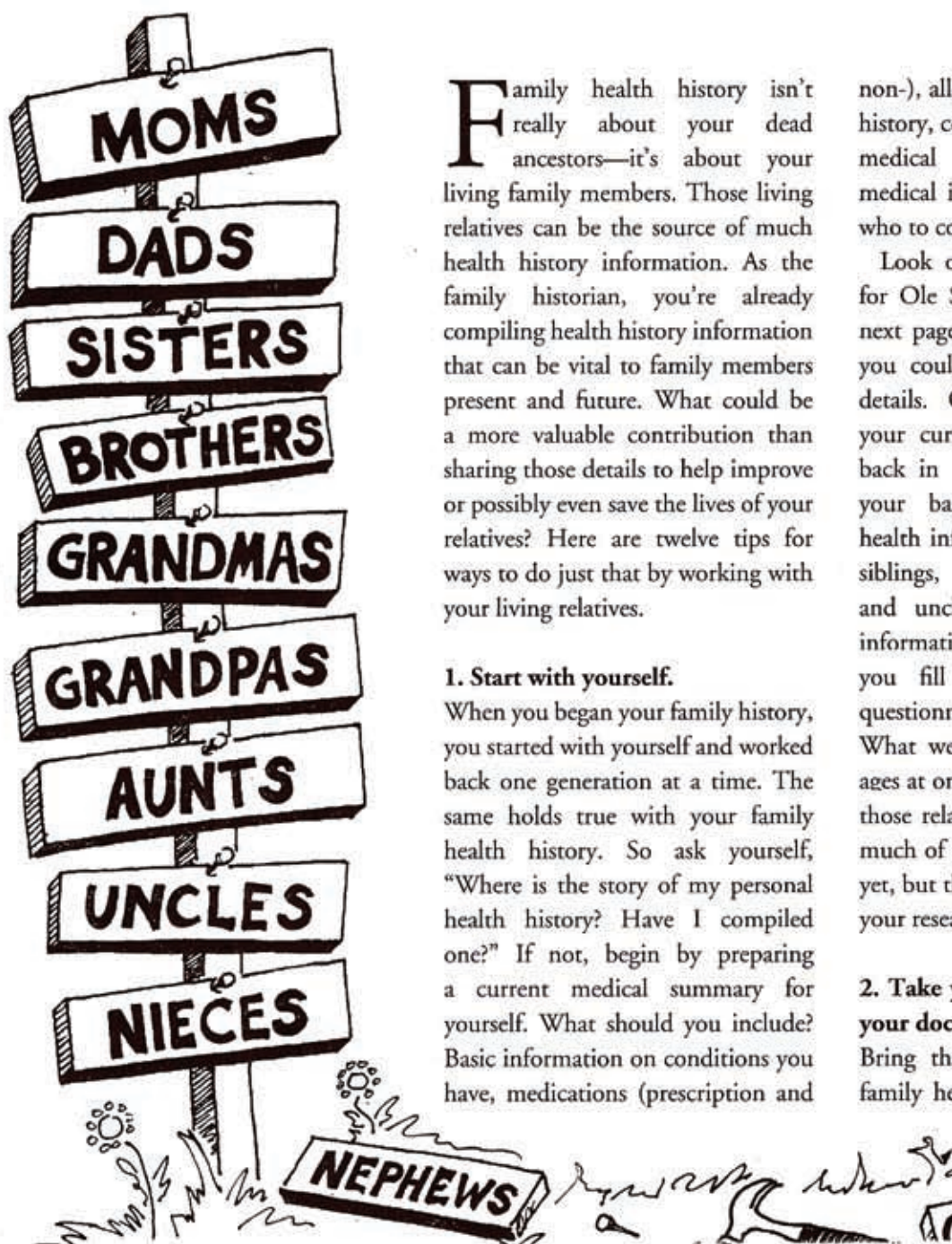


Easy Medical Summaries

Putting your family into family health history



Family health history isn't really about your dead ancestors—it's about your living family members. Those living relatives can be the source of much health history information. As the family historian, you're already compiling health history information that can be vital to family members present and future. What could be a more valuable contribution than sharing those details to help improve or possibly even save the lives of your relatives? Here are twelve tips for ways to do just that by working with your living relatives.

1. Start with yourself.

When you began your family history, you started with yourself and worked back one generation at a time. The same holds true with your family health history. So ask yourself, "Where is the story of my personal health history? Have I compiled one?" If not, begin by preparing a current medical summary for yourself. What should you include? Basic information on conditions you have, medications (prescription and

non-), allergies, surgical and hospital history, contact information for your medical providers and pharmacy, medical insurance information, and who to contact in an emergency.

Look over the medical summary for Ole Smirnoff Bernatelli on the next page. It's one example of how you could organize some of these details. Once you've summarized your current medical status, work back in time just as you do with your basic family history. Add health information on your parents, siblings, grandparents, and aunts and uncles. Include the kind of information that's requested when you fill out a medical history questionnaire at the doctor's office. What were the significant diseases, ages at onset, and causes of death for those relatives? You might not have much of that information assembled yet, but that can be another goal of your research.

2. Take your medical summary to your doctor.

Bring that compiled personal and family health information along on

**MEDICAL SUMMARY FOR
OLE SMIRNOFF BERNATELLI**

Updated as of 29 September 2004

Home address: 1154 East 378 South 215 West 7643 North, Trailer #3, Salt Lake City, UT 84101
Phone (day and evening): 007-598-0167
Email: <olesgenealogicals@juno.com>

White male. Age: 107. (d.o.b. 17 Oct 1897.) Height 5'3". Weight 125 lbs. Blood type A positive.
Non-smoker. Drinks one glass of red wine daily, seven or eight times. Consumes no other alcohol.

MEDICATION ALLERGIES: Allergic to penicillin and needles.

DIAGNOSED WITH

- Hypertension. (Diagnosed 1987) Well controlled with ACE inhibitor (Lisinopril).
- Attention Deficit Disorder. (Diagnosed by doctors in August 1999. Diagnosed by mother in 1993. Treated with Dexedrine starting August 1999.
- Depression. Reactive depression diagnosed November 2000. Currently being treated with Celexa.

CURRENT PRESCRIPTION MEDICATIONS

1. Celexa (Citalopram). 60 mg. once daily. A selective serotonin reuptake inhibitor. for depression.
2. Dexedrine (Dextroamphetamine). 10 mg. twice daily. A CNS stimulant for ADD.
3. Lisinopril. 20 mg. once daily. An angiotensin converting enzyme (ACE) inhibitor. for hypertension.
4. Viagra. 100 mg, taken as needed, usually 2-3 times per day.

CURRENT NON-PRESCRIPTION MEDICATIONS:

1. Acetaminophen. 650 mg caplets, taken occasionally as needed for arthritic joint or back pain.

SURGICAL AND HOSPITAL HISTORY

- 1913: Three fingers and four toes amputated after wounds during the Latvian Fishing Boat Captivity.
1993: Repair of Inguinal Hernia at Riverside Hospital in Salt Lake City.
2001: Removal of basil cell carcinoma from face.

FAMILY HEALTH HISTORY

Mother: Breast cancer at age 77, hypertension at age 86. Institutionalized with the widows at age 87. Still alive, age unknown, but assumed to be older than Ole. Father: Kidnapped at age 6 and never heard from again. Siblings: None. Maternal grandparents: Grandfather died at sea, grandmother died from a snake bite at age 113. Paternal grandparents: Both died in their fifties from apparent heart disease.

OLE'S CURRENT PHYSICIANS

NOTE: After Hours Emergency numbers for these doctors is: 007-339-3663. All are affiliated with and located at the Healthy Seniors Medical Center, 2601 Lost Dog Road, Salt Lake City, UT 84101.

DR. WANDA BRADLEY: Ole's primary care physician since 1985. Internal Medicine Dept. Phone: 007-641-3194.

DR. NORMA BRADLEY: Ole's psychiatrist since 1997. Psychiatry Dept. Phone: 007-641-3333.

IN EMERGENCY NOTIFY

1. A doctor. (What good is anyone else going to be in an emergency?)
2. My mother, Olga Little Feather Bernatelli. Phone: 007-341-2567. (She's pretty hard of hearing, so ask for her nurse.)
3. Tony Burroughs (Ole's cousin on our Italian side.) Phone: 007-544-6748.

any doctor appointment. Use it to answer questions. Show it to your doctor. Ask what other information might be useful if added to your summary. When your appointment is over, update the summary sheet while the conversation with your doctor is still fresh in your mind. You could include a section noting dates of doctor appointments, past and scheduled. If you've forgotten or are confused about any specifics after the appointment, call the doctor's office back. Either talk to the doctor again or ask a staff member to look up the information in your medical record.

While you're at the doctor's office, ask for a blank health history questionnaire. That may help you focus on the kind of additional information to search for. Take it home to fill out, and then return the completed form to your doctor. Taking the time to carefully complete the form at home, where you can look up specific information, will help make it as accurate and complete as possible. That's much better than having a health history in your file at the doctor's office that was completed as best as you could remember in the ten minutes before your doctor appointment!

Kim Feldman had compiled basic family health history information and took it to a doctor appointment. When her doctor saw her family health history chart with cause of death for her parents (heart), grandparents (heart), and aunts and uncles as heart, heart, heart, heart..., he immediately scheduled her for tests. Because Kim was not seriously symptomatic, he said he probably would not have done that had it not been for that health history

information. The tests showed that she, too, had a serious condition, and she might not be here today were it not for the bypass surgery she had just a couple of days later.

3. On the other hand ...

A story like Kim Feldman's brings home how critical that health history can be, but it's not all life and death. Many of the conditions you'll find in your health history research pose long-term risks and are things that individuals can take simple steps to prevent or delay. One of the most important things you can do by sharing health history with others is to reinforce the good sense information we're all bombarded with regularly. A family history of heart disease, diabetes, or cancer doesn't mean that all descendants will eventually develop that condition. But all those family members definitely can take sensible lifestyle steps to prevent or delay such a condition.

We all hear warnings and instructions about diet, exercise, stress, and proper medical care on the news almost daily. Don't expect your family health information will suddenly make every family member adopt a new healthy lifestyle. You can't live people's lives for them. But do hope that by sharing the health history facts of your own genetic line, some family members will find the necessary motivation to put those common-sense risk-reducers to work. They can decide to take the important steps to reduce health risks, including eating right and exercising regularly. They can also get the routine medical care necessary to prevent or postpone specific conditions that run in the family.

4. You don't have to go "way back."

Some genetic conditions can be clearly identified many generations back. But in most cases, by going back three generations you'll find most of the useable health history information that's available. The reasons are simple: earlier than that, both record-keeping and the degree of specific medical knowledge were limited. So it's not necessary to have researched back more than a couple of generations to start putting useable health history to work. It's important, however, to work "out" from your direct line. Information on your parent's and grandparent's siblings and their descendants is significant in building a useable family health history.

5. Get details from the death records.

Death certificates can provide important clues and details. Keep in mind that the "cause of death" listed needs to be interpreted. The stated cause may have been a complication of an underlying disease or condition. The meaning of many medical terms was much less specific eighty years ago than it is today. (Back then, that cause of death may have been just an educated guess by the doctor, too.)

Other family members may have copies of death certificates for parents, grandparents, aunts, uncles, or cousins. If not, try to obtain them for as many people in the most recent generations as possible. One source for death records is the microfilmed records collection of the Family History Library in Salt Lake City. The collection doesn't include death records from all states or counties.

Those that are filmed usually go only as far forward as the early twentieth century. But the filmed records can be an inexpensive option to ordering death certificates from the county courthouse or the state.

In some instances, death indexes and even digitized images of actual death certificates are starting to become available online. For links to such sites, start with Cyndi's List, <www.cyndislist.com/deaths>. Also go to the U.S. GenWeb Project site, <www.usgenweb.org>, and check the state sites of your interest. A guide to pinpointing sites with digitized or transcribed records is Rick Crume's *Plugging Into Your Past: How to Find Real Family History Records Online* (Cincinnati: Family Tree Books, 2004).

6. Family stories are important.

The available records may hold few significant medical details on your family. Even if they do, it's important to talk to family members. They'll most likely have more health history information than you'll find anywhere else. Gather their stories about the aunts, uncles, cousins, and grandparents. Ask for physical descriptions and their memories of those family members' actions, speech, travels, health, sickness, and problems. See who may have photos, old letters, or newspaper clippings that could contain information about illnesses or diseases. Make sure you talk to all the cousins. (Sometimes everyone in the family knew all about Uncle Arthur's "condition" except his descendants.) The clues that come from these family stories may point you to other sources of information for more details.

For additional information, these are useful resources:

"Concerns for the Family Health Historian" by Thomas H. Roderick, Ph.D. and Darlene McNaughton, CCRA. A "Viewpoints" piece in *National Genealogical Society Quarterly* 85 (June 1997): 120-125.

The Family Health and Heredity Committee page on the NGS web site <www.ngegenealogy.org/comfamhealth.htm>

Genetic Connections: A Guide to Documenting Your Individual and Family Health History by Danette Nelson-Anderson. (Washington, Mo.: Sonters Publishing, 1997.)

Geneweaver is a software program designed by genealogists Elizabeth Kelley Kerstens and Norma Storrs Keating for compiling and sharing family health history information. See information on the program Geneweaver Web site, <www.geneweaveronline.com> (Plymouth, Mich.: Genes & Things, 2001.)

"Heredity and Health: Basic Issues for the Genealogist" by William B. Saxbe, M.D. A "Viewpoint" piece in *National Genealogical Society Quarterly* 82 (June 1994): 127-133.

"How to be a Family Health Historian" by Anita A. Lustenberger. *National Genealogical Society Quarterly* 82 (June 1994): 85-96.

Past Imperfect: How Tracing Your Family Medical History Can Save Your Life by Carol Daus and Jeanne Homer. (Santa Monica, Calif.: Santa Monica Press, 1991.)

7. Enlist the cooperation of the young mothers on your family tree.

Not all your relatives are necessarily eager to share family history information with you, much less health details on their family. Sometimes it's helpful to find an ally in each branch of the family who can try to gather information. Mothers with small children may appreciate better than anyone the importance of your family health history efforts. Try to enlist the help of Uncle Arthur's granddaughter. He wouldn't open up to you, but she can visit him with his

new great-grandson and try to coax him into talking about his parents and the brothers who died young.

You could provide other family members with photos that you have, simple charts, anything that will help trigger memories and start conversations when they talk to other family members. One way to demonstrate health history information is a simple three-generation ancestor chart that includes cause of death information. (For an example of a simple, useable chart showing the cause of death information, go to the Geneweaver

Web site, <www.geneweaver.com>, and click on the "Feature" button, then select "Medical Pedigree Chart.") A simple, clear form can be a great starting point for explaining to relatives one important result of your genealogical research and their shared information.

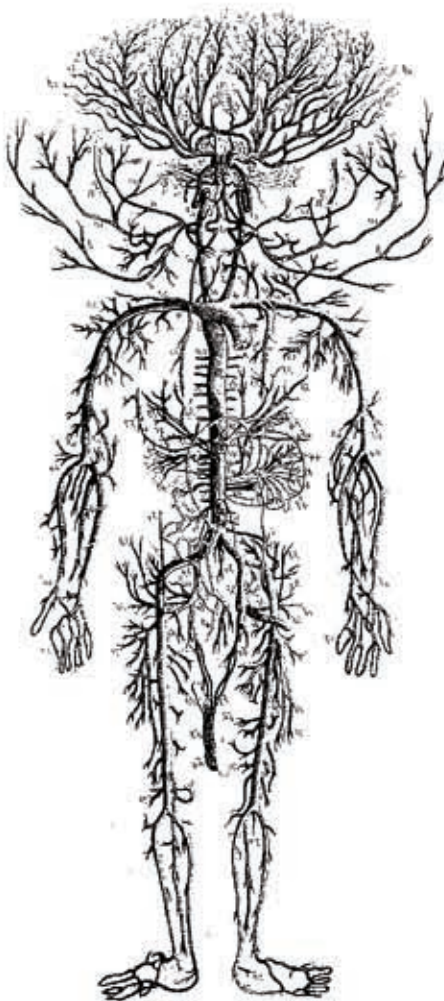
8. Prepare medical summaries for other family members.

You can provide practical assistance by doing the same thing for relatives, particularly elderly family members, that you did for yourself. Are you the caregiver for a parent or other relative? Do you have an aunt, uncle, older sibling, or cousin who could use help in keeping track of their medications and overall health status? Help one of these folks by preparing a medical summary form for them. (Look again at that example for Ole Smirnoff Bernatelli.)

You may not get all the information listed right away. Consider offering to start this by just listing their medications, and then grow the detail on the summary over time. As you prepare and then periodically update their medical summary, your conversations can cover the more general family history, and in the process, add to the family stories you've recorded.

9. Get the facts.

You can request copies of your own medical records. I began doing that because I travel so much. It was practical as well as reassuring to have my current record along in the event of an emergency. But I found that the big benefit in having those records was that I read them. Doing that helped me understand



my conditions and treatments much better. I realized where I had questions. Where unfamiliar terms were listed, I looked them up in medical dictionaries. It reinforced things the doctor had recommended to do or not to do. It helped me be more educated and sure about my medical conditions and care. Your medical record is simply the big book of your own personal health history, and nothing is much more important to understand. (Do remember that if you see the abbreviation SOB in your medical records, it means shortness of breath!)

Access to other people's medical records is a whole different story,

even if they are your ancestors. Often health care professionals consider deceased individuals still entitled to privacy. Public hospital and medical records are governed by the laws and practices of their state. Private hospitals, clinics, and physicians determine individually what, if any, access may be granted to records. Hospital records, when they have survived, may include register and discharge records, but individual patient files aren't often available, even to descendants. The laws, at both state and federal levels, are always changing. If you know or have good reason to believe that records for an ancestor exist that may provide important family health history, in some cases you can try one other possibility. Ask your physician to attempt to obtain the records as part of your treatment or counseling. In some cases the information may be indirectly accessible to you that way.

10. Don't create problems!

With all that you can do to help your family with health history information, you can also open a hornets' nest of problems. Educate yourself, but rely on the medical professionals. Don't assume all the old information is completely accurate, in either the records or family stories. Don't rely on self-diagnosis. Don't assume the worst regarding an inherited, or an individual, medical condition. Work with medical professionals, including family doctors and specialists, and rely on quality information from books, magazines, and Web sites. There's lots of bad information out there also, so look instead for articles

and sites that are peer-reviewed by medical professionals.

Remember that people, including those in your family, don't always know how to interpret information. Just the mention of some words (such as cancer) may cause some people to overreact, with either more fear than is realistic, or withdrawing like turtles into a shell of denial. Be aware that many of the legal, ethical, and practical issues surrounding health history and personal health information are difficult to answer clearly. Check out two excellent brief discussions of such issues: "Heredity and Health: Basic Issues for the Genealogist" by William B. Saxbe and "Concerns for the Family Health Historian" by Thomas H. Roderick and Darlene McNaughton. (See the sidebar on page 21.)

In each family situation, the attitudes of individuals, factors involved, and approach you need to take may vary greatly. Confidentiality is an important and often overriding issue. There are people it is appropriate to share information with, and many people who have no business knowing it. (Your family health history impacts your nephew's health, but your husband's family information does not.) Insurability concerns, present or future, are genuine concerns, particularly where a strong genetic link to a serious condition or disease is evident.

11. Use all your research results, but know your limits.

As a genealogist, you don't just accumulate birth, marriage, and death certificates. You learn about the people who populate your family

history. You come to understand better than most family members what their environment was like, what times they lived through, the stresses and struggles and joys of their lives. Bring that knowledge and understanding to the health history as well as the family history.

Family health history goes beyond causes of death and awareness of inherited genetic conditions. Realize that the family health history you compile provides clues on possible tendencies. It doesn't usually forecast the specific occurrence of disease. Most genealogists are not medical professionals or geneticists. Don't overstate your knowledge. Don't take it upon yourself to interpret general information about a condition or disease in order to draw specific conclusions about the risks to living family members. But do not stay silent: at the doctor's office, with your family, or within that place in your mind where worry and fear reside. One of the important things you can provide is the encouragement for family members to educate themselves, to talk to their doctors regularly and to medical and genetic specialists when appropriate.

12. One sure-fire bet.

What's the single most important thing you can do for a healthy future, or help convince a family member to do? According to Dr. Bart Saxbe, it's two simple words. Quit smoking. Medical science is finding that no other single factor contributes to and increases your risk for more diseases than smoking.

Fortunately, we live in an age of wondrous advances in the care

and prevention of disease. Specific knowledge of how disease and healing occur have multiplied geometrically the past ten years, in no small part because of the Human Genome Project. Practical applications for treatment and prevention are following. That holds great hope for many of the major causes of physical human suffering and death. But it's all still amazingly new. Medical genetics wasn't recognized as a full medical specialty until 1992. You're fortunate to be both the beneficiary of these many medical breakthroughs and have the opportunity to play a significant role in your family's future health care. Even more than your family tree, your family health tree is always changing. Keep current, update the information, and do that by sharing with and talking to your family.

Good health is not just a matter of good luck and good genes. Individuals also determine their health by lifestyle choices and preventive steps. Medical care has fundamentally changed in our lifetimes. Your doctor is no longer just the person you go to when you've had an accident or are showing serious symptoms. She's the person you go to in order to stay healthy. An accurate personal and family health history can be a critical key to medical care for you, your living relatives, and family members not yet born. Is yours up to date? 🌿