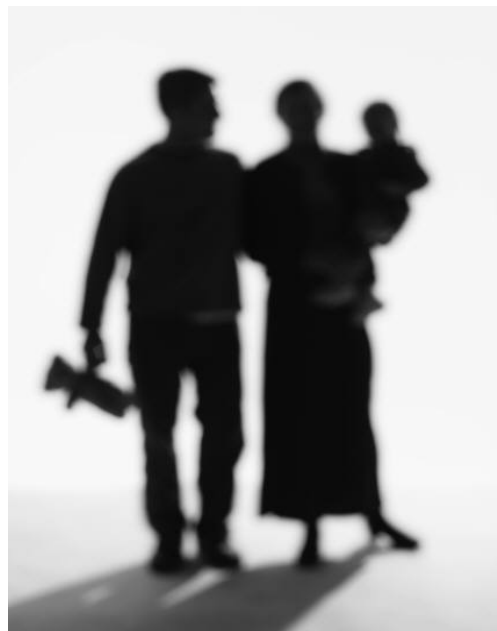


Family Health History Toolkit

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MAKE FAMILY HEALTH HISTORY A TRADITION



Heartland Regional Genetics and Newborn Screening Collaborative

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. Families share their genetics, environment, and habits. These can be passed down in families and affect your health. By knowing your family's past, you can make choices to protect your future.

This 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 other family members. Take it to your next family gathering and make family health history a tradition!

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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 member of your family knows 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 and country of origin

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ONE-ON-ONE APPROACH

If your family members don't want to talk about your family health history together, try talking one-on-one with relatives. 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 having a family history can increase the chance that other family members may get the same problem. But lifestyle

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TALK TO YOUR FAMILY

Use these suggestions as a guide:

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)?

**“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.”**

Richard H. Carmona, MD, MPH
US Surgeon General

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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, Bipolar disease, Schizophrenia
- Heart disease or sudden heart attack
- High blood pressure and high cholesterol
- Pregnancy losses (stillbirths and miscarriages)
- Stroke or blood clots

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WRITE IT DOWN

Don't forget what your family talked about - write it down! Use the US Surgeon General's Family Health History toolkit "My Family Health Portrait" to record your family health history included in this guide. Or come up your own way of keeping track of what you learn.

Start with the 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.



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WEBSITES

These websites can help you collect a family health history:

- Health Family Tree : www.heartlandfamilyhistory.org. 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

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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 questions listed below as a guide for sharing your family health history with 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? Or about a genetic test that would clarify my risk?

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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.

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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.



Share your family health history at:

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



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10 Questions to Ask Your Family

- 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.)
- Did our family members have any health problems?
- How old were our family members when their health problem started or were diagnosed?
- How old were our family members when they died?
(If you don't know exact dates, ask about the approximate age at death.)
- What were the reasons they died?
(Note if the cause of death was unknown.)
- Were there any pregnancy losses or babies born with birth defects?
- Where were our family members born?
(Ethnicity can be a risk factor for some health problems.)
- Did any of our family members smoke? If yes, how much and for how long?
- What other lifestyle habits did our family members have?
(For example: Did they exercise regularly? Were any overweight or extremely thin? Did any have addictive behaviors?)
- What types of allergies did our family members have?
(For example: hay fever, food or medication allergies)

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References: Carol Daus, Past Imperfect: How tracing your family medical history can save your life. California: Santa Monica.
Mayoclinic.com How to compile your family medical history.

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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 similar problems. Families share their genetics, environment, lifestyles, and habits. The good news is, by knowing your family health history, you can make screening and lifestyle choices to lower your risk or detect problems earlier.

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, 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 (tobacco use, 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, Bipolar, Seizures, Schizophrenia
- Heart disease or sudden heart attack
- Other heart problems
- High blood pressure and high cholesterol
- Pregnancy losses, stillbirths, and miscarriages
- Stroke or blood clots

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Question and Answers – Continued

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)

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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 own 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 hard 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 do not 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.

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Question and Answers – Continued

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. 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.



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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 as a source of 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) or your local library. Do a Place Search in the FHL Catalog for the state and the county levels. Big cities may also have records.

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Genealogy Resources

For records not at the FHL

- Find addresses for state vital records offices at www.vitalrec.com and at Cyndi's List www.cyndislist.com/usvital.htm#States.
- For records at the county level, use Everton's HandyBook for Genealogists (Logan, UT: Everton Publishers, 1999. FHL book 973)

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 the 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.

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Genealogy Resources

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, a hatter 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.

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Genealogy Resources

How to obtain census records

1850-1930: Use www.Ancestry.com. These websites have all census images and every name indexes to most years.

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 or your local public 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. 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. Why not collect your family's health history as well? It may save the life of a child or grandchild. Your family health history is your gift to the future.

Copyrights and Permissions Coordinator, Family and Church History Department
50 East North Temple Street
Salt Lake City, UT 84150-3400 USA

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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?

www.heartlandfamilyhistory.org

Call your local state genetics coordinator listed in this guide.

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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. Working together provides a great wealth of information. It can also be lots of fun!
- Instead of using a tablecloth, use sheets of butcher paper to cover the table and put crayons out for everyone to color. Write down what you know about your family health history on the paper and then share what you wrote. If you do not want to read out loud, play musical chairs by moving to each person's section and reading their information.
- Bring a copy of your family health history to your summer family reunion. Plan time during your summer reunion to talk about your family health history.
- Take a child or grandchild to your Family History Center or local public library 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 holiday 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.
- Put a copy of your family health history in your baby's keepsake book. Or if you have a new grandchild, give a copy of your family health history to new parents.

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Fun Ideas – Continued

- Write a letter or send an e-mail to your family telling them how important you think knowing your family health history is and encourage them to make one of their own.
- Make a family scrapbook. Place a picture of every family member inside. Have little pieces of scrapbook paper available so that others can add their favorite stories along with any information they know regarding the person's health history.
- 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. Combine the recipes in a family cookbook.
- Make a family scrapbook. Place a picture of every family member inside. Have little pieces of scrapbook paper available so that others can add their favorite stories along with any information they know regarding the person's health history.
- At Thanksgiving, instead of selecting a family member to buy a gift for, you can select a family member to learn about. Put names of family members in a hat. Then each person has the task of learning more about the person they draw. At year end holiday, bring the information to the family event and share.
- At holidays, make an ornament for each family member. Use clear holiday bulbs and decorate their name in glitter paint or craft markers. Cut up little stripes of colored paper . Each person can add stories about the family member as well as any known health information. Curl the papers and put them inside the bulb. When you are taking down the tree, remember to make a list of all the information and add something new about each person every year.

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Fun Ideas – Continued

- Make a family website or blog! Lots of families today are long distance; therefore using the Internet is a great way to stay in touch. You can share family photos, favorite recipes, funny stories, and your family tree research. You can make it interactive by selecting a family member each week or month to highlight. Everyone can compile and post his or her stories and information about that person.
- Make a genealogy calendar. Use your computer to compile photos and make a calendar. There are free templates and ideas on the Web. Use current family photos or commemorate your ancestors with old photos. Include sections with a list of their favorite things, their health history, and family member's favorite memories about the person. Enlist other family members to provide their input on things to include.
- Decorate your newborn's nursery with an outdoor scene. Paint a large tree on the wall. Use green chalkboards and make a family tree. When family members come over, have them write their information on the board as well as known information about other family members, including health history. This will help the family history come to life!
- Make a time capsule. Include all the information you discover regarding your family health history along with items that represent each person. Place in a capsule for future generations!
- Teach your children to be detectives. Make it an ongoing game to learn information about their family. They can find artifacts of loved ones that tell stories they may have otherwise been lost to the past. There are lots of resources to help your child learn how to uncover the excitement of their ancestors.

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Fun Ideas – Continued

- Talk with your child's teacher about family health histories and encourage them to do a lesson on how to learn about their heritage for Grandparents Week. This will not only encourage your family to do some searching, but will help other families learn the importance of a family health history.
- Go on a scavenger hunt. Look through your attic full of family heirlooms. See if there is any information regarding lifestyles or health histories related to the items you find. Taking a journey to the past can help trigger lots of memories!

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Turkey Talk

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” guide to start 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.

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 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 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.

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Turkey Talk – Continued

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.

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.

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.

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 health history a tradition.

1-888-881-8852 to get free copies of this toolkit for your family members.

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Turkey Talk – Talk to Your Family Guide

- 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.
- 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 our 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.

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.

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For more information about Family Health History Activities in your State:

Arkansas:

State Genetics Coordinator
Jackie Whitfield, RN
AR Dept. of Health and Human Services
4315 W. Markham St
Little Rock, AR 72203-1437
Tel: (501) 280-4756
Fax: (501) 280-4082
Email: Jackie.Whitfield@arkansas.gov

Kansas:

State Genetics Coordinator
Linda Kenney, MPH
Kansas Department of Health and
Environment
Bureau of Children, Youth & Families
Children's Developmental Services
1000 S.W. Jackson, Suite 220
Topeka, KS 66612-1274
Tel: (785) 296-1310
Email: lkenney@kdhe.state.ks.us

Nebraska:

State Genetics Coordinator
Julie Miller, BS
Nebraska State Health Dept.
P.O. Box 95044
Lincoln, NE 68509-5044
Tel: (402) 471-9731
Fax: (402) 471-7049
Email: julie.miller@dhhs.ne.gov

Oklahoma:

State Genetics Coordinator
Pam King, MPA, RN
Oklahoma State Department of Health
1000 NE. 10th St. #709
Oklahoma City, OK 73117-1299
Tel: (405) 271-9444 ext 56737
Fax: (405) 271-4892
Email: pamk@health.ok.gov

Iowa:

State Genetics Coordinator
Kim Piper, RNC, BSN
Iowa Dept of Public Health
321 E 12th Street
Des Moines, Iowa 50319-0075
Tel: (515) 281-6466
Fax: (515) 242-6384
Email: kpiper@idph.state.ia.us

Missouri:

State Genetics Coordinator
Sharmini Rogers, MBBS, MPH
Missouri Dept of Health & Senior Services
Bureau of Genetics and Healthy Childhood
930 Wildwood Dr, PO Box 570
Jefferson City, MO 65109
Tel: (573) 751-6266
Fax: (573) 751-6185
Email: sharmini.rogers@dhss.mo.gov

North Dakota:

State Genetics Coordinator
Mary Riske, RN, MS
University of North Dakota
Department of Pediatrics and Medical Genetics
Room 5910
501 N Columbia Rd Stop 9037
Grand Forks, ND 58202-9037
Tel: (701) 777-4277
Email: mriske@medicine.nodak.edu

South Dakota:

State Genetics Coordinator (vacant)
Contact: Lucy Fossen
South Dakota Dept. Health
615 East Fourth Street
Pierre, SD 57501-1700
Tel: (605)-773-2944
Fax: (605)-773-5942
Email: lucy.fossen@state.sd.us



**FOR MORE INFORMATION
PLEASE CONTACT**

1-888-881-8852

WWW.HEARTLANDFAMILYHISTORY.ORG

The Heartland Regional Genetics and Newborn Screening Collaborative (HRGNSC) would like to thank the Utah Department of Health for their assistance and for the use of the Family Health History toolkit. The HRGNSC would also like to thank the members of the HRGNSC education subcommittee for reviewing, editing and formatting this toolkit.

Supported in part by grant U22 MC03962 from the Health Resources Services Administration, Genetic Services Branch, Heartland Regional Genetics and Newborn Screening Collaborative.