

15

CHARTING YOUR FAMILY'S HEALTH THROUGH THE GENERATIONS

Teacher's Packet

HANDOUTS TO COPY

Family Health History questionnaire
What Are Genes and Chromosomes?
Family Health Tree File card page
Medical Family Tree
Charting Your Family's Health

OUTLINE OF WORKSHOP

Introductions, opening	FAMILY IS A GIFT
Bonding game	WHO ARE WE?
Workshop's history	A FAMILY STORY
Handout one	DO YOU KNOW YOUR MEDICAL HISTORY?
Handout two	WHAT ARE GENES?
Handouts three - five	DIGGING UP YOUR ROOTS!
	DIALING FOR DETAILS
	LOOKING FOR PATTERNS
	IMPROVING THE ODDS OF LIVING HEALTHY
	SAFE GUARDING YOUR MEDICAL RECORDS
Evaluation	
References	

OPTIONAL VISUALS

Overhead projector or flip chart
A few family photos or family albums
Detective or funny hat, magnifying glass
Shovel or trowel
Telephone, pen & paper
Large filled out chart with your family's medical history

Family is precious. We snap pictures, research our beginnings and polish heirlooms to pass on to our grandchildren. Yet, we have forgotten to record a very important part of our history . . . our own family's health through the generations.

Family Health History

Name _____

Date of Birth _____

Blood and Rh Type _____

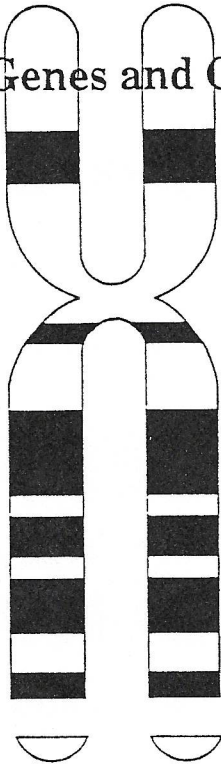
Occupation _____

Please note any serious or chronic diseases you have experienced, with special attention to the following:

- Alcoholism
- Allergies
- Arthritis
- Asthma
- Blood diseases (hemophilia, sickle cell anemia, thalassemia)
- Cancer (i.e., breast, bowel, colon, ovarian, skin and stomach)
- Cystic Fibrosis
- Diabetes
- Epilepsy
- Familial high blood cholesterol levels
- Hearing defects
- Heart defects
- Huntington disease
- Hypertension (high blood pressure)
- Learning disabilities (dyslexia, attention deficit disorder, autism)

- Liver disease (particularly hepatitis)
- Lupus
- Mental illness (manic-depressive disorders; schizophrenia)
- Mental retardation (Down syndrome, fragile X, etc.)
- Migraine headaches
- Miscarriages or neonatal deaths
- Multiple Sclerosis
- Muscular Dystrophy
- Myasthenia Gravis
- Obesity
- Phenylketonuria (PKU)
- Recurrent or severe infections
- Respiratory disease (emphysema, bacterial pneumonia)
- Rh disease
- Skin disorders (particularly psoriasis)
- Thyroid disorders
- Tay-Sachs disease
- Tuberculosis
- Visual disorders (dyslexia, glaucoma, retinitis pigmentosa)
- Other: _____

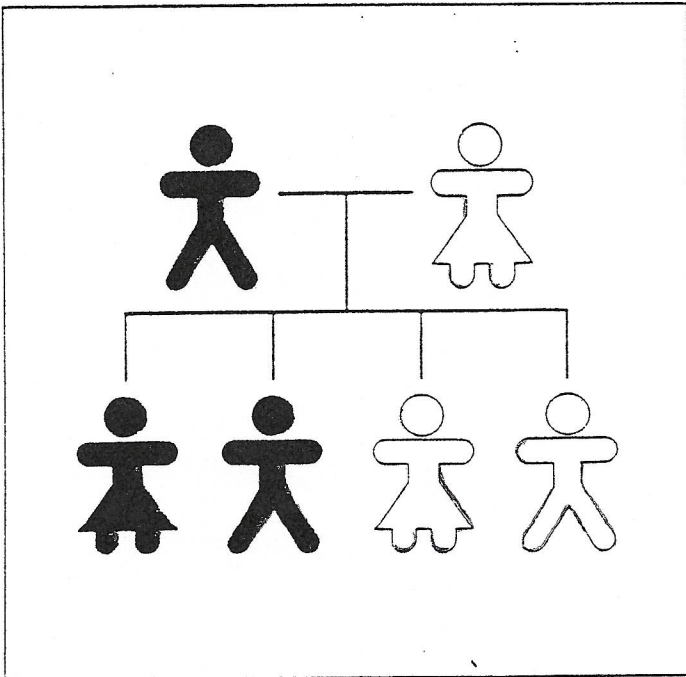
What Are Genes and Chromosomes?



Every human being has over 100,000 genes that determine their hair and eye color, type of build and other traits. The genes are like tiny switches that direct the growth and development of every part of our physical and biochemical systems. Genes are packaged into each of the 46 chromosomes inside most of our cells.

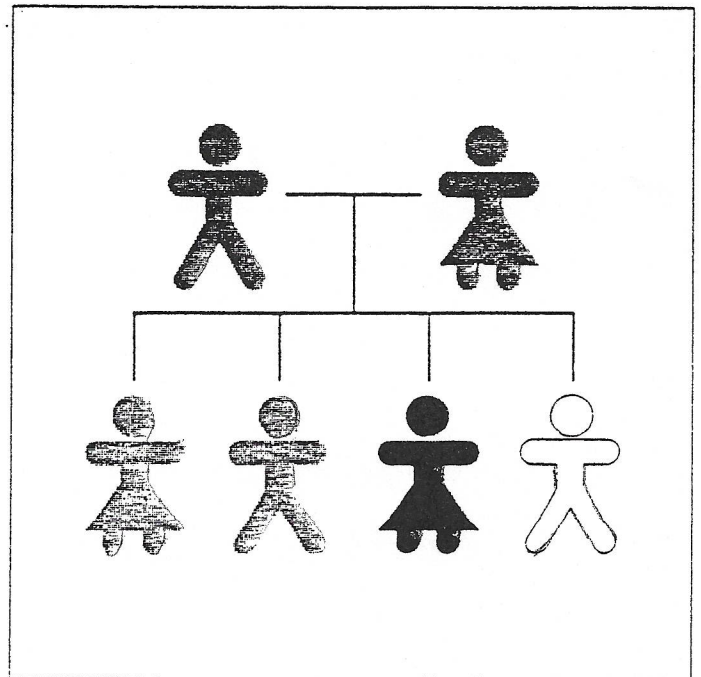
Sperm and egg cells are different from other body cells. These reproductive cells each have only 23 unpaired chromosomes. When a single sperm and egg come together — when pregnancy begins — they form their own new cell with 46 chromosomes. The human being that results is genetically unique, with a blueprint half from each parent.

Autosomal Dominant Disorders



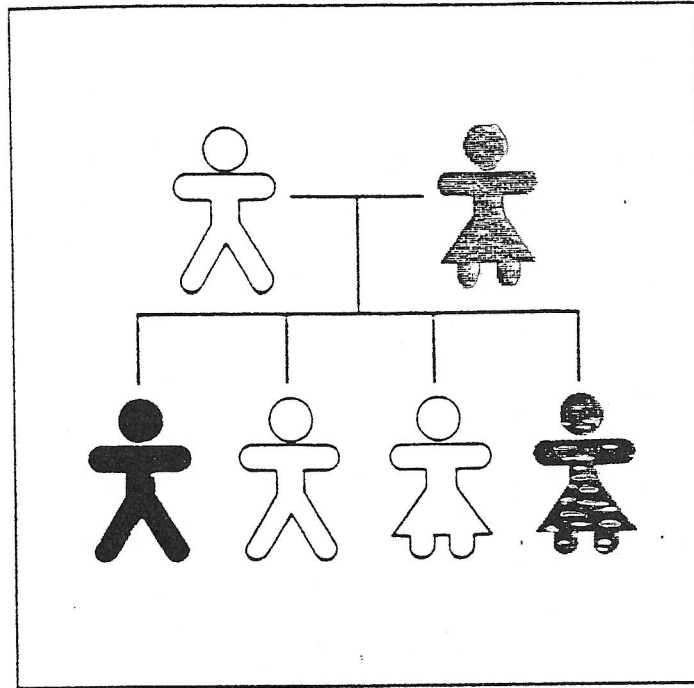
If one of the parents has an autosomal (not sex-linked) dominant gene disorder, there is a 50 percent risk that it will be passed to each child.

Autosomal Recessive Disorders



If both parents are carriers of an autosomal recessive disorder, there is a 25 percent risk that each child, male or female, will inherit the condition; a 50 percent chance that each child will be a carrier who does not have the disorder; and a 25 percent chance of each child being completely unaffected.

X-Linked Recessive Disorders



If the mother is a carrier of an X-linked recessive disorder, there is a 50 percent chance that each male child will receive the abnormal X chromosome and be affected, and a 50 percent chance that each of her female children will be a carrier.

A Common Mistake With Recessive Inheritance

Parents with one child affected by a disorder due to recessive inheritance may think that a 25 percent — or one in four — risk means that the next three children are not in danger. **This is not true.** The risk of genetic disease is the same for every child of the same mother and father. An important exception is families with X-linked disorders that affect only males, where the equal risk of disease applies only to sons.

FAMILY HEALTH TREE FILE

THIS RELATIVE IS MY _____
(for example: maternal grandmother, mother, brother)

RELATIVE'S NAME _____

BIRTH DATE _____ DATE OF DEATH *(If applicable)* _____

CAUSE OF DEATH _____

BLOOD TYPE and Rh _____

OCCUPATION _____

DISEASES AND INFIRMITIES _____

WEIGHT:	Underweight	Average	Overweight
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

HABITS:	Never	Moderate	Heavy
TOBACCO	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ALCOHOL	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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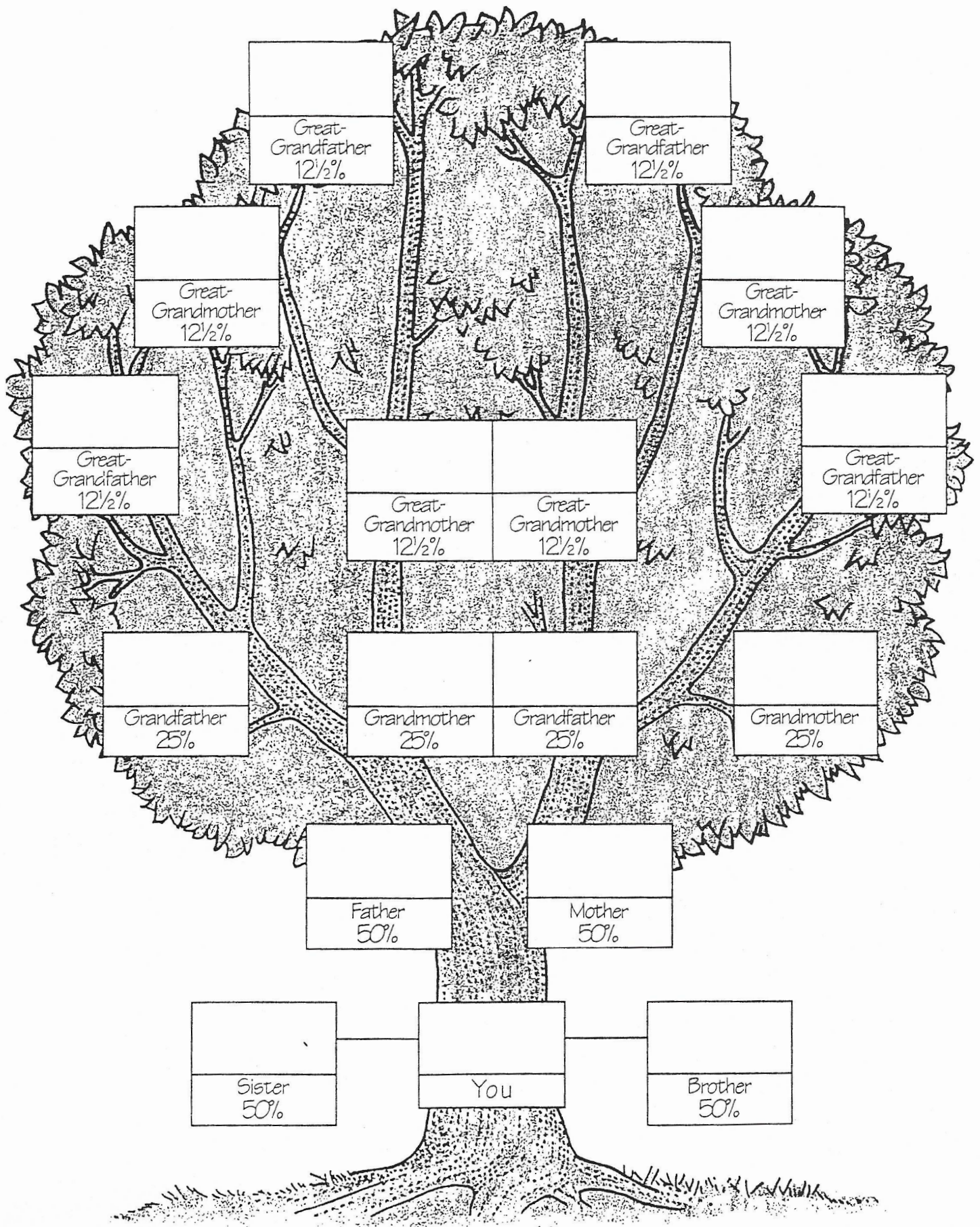
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Medical Family Tree



Charting Your Family's Health Through the Generations

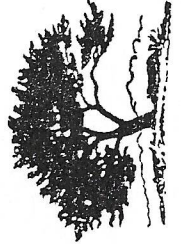
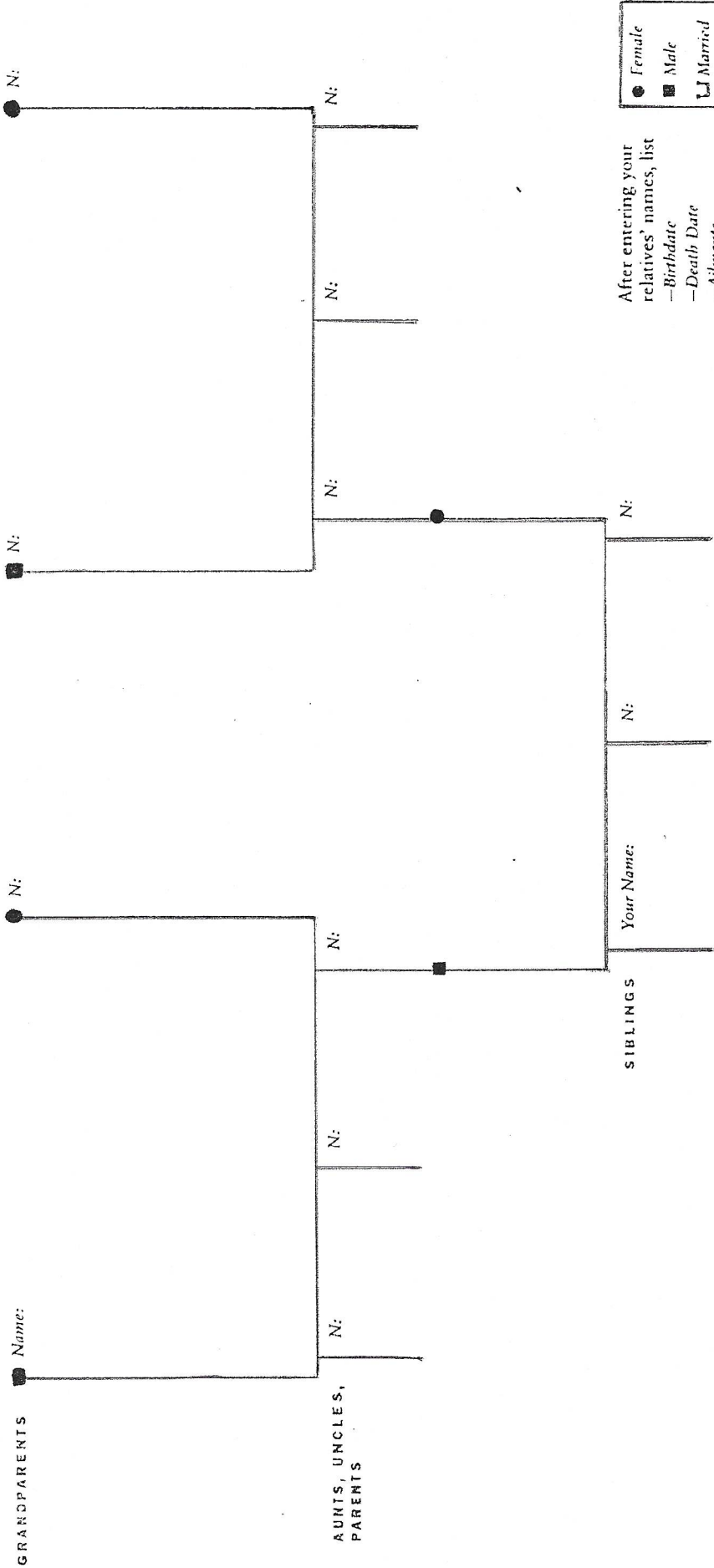
THIS BLANK GENOGRAM has room for only your own family history. But you can photo copy the page, add your spouse's family, and combine the two for your children's full health history. Squeeze in extra names, of course, if you have an especially large family.

When your genogram is complete, give your doctor a copy for your medical files and make separate copies for your spouse's and children's files. Store another copy for each of your children and update it periodically. This is one card no home should be without.

Name of Person Submitting Genogram

Date

Address



CHARTING YOUR FAMILY'S HEALTH THROUGH THE GENERATIONS

1. (OPENING) FAMILY IS A GIFT

Set out framed photos or albums of your relatives - grandparents through the babies in your family.

Family is a gift we open and reopen with every glance, touch and hug. We open picture albums recognizing our grandparents and great grandparents. We know if they came from Italy, Germany, China, Russia, England, Japan or Norway. We research and organize family genealogies. We restore homes and historic landmarks. And yet, we have forgotten to record a very important segment of our history our own Family's health through the generations!

2. (BONDING GAME) WHO ARE WE???

Have participants turn to the person beside them sharing for several minutes some of the following questions. If you want, have a few people share their answers.

Did your mother have ailments that she kept silent about?
What is the cause of death on your parent's or grandparent's death certificate? Does it match what people were told?
Were you adopted, or did you adopt? You have medical facts?
In the past what names were used for Tuberculosis, cancer, mental illness or depression?

3. (WORKSHOP'S HISTORY) A FAMILY'S STORY

This workshop grew out of a concern Dorothy Nothdurff of Beresford, South Dakota had for her family. Her sister felt ill at 10 a.m. and died that evening leaving four small children. Only her husband was allowed access to her autopsy and death certificate which he would not share. When other questions of family problems arose, Dorothy developed this lesson and started working with the South Dakota legislature to change information laws. This is an edited version of the lesson taught at the FCE National Conference.

4. (HANDOUT ONE) DO YOU KNOW YOUR MEDICAL HISTORY?

Hand out the "Family Health History" questionnaire. Allow several minutes for the group to fill it out.

If you have allowed your own family's medical health history to go largely unrecorded, there is no better time than now to get the crucial details down in writing. More than 3,000 ailments are known to be inherited or the risk factor is higher, such as heart disease, cancer, diabetes, arthritis, Alzheimer's, alcoholism, skin disorders, thyroid disease, allergies and schizophrenia.

5. (HANDOUT TWO) WHAT ARE GENES?

This handout could be made into 2 overheads, or drawn on a flip chart instead of being copied. Share information.

Many people are familiar with the hereditary diseases such as hemophilia and cystic fibrosis, but few realize that genes also play a role in heart disease, cancer and high blood pressure.

Genetics doesn't always doom you to repeat your family's medical past. While heredity plays a role in breast cancer, three-fourths of women with a strong family history of the cancer will not develop the disease but just have a genetic tendency, according to the National Cancer Institute.

Any disease that appears in your family puts you at RISK. Regardless of whether the risk stems from your genetic code or from habits nurtured in your childhood. Think of the diseases that may involve hereditary AND environmental factors, such as smoking, diet, weight and exposure to certain chemicals.

Put on a "detective" hat or hold up a large magnifying glass.

Creating a medical family tree requires you to become part genealogist, detective, psychologist and decipherer of family tales.

6. DIGGING UP YOUR ROOTS!

(HAND OUT - Family Health Tree File card page
Medical Family Tree
Charting Your Family's Health

You could enlarge the last chart, filling in your family's medical history, to show possibilities.)

Hold up a shovel or trowel, or telephone and pencil.

Begin "digging up your roots" by asking your relatives about every disease or medical condition that has occurred in your family. Place phone calls, send out questionnaires or plan a big reunion so family members can swap medical details. Stress how a comprehensive health tree will benefit the whole family. Health topics can be highly sensitive, but remember that medical secrets can hurt following generations. Listen to the stories how in the past, diseases especially women's ailments were handled, treated and sometimes kept secret.

Copy and fill out the files on the Family Health Tree page. (Hold up this page of 6 file cards.) Start with your parents, siblings and children as they are your first degree relatives. They share 50% of you genes. There is a strong correlation between their genetic legacy and yours. Look at the hand out Medical Family Tree. (Hold up this page to your participants.) Then move on to second degree relatives, such as aunts, uncles and grandparents with whom you share 25% of your genes. Your third degree relatives are great grandparents of whom you share 12 1/2% of your genes.

You are ready to start recording. Use either the one page Family Health History copying one page for each relative, or use the small file cards or jot down the information in a notebook.

Here are the questions you need to answer.

- * Full name
- * Dates of birth, marriage, divorce, remarriages
- * Ethnic background
- * Height and weight
- * Any health problems, allergies, miscarriages, major surgeries, chronic ailments, cancer, heart attacks or strokes - types and severity, and age they occurred. High blood pressure, high cholesterol, diabetes, ulcers and recurring headaches.
- * Serious eye or hearing problems
- * Substance abuse
- * Serious depression, mental illness and suicide attempts.

7. DIALING FOR DETAILS

When memories fail, official records may be useful. Death certificates typically contain information about the medical cause of death. You may reach Oregon Vital Records in Portland at 503-731-4095. They have certificates from 1903 forward. Before 1903 you will have to research the State Archives in Salem. Access the proper forms requesting a death certificate at your County Courthouse Clerk's office. They can help you with requesting information from other states. Certified certificates cost \$15.

Many adoptees know little about their biological heritage if records were legally sealed. The references quoted at the end of this workshop list ways for adult adoptees to seek birth parents.

8. LOOKING FOR PATTERNS

When your Medical Family Tree is complete, consult your Doctor, a specialist or a genetics counselor to talk about any obvious patterns or a health condition that appears more than once, or shows up in first degree relatives before age 55. See your Doctor promptly if a first degree relative under the age of 50 got an illness usually associated with someone much older.

9. IMPROVING THE ODDS OF LIVING A WONDERFUL LIFE

- * Research your medical history.
- * Lead a healthful life.
- * Get screened.
- * Be an assertive advocate for a healthy you.
- * Don't fret, bad things don't always happen.

10.

SAFE GUARDING YOUR MEDICAL RECORDS

We try to remember to carefully read the fine print on insurance policies, ask intelligent questions of health professionals and be honest in answering queries by our doctors. Yet we worry about what happens to our information once it enters someone's computer files.

In signing the form applying for medical insurance and sometimes life insurance you are giving your permission for the insurance company to request your medical records from your doctor. They may just trust what you are saying on their forms is correct, but your age and condition may signal them to ask for your records including the doctor's notes. If you have never been treated or diagnosed for a certain medical condition you can honestly say "I don't know" when asked on the insurance forms.

When you make a claim against an insurance company or they pay a claim that information is recorded in the Medical Information Bureau files. Numerous insurance companies get information from this Bureau. Its purpose is to prevent fraud by uncovering omissions and misrepresentations in an individual insurance application. If you lie on a claim your claim may be denied, and your policy terminated.

SO BE HONEST!!

Insurance companies will not release your medical records to you or to another insurance company. Most doctors willingly share records with their patients, or will usually forward files to another physician you are consulting.

Consumer protection laws are scattered, and not easy to find. if you have questions, start your search by calling the State Insurance Division at 503-947-7984. HIV regulations and laws against the use of Gene testing to deny you insurance are two of the hottest protection topics in Oregon.

Many challenges face our families. Only you can give the ones you love and the children yet unborn a precious gift. Something to slip into those wonderful family albums and genealogies. A resource that might answer questions and make a difference in the life of someone special.

CHARTING YOUR FAMILY'S HEALTH THROUGH THE GENERATIONS

EVALUATION OF WORKSHOP

1. This class made me stop and think about my medical history.
 Yes No, I already know my medical history.

2. I intent to start "digging up my roots" by asking my relatives about our medical history.
 Yes No

3. I plan on sharing this information with others.
Check all that apply.
 Yes, with FCE members, Relatives, Other groups
 Will probably be asked to teach this workshop.
 No, I'll probably end up giving this information away.
 No, I'll probably end up putting this information in a box or file or wastebasket. (feel guilty?)

4. I feel this was a worthwhile workshop, which was written and taught by FCE members.
 Yes No

If this evaluation is a compilation of many evaluations put compiled numbers in above blanks. Answer the following questions.

Number of participants _____

Number of FCE members _____ Number of guests _____

Name of group, City and County _____

Workshop developed by Dorothy Nothdurft
47630 292 Street
Beresford SD 57004

Workshop edited/formatted by Anne Engen
13325 NW Willis Road
McMinnville OR 97128-8047

SEND EVALUATIONS TO **DORENE GARLAND**
1030 W LOCUST STREET
STAYTON OR 97383-1137

THANK YOU!

References

The March of Dimes Birth Defects Counseling-Family Health History
National Office, 1275 Momaronek Ave., White Plains, NY 10605

Articles

- "Genetics: The Future Is Now" Time January 17, 1994
- "Your Medical History" Better Homes & Gardens March 1994
- "Family Health Tree File" Readers Digest 1993
- "Fruit From the Family Tree" Saturday Evening Post July/Aug. 1995
- "Living Legacy: Knowing Your Medical Tree Can Save Your Life" Life April 1995
- "Why You Need To Know Your Family Medical History" Family Safety & Health Fall 1994
- "The Better Way: How to Research Your Medical Family Tree" Good Housekeeping August 1994
- "Look For The Best Years of Life: Rediscover Your Family History" McCalls February 1994
- "Your Family History-What Risks Did You Inherit" Health October 1996
- "Safeguarding Your Medical Records" Better Homes & Gardens Sept. 1994
- "Record Retention Statutes and Regulations by State" Journal of AHIMA September, 1992

Books

How Healthy Is Your Family Tree?

Carol Krause

National Genealogical Society-2 publications (\$6 each) 4527 17th ST, N Arlington VA 84150

Some Major Registries To Help Search For Details

Family History Library of the Church of Jesus Christ of the Latter Day Saints-35 Northwest Temple, Salt Lake City, UT 84150 Phone 801-240-2331

Hereditary Cancer Institute, Creighton University (all cancers) Phone 402-280-2942

Strang High Risk Breast Registry (breast cancer) Phone 800-521-9356

Gilda Radner Familial Cancer Registry (ovarian cancer) Phone 800-682-7426

National Society of Genetic Counseling 233 Canterbury Drive, Wallingford, PA 19086

Computer Program- Family Health Tracker

If You're Seeking Your Parents

National Adoption Information Clearinghouse-Sends important facts on state adoption laws and on searching for birth relatives, including a list of mutual consent registries as well as other organizations and support groups. 5640 Nicholson Lane, Suite 300, Rockville, MD 20852; phone 301-231-6512.

International Soundex Reunion Registry-Matches data on adopted children with data on biological parents who have given up a child for adoption (a free service). Call for a registration form. The registry will contact you if the computer turns up a match. P. O. Box 2312, Carson City, NV 89702; phone 702-882-7755.

American Adoption Congress-Has local support groups across the country for adoptees, birth parents, and adoptive parents. Each group offers psychological as well as search guidance. 1000 Connecticut Ave. NW, Suite 9, Washington, DC 20036; phone 202-483-3399.

Concerned United Birthparents-Provides support and some search help through a monthly newsletter and 14 local branches around the country. First-year membership is \$50. 2000 Walker Street, Des Moines, IA 50317; phone 800-822-2777.

Adoptee Liberty Movement Association-Holds search workshops at 62 chapters worldwide. Also provides a registry for people adopted from foreign countries who are seeking their biological relatives. P.O. Box 727, Radio City Station, New York, NY 10101; phone 212-581-1568.

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- Skin disorders (particularly psoriasis)
- Thyroid disorders
- Tay-Sachs disease
- Tuberculosis
- Visual disorders (dyslexia; glaucoma, retinitis pigmentosa)
- Other: *Osteoporosis*
- Birth Defects*