, and cousins. Things that are important to collect include:

- Health problems of family members
- Age when the problem started or was diagnosed
- Age and cause of death
- Lifestyle habits (smoker/nonsmoker, diet, weight, and exercise habits)
- Ethnic background

WHAT HEALTH PROBLEMS RUN IN FAMILIES?

A family health history can help you understand your tendency to get just about any health problem. These health problems can run in families:

- Alzheimer's disease or dementia
- Arthritis
- Asthma
- Birth defects
- Cancer (breast, colon, lung, prostate, ovarian, and other cancers)
- Diabetes
- Depression
- Heart disease or sudden heart attack
- Other heart problems
- High blood pressure and high cholesterol
- Pregnancy losses, stillbirths, and miscarriages
- Stroke or blood clots

HOW DO I KNOW IF I'M AT RISK FOR A HEALTH PROBLEM?

You may have an increased risk of getting a health problem if your family has:

- Health problems that occur at an earlier age than expected (10 to 20 years before most people get the problem)
- The same health problem in more than one close family member
- A health problem that does not usually affect a certain gender (For example, breast cancer in a male family member)
- Certain combinations of health problems within a family (For example, breast and ovarian cancer or heart disease and diabetes)

WHAT IF I DON'T HAVE HEALTH PROBLEMS THAT RUN IN MY FAMILY?

Not having a health problem in your family can be good news. But you could still develop a problem because:

- Your lifestyle, personal health history, and environment affect your risk
- You may be unaware of health problems in family members
- A family member may have died young before even developing a health problem

Make healthy choices no matter what your family health history is.

WHAT IF I'M ADOPTED?

If you are adopted it can be harder to learn about your family health history. But you should still ask your adoptive and birth family about their lifestyle and the places where they have worked or lived. Even though you don't share the same genes, you share habits and environments with your family members. These can also affect your risk of getting a health problem. You may also find health information from birth parents through the National Adoption Clearinghouse.

WHAT SHOULD I DO WITH MY FAMILY HEALTH HISTORY AFTER I'VE COLLECTED IT?

Share your family health history with your family. Pass it on to your children and grandchildren. By sharing this, you can work together to make healthy choices that could save your life. And remember to keep your family health history updated and in a safe place.

COULD MY FAMILY HEALTH HISTORY BE USED TO HARM ME?

Your family health history is treated like any other medical information by your doctor. The HIPAA law protects your private health information, which includes your family health history. In Utah, the Utah Genetic Testing Privacy Act also protects you from discrimination based on your genetics.

Be mindful of other family members' health information and keep it private.

HOW DO I GET STARTED?

Getting started is easy! Simply talk with your family at reunions, holidays, or other family gatherings. Then write down what you learn and share it with your family members and doctor. Use the Family Health History Toolkit to help you collect a family health history.

References

•CDC Office of Genomics and Disease Prevention www.cdc.gov/genomics

•U.S. Surgeon General Family History Initiative www.hhs.gov/familyhistory

•National Society of Genetic Counselors www.nsgc.org

•Daus, Carol. Past Imperfect: How tracing your family medical history can save your life. California: Santa Monica Press, 1999.

Genealogy Resources

INTRODUCTION

Many health problems tend to run in families. Knowing your family's health history can be life-saving and fun too. Living relatives are not only the best source of family health history, they are also the ones who will benefit the most from it.

Following are genealogical resources to help you learn what living relatives may not know about your family health history.

DEATH RECORDS

Death records usually mention the cause and date of death, making them second only to living family members for family health information. These records were originally kept for public health purposes—to alert officials of diseases or trends of concern, especially in cities and populated areas.

City or county officials typically record the death information and forward copies to the state. As a result, there are often both a county and a state copy. There may be differences in the two sets, where photocopiers and computers were not used.

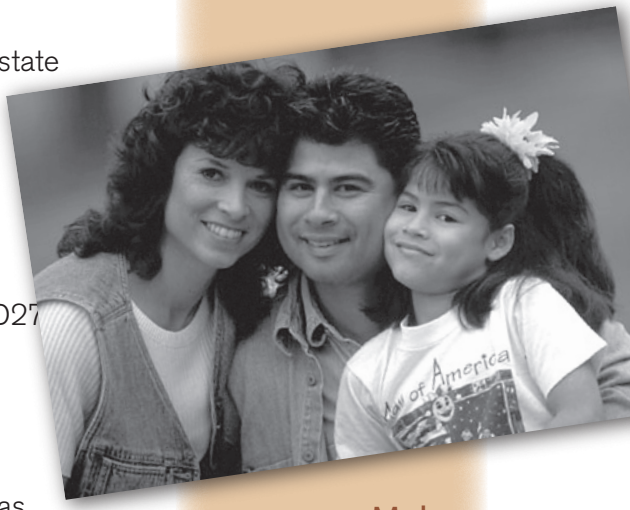
How to obtain death records

First, search an index, if available. An increasing number of statewide indexes are appearing on the Internet. Search (using Google.com, MSN.com, or other search engine) by the name of the state with keywords such as "death index." Indexes may be available at www.Ancestry.com (free at Family History Library), or links to indexes may be found on Cyndi's List at www.cyndislist.com/usvital.htm#States.

Next obtain a copy of the record. Many will be available at the Family History Library (FHL). Do a Place Search in the FHL Catalog for the state and the county levels. Big cities may also have records.

For records not at the FHL, see:

- Find addresses for state vital records offices at www.vitalrec.com and at Cyndi's List, previously cited.
- For records at the county level, use Everton's HandyBook for Genealogists (Logan, UT: Everton Publishers, 1999. FHL book 973 D27



FUNERAL HOME RECORDS

Funeral homes are a wonderful source of family health history. Their records often go back to around 1900, even when ownership has changed. In many states, new owners were required by law to keep the old records.

Funeral homes often assisted in recording the death certificate and obituary. Therefore, these records may have even more detail about the cause of death. Funeral programs will name relatives who participated and whose health information may also be important to your family.

How to obtain funeral home records

Use a directory:

- Online: www.funeralnet.com
- Book: National Yellow Book of Funeral Directors (Youngstown, Ohio: Nomis Publications. FHL book 973 U24y.) This book is arranged by state, then by town. It gives addresses, phone numbers, and other information about the funeral homes. Funeral directors near you should also have it.

Phone them, state what you need, and ask when you can call back. Writing takes more of their time and you have to wait longer. Please treat them like the "golden goose" they are.

OBITUARIES

In the late 1800s, newspapers began to publish obituaries on a regular basis. Even today, it is one of the most popular sections. The cause of death was often included in earlier years, but may be masked or omitted altogether now.

How to obtain obituaries

- Many obituaries within the last 10 years or so can be found online. A search for "Obituaries" will find several sites.
- Contact public libraries in the area. If they have copies, they may search for a small fee.
- Most states have made an effort to obtain old newspapers. Try state archives, libraries, or major universities.

UNITED STATES CENSUSES

Health clues from censuses, 1850–1930

Beginning in 1850, censuses started giving information about every person in each household. Each census has health clues to notice, such as:

- The age of the mother. Children born to older women may have health issues.
- A parent or child may have died. Death was more common than divorce until recently. Young deaths were often due to accidents, health issues, or genetics.
- You may find a single-parent family, one parent with a different spouse, large gaps between children, and nieces, nephews, and grandchildren living with them.
- The occupation could affect health. For example, hatters worked with chemicals that affected the brain, thus the term "mad hatter."

Health clues from specific censuses

- 1850-1880 Mortality Schedules give the date and cause of death.
- 1850-1880, and 1910 indicate if a person was blind,

deaf, or mute.

- 1900-1930 censuses on www.Ancestry.com allow you to search by relationships such as "patient" and "inmate" to find residents of hospitals, orphanages, and other institutions.

How to obtain census records

- 1850-1930: Use www.Ancestry.com at the Family History Library or at a Family History Center with an Internet connection. These locations have all census images and every name indexes to most years.

In Utah, most public libraries have a subscription to ProQuest's Heritage-QuestOnline, which has all the census images and head-of-family indexes to several census years.

Microfilms of censuses and head-of-family indexes for many years are available at the Family History Library. 1940–present: These censuses have not been released to the public. Since proof of death is a requirement for obtaining census information on your direct line (parent, grandparent), you will already have more health information than the census will offer.

OTHER RESOURCES

Family items such as journals, religious records—even old prescription bottles—have clues to your family health history. Other records include hospitals, medical professionals, pensions, schools, passports, insurance forms, immigration, old newspaper articles (accidents or local health concerns), military, and occupational records. The list can go on and on. Check at the reference counters for ideas on how to find some of these records.

SUMMARY

Living family members are the best source for collecting your family health history. They are also the ones who will benefit the most from your work. We're already looking at these records for family history. Why not collect your family' health history as well? It may save the life of a child or grandchild. Your family health history is your gift to the future.

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50 East North Temple Street
Salt Lake City, UT 84150-3400 USA

When to See a Genetic Counselor

You may be worried about your family health history. Most people do not have a high risk for a health problem based on their family health history. But some families may need to talk with a genetic counselor or other trained specialist about their family health history. Genetic tests may also be an option. You should always talk to your doctor before getting any tests.

WHO SHOULD TALK TO A GENETIC COUNSELOR?

You may need to talk to your doctor or a genetic counselor if your family has:

- Health problems that occur at an earlier age than expected (10 to 20 years before most people get the disease)
- The same health problem in more than one close family member
- A health problem that does not usually affect a certain gender (for example, breast cancer in a male family member)
- Certain combinations of health problems within a family (for example, breast and ovarian cancer or heart disease and diabetes)
- Birth defects, growth or development problems, pregnancy concerns, and other known genetic conditions in the family

WHAT WILL I LEARN FROM A GENETIC COUNSELOR?

A genetic counselor will help you:

- Assess your risk for a health problem that runs in your family
- Diagnose a health problem and causes of it
- Decide if genetic testing is an option
- Tell you about treatment or management of the problem
- Refer you to support groups and resources

WHERE CAN I LEARN MORE?

Huntsman Cancer Institute, www.huntsmancancer.org
- To schedule an appointment with a genetic counselor, call 801-587-9555
- For other questions, call 801-585-0100 or toll-free 866-275-0243

Intermountain Health Care, Clinical Genetics Institute
- To talk with a genetic specialist, call 801-408-5014

University of Utah Hospital
- To schedule an appointment with a genetic counselor, call 801-581-7825

March of Dimes, www.marchofdimes.com

Fun Ideas

Try these fun ideas to get your family talking about your family health history.

- Bring as much family health history as you can to your next family gathering. This will jump-start a conversation. Then ask other family members to help you find missing pieces of information.

- Write a chapter on your family health history in your personal history.

- Instead of using a tablecloth, use sheets of butcher paper to cover the table and put crayons out for everyone to color with. Write down what you know about your family health history on the paper and then share what you wrote.

- Bring a copy of your family health history to your summer family reunion. Or plan time during your summer reunion to talk about your family health history.

- Take a child or grandchild to your Family History Center to research your family health history. To find a center near you visit, www.familysearch.org.

- Collect your family health history and give it as a Christmas or birthday gift.

- Pick a family member to be your "health buddy." Then work together to learn more about your family health history.

- Add a section on family health history to your family newsletter.

- Add your family health history to your baby's keepsake book. Or if you have a new grandchild, give a copy of your family health history to his or her parents.

- Write a letter or send an e-mail to your family telling them how important you think knowing your family health history is.

- Turn family health history into a youth project for school or church. It may even count toward earning Boy Scout and Girl Scout merit badges and other awards.

- Have a recipe contest to turn family recipes into healthy treats and use this activity to share stories about your family, including your family health history.

Turkey Talk Health Discussion

If you have time – and think your family would be open to a short talk – think about having a "Turkey Talk" health discussion at your next family dinner. The "Turkey Talk" will tell your family why a family health history is important, how to collect one, and what to do with it.

Here's how the "Turkey Talk" works: Use the "Talk to your family" boxes to guide the conversation. Feel free to use your own words so your family feels comfortable. Get everyone to join in but be mindful of family members who may not want to talk about their family health history.

1| INTRODUCE THE "TURKEY TALK"

Start by telling your family why you think knowing your family health history is important. Explain that health problems, like cancer, diabetes, and heart disease, can run in families. Having a family history of these may increase your risk of getting them too.

Talk to your family

- Why should we know our family health history?
- Because having a family history of a health problem is common – almost everyone has a family history of something.
- Because it is likely that some of us are at risk. Some of us may know it, and others may not.
- Because collecting a family health history can be fun.
- And because there's good news – knowing your family health history could save your life. Even if a health problem runs in our family, we can make healthy choices to lower our chance of getting it.

2| TALK ABOUT RISK FACTORS

Family health history is more than just genetics. Families also share their lifestyles, habits and environment. These are called risk factors because they can affect your risk of having a health problem. Having a family history of something is also a risk factor. What do your family members know about these risk factors?

Give family members a chance to offer ideas You're likely to get a lot of answers. Explain that risk factors like diet, weight, exercise and smoking can affect risk. For example, if you have a family history of diabetes, are overweight, and don't exercise, your risk is even greater than someone who doesn't have these risk factors.

Talk to your family

- What health problems tend to run in our family?

- What other risk factors do we have that may increase our chance of getting these problems?

- Smoking, eating an unhealthy diet, being overweight, and not getting enough exercise are risk factors of health problems. A family history also increases a person's chance of getting a problem.

- But the good news is, even if we have a family history of something, we can learn from out past and protect our future. Eating a healthy diet, exercising, maintaining a healthy weight, and not smoking are ways that we can each stay healthy.

- We can't change our genes but we can make healthy choices to lower our risk for health problems in our family.

3| TALK ABOUT HOW TO COLLECT A FAMILY HEALTH HISTORY

Now that your family knows why you want to learn about your family health history, it's time to collect one. Remind your family that this will be useful for them personally as well as for younger family members.

To get started, ask your family to tell you a story about one of your family members, maybe a grandparent. Ask about where they worked and lived or what they looked like – anything to get your family talking. Then ask if this person had any health problems. Use the "10 Questions to Ask Your Family" to guide your questions.

4| TALK ABOUT WHAT TO DO IF YOU ARE WORRIED ABOUT YOUR RISK

A family may have a high risk of developing a health problem because several of their family members had the problem at a young age. These families should talk to their doctor or a genetic counselor to learn what they can do to prevent or delay the problem. Genetic testing may be helpful in some cases. But even for families with an increased risk, steps can be taken to lower the chance of getting the health problem.

Talk to your family

- So, what can we do if we are worried about our family health history?

- Talk to our doctor. Our doctor can tell us what our risk may be for a health problem, based on our family health history and other risk factors we talked about. Our doctor can also tell us about lifestyle choices and screening tests that can lower our chances of having a problem.

5| ASK FAMILY MEMBERS TO LOOK OUT FOR EACH OTHER

Here are two ideas to follow up with family members who may have a tendency to develop a health problem based on your family health history:

- Give family members a call, e-mail, letter, or visit some time over the next three months to talk to them about your family health history. A friendly reminder gives you and your family a chance to talk about your family health history and ways to stay healthy.

- Have family members pick a "health buddy" they feel comfortable talking to. Ask health buddies to talk about what they have learned from their family health history. If your family didn't know a lot about your family health history, ask health buddies to find out more. Health buddies can also encourage each other to talk to their doctor about what they can do to stay healthy.

6| END THE TURKEY TALK

Thank your family for their help. Remind them again why you feel knowing your family health history is important and ask your family to keep making family heath history a tradition.

Visit www.health.utah.gov/genomics or call the Health Resource Line at 1-888-222-2542 to get free copies of this toolkit for your family members.

PROJECT PARTNERS

Utah Department of Health
LDS Family History Library
Intermountain Health Care, Clinical Genetics Institute
Salt Lake County Aging Services, Healthy Aging Program
Huntsman Cancer Institute
Utah Genealogical Association
Heirlines Family History and Genealogy
Spencer S. Eccles Health Sciences Library
American Heart Association
Utah's Local Health Departments

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Family Health History Toolkit

health.utah.gov/ genomics

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