

# Documenting the Family History:

## An Overview of Available Tools

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# Overview

- Collecting family history information
  - Who, How, What and Why
- Overview of different approaches and formats
- Examples of available tools

# Collecting Family History

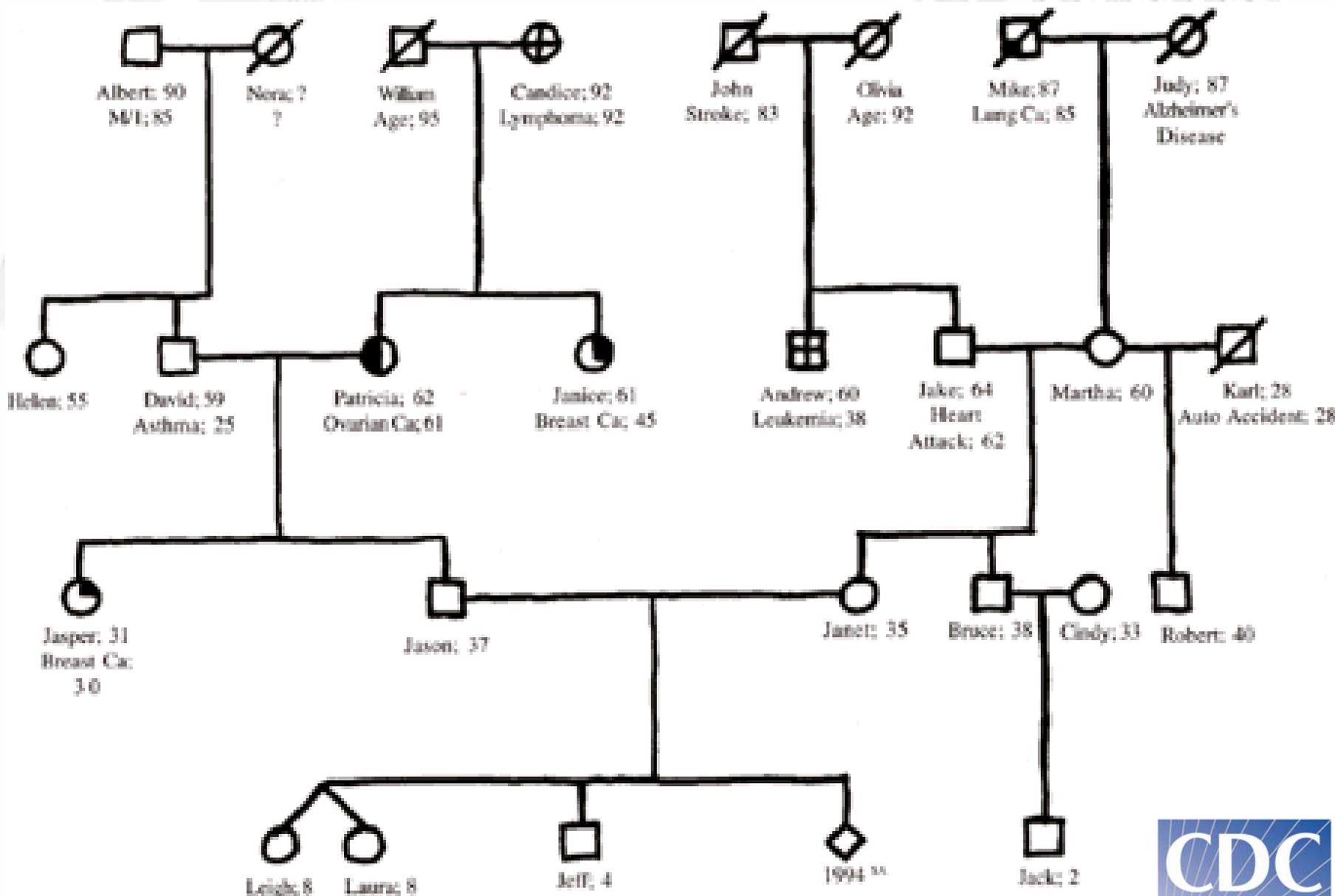
- Who?
  - Providers, Insurers, Employers, Individuals, Genealogists, Courts, Social Services, Researchers

- How?
  - Pedigree, table or chart, questionnaire, narrative



# Collecting Family History

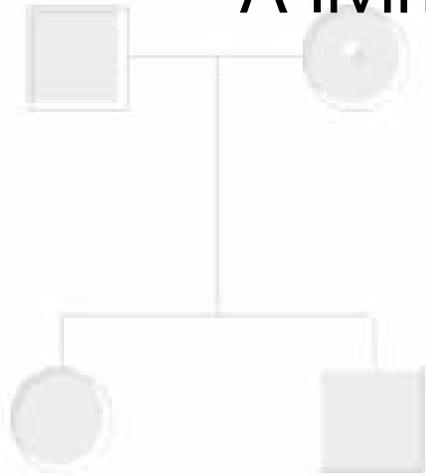
- What?
  - Medical and health info in families, social and cultural traditions, behaviors and habits that impact health, environmental exposures
- Why?
  - Provide care, assess risks, provide anticipatory guidance, disease prevention, adoption, social services, genealogy, research



# Family History Tools: Multi-Generation Pedigree

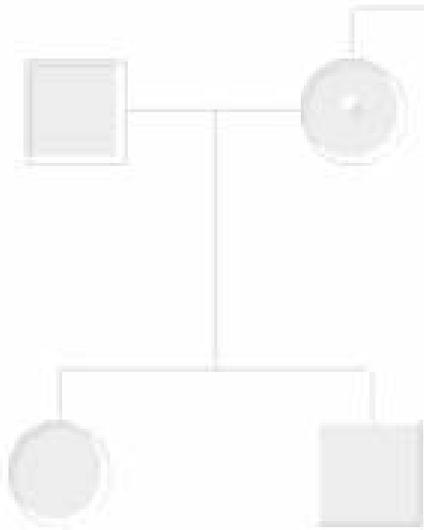
- The gold standard
  - Captures large quantities of information
  - Compact, standardized format
  - Amenable to analysis
  - A living document

However.....



# Family History Tools: Multi-Generation Pedigree

- Requires training and skill for maximal effectiveness
- Time consuming to collect
- Usefulness as screening tool?



# So many tools, so little time...

- Many tools available
- Common purpose
  - Diagnosis of a present medical condition
  - Risk assessment to prevent a medical condition
- Several formats
- Several sources

# Descriptive Evaluation Criteria

- **Tool Format:** Pedigree, table, questionnaire
- **Degree of relationship:** 1<sup>st</sup>, 2<sup>nd</sup> or 3<sup>rd</sup> degree
- **Length of tool:** <2 pgs, >2 pgs
- **Source of tool:** Med or pop lit, gov, advocacy or professional org, social services
- **Types of questions:** Broad, focused, disease-specific, non-prescribed
- **Information collected:** Genetic, exposures, medical, cultural, behavioral, social
- **Intended use(s):** Diagnosis, risk assessment, planning, prevention, research

# Descriptive Evaluation Criteria: Screening Pedigree

- **Tool Format: Pedigree**
- **Degree of relationship: 2<sup>nd</sup> degree**
- **Length of tool: <2 pgs**
- **Source of tool: advocacy organization**
- **Types of questions: focused, disease-specific (colon ca)**
- **Information collected: genetic, medical**
- **Intended use(s): risk assessment, prevention**

# CREATING YOUR FAMILY MEDICAL HISTORY

**Instructions:** You may have a greater risk for colorectal cancer if you have a personal or family history of certain kinds of cancer or of polyps in the colon. To help you determine your risk, complete this family medical history. For each blood relation, mark in the box if they have had any of the following medical problems and their age at diagnosis: **colorectal cancer, inflammatory bowel disease (Crohn's or colitis) or stomach or bowel problems, breast, uterine or endometrial cancer, or colorectal polyps (adenomas).**

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

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

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

YOU

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



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

*March is National Colorectal Cancer Awareness Month, founded by the Cancer Research Foundation of America in collaboration with many partner organizations. Talk with your health care provider about colorectal cancer. Colorectal cancer is preventable, and is easy to treat and often curable when detected early. Ask your health care provider what kind of screening test you should have and when.*

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

# Descriptive Evaluation Criteria: Primary Care Screening Tool

- **Tool Format: Table**
- **Degree of relationship: 1<sup>st</sup> degree plus**
- **Length of tool: <2 pgs**
- **Source of tool: Medical group (Fox Valley Family Practice)**
- **Types of questions: Broad, disease-specific**
- **Information collected: Genetic, medical**
- **Intended use(s): Risk assessment, prevention**

Please complete and return this form a few days before your appointment.

Name: \_\_\_\_\_ Pre-op: \_\_\_\_\_ Complete PX \_\_\_\_\_ PH \_\_\_\_\_  
 Address: \_\_\_\_\_ Appt.: \_\_\_\_\_ Time: \_\_\_\_\_  
 Date of birth: \_\_\_\_\_ Phone: \_\_\_\_\_ Dr. \_\_\_\_\_

**FAMILY HISTORY**

	If Living		Age At death	If Deceased Cause	Has any blood relative ever had:	Please check		Who
	Age	Health				No	Yes	
Father					Heart disease			
Mother					Cancer			
Brothers					Glaucoma			
					Sugar diabetes			
					Tuberculosis			
					Nervous disorder			
Sisters					Epilepsy			
					Allergy			
					Stroke			
					Hardening of the arteries			
Weight		Immunizations		Date	High blood pressure			
Present _____		Tetanus			Anemia			
One year ago _____		Smallpox						
		Oral Polio						

**PERSONAL HISTORY**

Have you ever had: (please check)

	No	Yes		No	Yes		No	Yes
Measles			Polio			High blood pressure		
Mumps			Meningitis			Nervous breakdown		
German measles			Kidney disease			Hay fever		
Scarlet fever			Gonorrhea			Asthma		

# Descriptive Evaluation Criteria: Family History Table

- **Tool Format: Table**
- **Degree of relationship: 2<sup>nd</sup> degree (grandparents)**
- **Length of tool: <2 pgs**
- **Source of tool: Internet (Mactopia)**
- **Types of questions: Disease specific, broad**
- **Information collected: Genetic, medical**
- **Intended use(s): Risk assessment, prevention**



# Descriptive Evaluation Criteria: Cancer Fam Hx Questionnaire

- **Tool Format:** Table, questionnaire
- **Degree of relationship:** 3<sup>rd</sup> degree
- **Length of tool:** <2 pgs
- **Source of tool:** Medical org (ACMG), government (NYS DOH)
- **Types of questions:** Broad, disease-specific
- **Information collected:** Genetic, medical
- **Intended use(s):** Risk assessment, prevention

## SAMPLE CANCER FAMILY HISTORY QUESTIONNAIRE

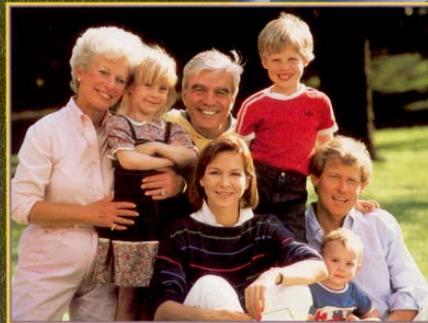
- Name \_\_\_\_\_
- Date \_\_\_\_\_
- Age \_\_\_\_\_
- Ethnic Background [Certain ethnic groups have an increased risk for specific kinds of cancer.] \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_
- Do you have any specific concerns about cancer in yourself or your family?  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_
- Do you or any members of your family have a history of cancer?  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

	Yes/No	Type of Cancer (if known)	Age at Diagnosis (if known)	Living/ Deceased
yourself				
your mother				
your father				
your sisters and brothers				
your half sisters and half brothers				
your children				
your mother's sisters and brothers				
your father's sisters and brothers				
your nieces and nephews				
your mother's parents				
your father's parents				

Family  
History  
Tools  
in the  
Popular  
Literature

# Genetic Connections®

A Guide to  
Documenting  
Your Individual  
and Family  
Health History



Special Condensed Edit

*Danette L. Nelson-Anderson, R.N., B.S.N., and*

THIS BOOK CAN SAVE YOUR LIFE

# HOW HEALTHY IS YOUR FAMILY TREE?

A COMPLETE GUIDE  
TO TRACING YOUR FAMILY'S  
MEDICAL AND BEHAVIORAL  
HISTORY

CAROL KRAUSE  
FOREWORD BY LEO LAGASSE, M.D.

# Summary

- Family history info collected in many ways
  - Many tools, many formats, many approaches, varying degrees of detail and emphasis
- Primary purposes are diagnosis, risk assessment, and prevention
- Family history may be a useful tool for disease prevention

