# Family History: a Disease Prevention Tool for Public Health Practice

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# Family History

I. Defining and measuring family history

II. Rationale for using family history for disease prevention

III. New tools and initiatives – Family Healthware and My Family Health Portrait

IV. Incorporating family history into state programs

# Risk factors for chronic diseases

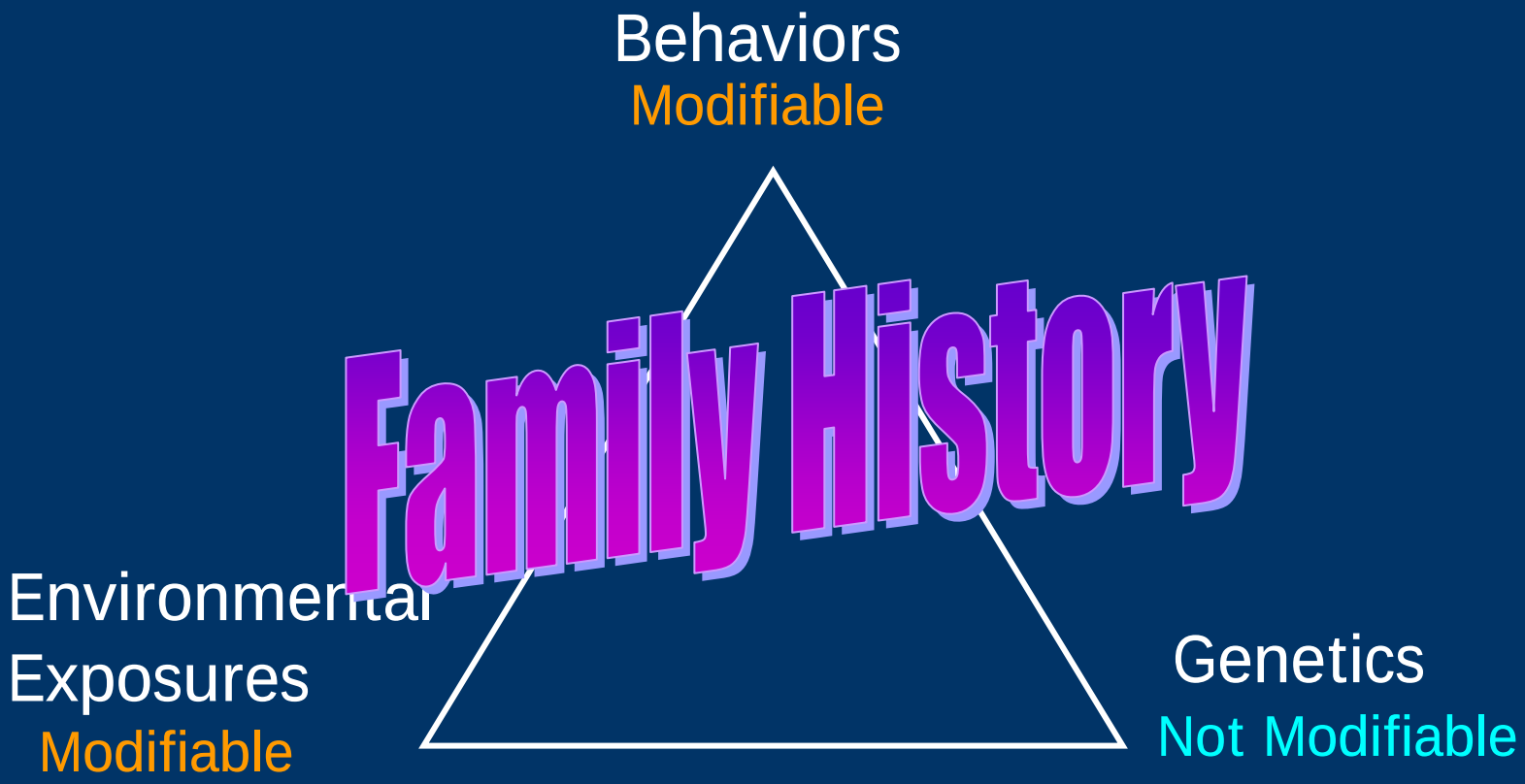
Behaviors

Genetics

Environmental Exposures

Interaction

# Risk factors for common diseases



# What is family health history?

A family's combination of shared genes, environment, behavior, and culture

A risk factor

# How is family history measured?

Have any of your blood relatives ever been diagnosed with asthma?

Yes No

Has your "relative" ever been diagnosed as having coronary heart disease?

At what age was "relative" diagnosed?

Is "relative" still alive?

What did "relative" die of?

Relative = parents, grandparents, aunts, uncles, siblings, children, nieces, nephews, cousins…..

# Recording your family history
# ASHG.org

For each relative, try to write down as many of these items as possible:

Age or date of birth (and, for all family members who have passed on, age at death and cause of death). When the information is unavailable, write down your best guess (for example, "40's").

Medical problems such as:

| | |
|---|---|
| Cancer | Stroke |
| Heart disease | High blood pressure |
| Diabetes | Kidney disease |
| Asthma | Kidney disease |
| Mental illness | Alcoholism |

Birth defects such as spina bifida, cleft lip, heart defects, others

Learning problems, mental retardation

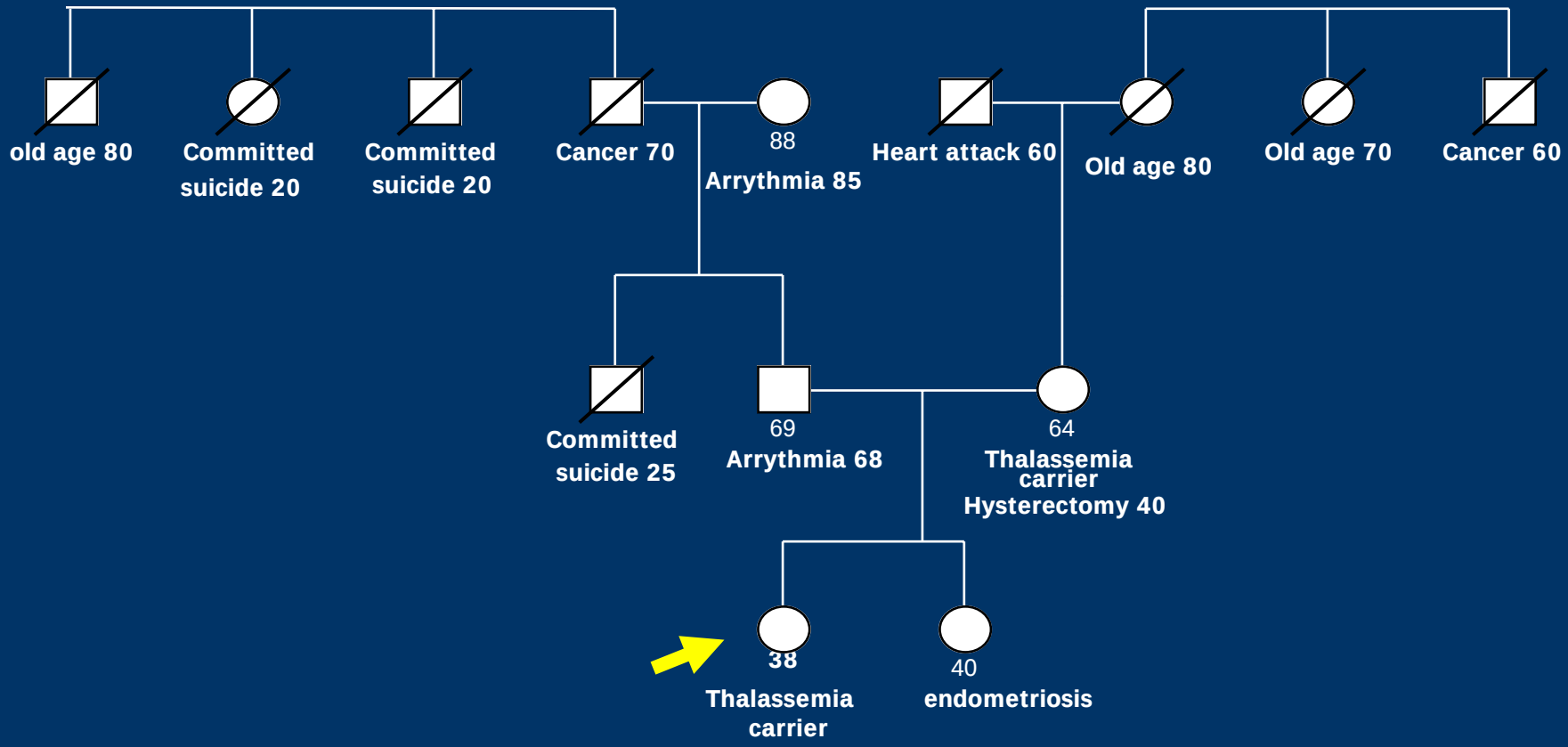
Vision loss/hearing loss at a young age

Others

Note the ages at which the conditions occurred.

For family members with known medical problems, jot down if they smoked, their diet and exercise habits, and if they were overweight.

# Family Tree (Pedigree)



# Algorithms for classifying risk

Scheuner M et al.
*Am J Med Genet*
1997;71:315-324.

**Table 2**
Suggested guidelines for risk stratification based on family history

High risk

1. Premature disease in a 1st-degree relative
2. Premature disease in a 2nd-degree relative (coronary artery disease only)
3. Two affected 1st-degree relatives
4. One 1st-degree relative with late or unknown disease onset and an affected 2nd-degree relative with premature disease from the same lineage
5. Two 2nd-degree maternal or paternal relatives with at least one having premature onset of disease
6. Three or more affected maternal or paternal relatives
7. Presence of a "moderate risk" family history on both sides of the pedigree

Moderate risk

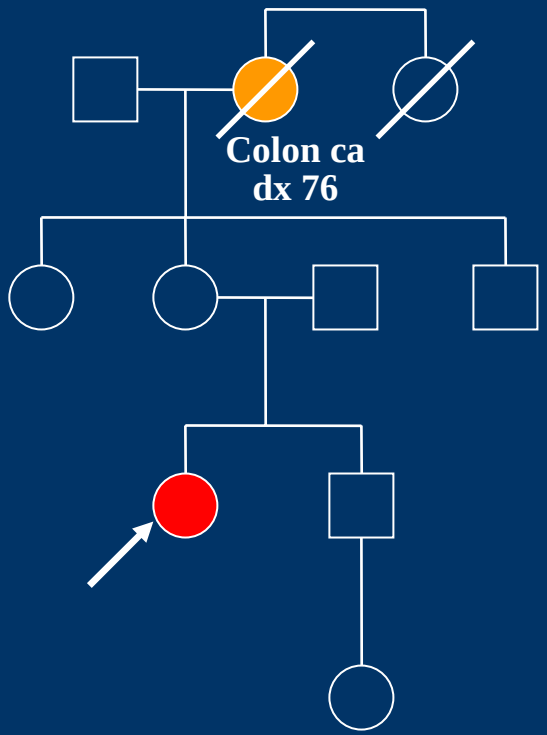
1. One 1st-degree relative with late or unknown onset of disease
2. Two 2nd-degree relatives from the same lineage with late or unknown disease onset

Average risk

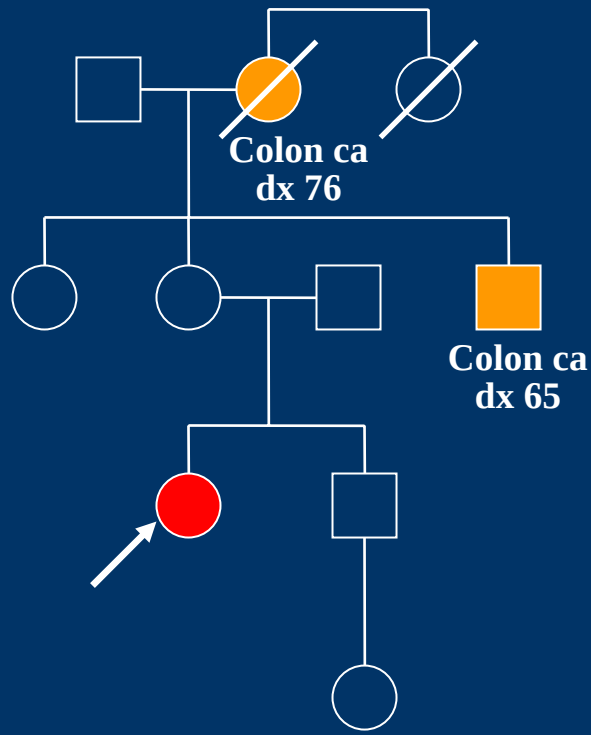
1. No affected relatives
2. Only one affected 2nd-degree relative from one or both sides of the pedigree
3. No known family history
4. Adopted person with unknown family history

From Scheuner et al.[9]

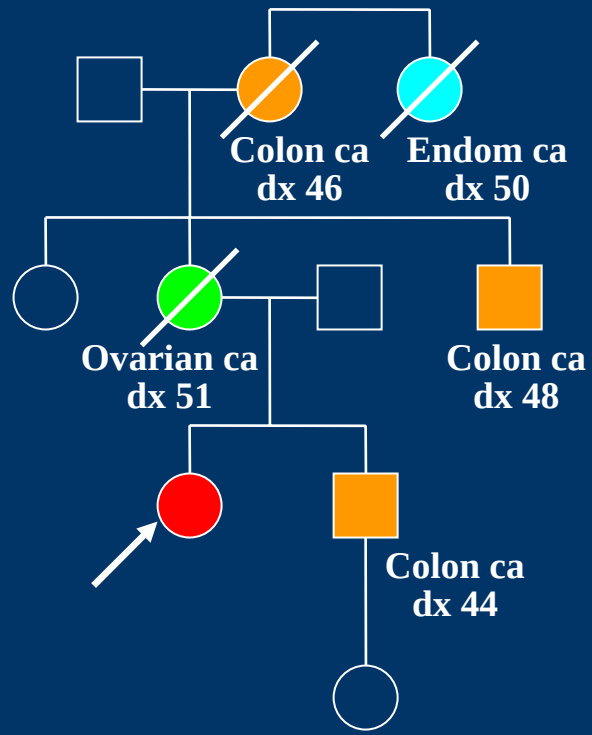
# Risk Stratification/Pedigree Analysis




Weak




Moderate




Strong

Scheuner M et al. *Am J Med Genet* 1997;71:315-324.

# Family history features associated with increased risk

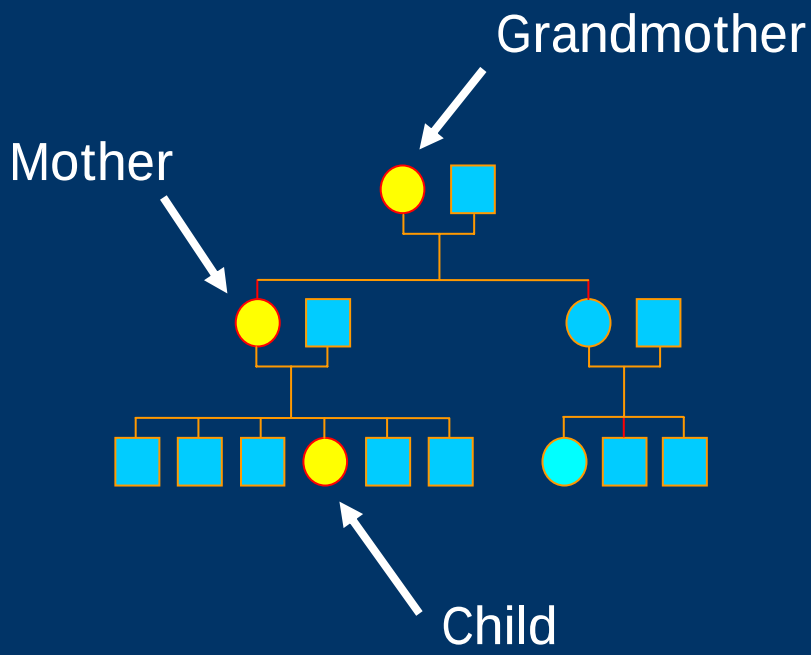
- Early age at disease onset
- Two or more closely related affected relatives
- Two or more generations with affected relatives
- Multifocal disease/severe phenotype
- Disease in the less often affected sex
- Presence of related conditions
- Patterns suggestive of a known Mendelian disorders

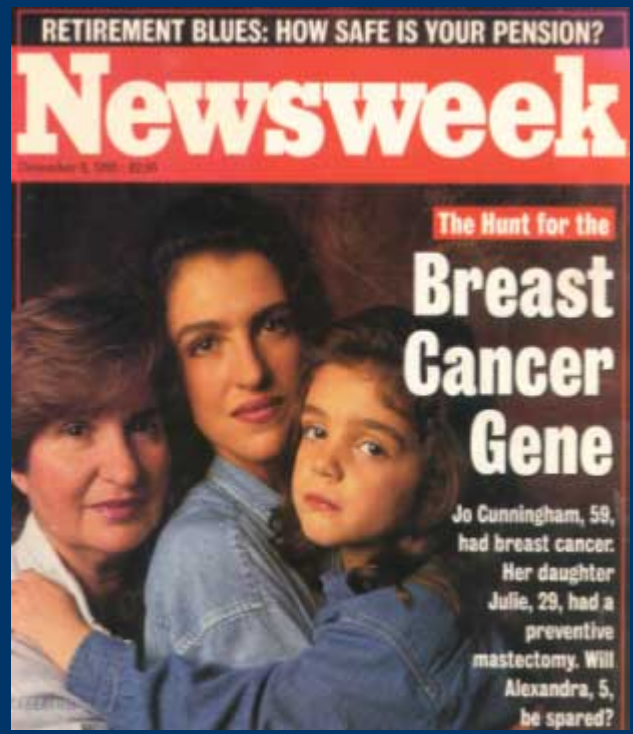
# What is the evidence for the association of family history with chronic disease?

| | Relative Risk |
|---|---|
| Heart disease | 2.0 – 5.4 |
| Breast cancer | 2.1 – 3.9 |
| Colorectal cancer | 1.7 – 4.9 |
| Prostate cancer | 3.2 – 11.0 |
| Melanoma | 2.7 – 4.3 |
| Diabetes | 2.4 – 4.0 |
| Osteoporosis | 2.0 – 2.4 |
| Asthma | 3.0 – 7.0 |

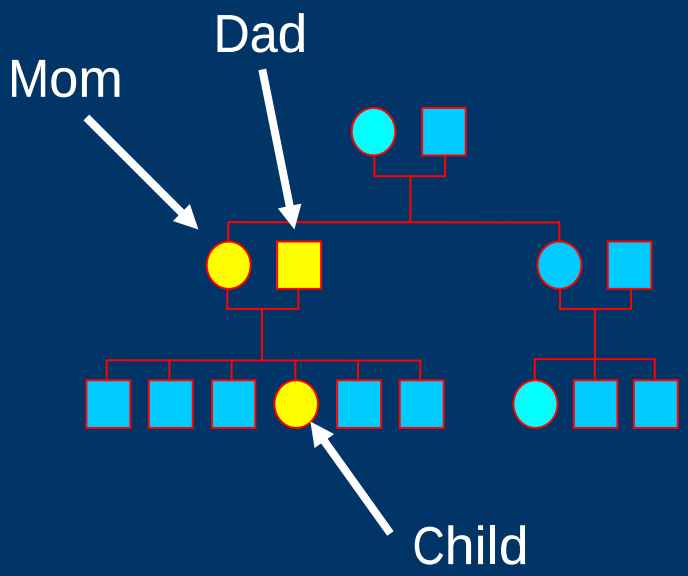
Am J Prev Med
February 2003

# Risk factors for common diseases – Family History



# Risk factors for common diseases – Family History




Type 2 Diabetes

# Usefulness of Cardiovascular Family History Data for Population-Based Preventive Medicine and Medical Research (The Health Family Tree Study and the NHLBI Family Heart Study)

Roger R. Williams, MD*, Steven C. Hunt, PhD, Gerardo Heiss, MD, PhD, Michael A. Province, PhD, Jeannette T. Bensen, MS, Millicent Higgins, MD, Robert M. Chamberlain, PhD, Joan Ware, MSPH, and Paul N. Hopkins, MD, MSPH

Detailed medical family history data have been proposed to be effective in identifying high-risk families for targeted intervention. With use of a validated and standardized quantitative family risk score (FRS), the degree of familial aggregation of coronary heart disease (CHD), stroke, hypertension, and diabetes was obtained from 122,155 Utah families and 6,578 Texas families in the large, population-based Health Family Tree Study, and 1,442 families in the NHLBI Family Heart Study in Massachusetts, Minnesota, North Carolina, and Utah. Utah families with a positive family history of CHD (FRS ≥0.5) represented only 14% of the general population but accounted for 72% of persons with early CHD (men before age 55 years, women before age 65 years) and 48% of CHD at all ages. For strokes, 11% of families with FRS ≥0.5 accounted for 86% of early strokes (<75 years) and 68% of all strokes. Analyses of >5,000 families sampled each year in Utah for 14 years demonstrated a gradual decrease in the frequency of a strong positive family history of CHD (−26%/decade) and stroke (−15%/decade) that paralleled a decrease in incidence rates ($r = 0.86$, $p < 0.001$ for CHD; $r = 0.66$, $p < 0.01$ for stroke). Because of the collaboration of schools, health departments, and medical schools, the Health Family Tree Study proved to be a highly cost-efficient method for identifying 17,064 CHD-prone families and 13,106 stroke-prone families (at a cost of about $27 per high-risk family) in whom well-established preventive measures can be encouraged. We conclude that most early cardiovascular events in a population occur in families with a positive family history of cardiovascular disease. Family history collection is a validated and relatively inexpensive tool for family-based preventive medicine and medical research. 

(Am J Cardiol 2001;87:129–135)

# Effects of a Controlled Family-based Health Education/Counseling Intervention

Marika Salminen, MSc; Tero Vahlberg, MSc; Ansa Ojanlatva, PhD, CHES, CSE
Sirkka-Liisa Kivelä, MD, PhD

*Objective*: To describe the effects of a controlled family-based health education/counseling intervention on health behaviors of children with a familial history of cardiovascular diseases (FH-CVDs). *Methods*: The intervention group (IG, n=432) received 5 counseling sessions. The control groups 1 (CG1, n=200) and 2 (CG2, n=423) received no counseling. Outcome measures comprised changes in diet, exercise, and cigarette smoking. *Results*: The changes in the use of fats and salt, and in exercise, were more favorable in IG than in CG1 and/or CG2. *Conclusion*: Health education/counseling produced positive effects on diet and nutrition in particular and in part in exercise.

*Key words*: adolescent, child, early intervention, health behaviors, primary prevention

*Am J Health Behav.* 2005;29(5):395-406

# Family History

## How can we use family health history to...

- assess risk for common diseases
- influence early disease detection
- target and prioritize prevention strategies

# Why focus on family history...

....as a public health strategy when it's pretty obvious what we need to do to prevent common chronic diseases?

Exercise more

Eat a healthier diet

Stop smoking

Drink alcohol in moderation

Take an aspirin per day

See your doctor

Get screened

Etc.

# Prevention Efforts - Obesity

Prevalence of overweight and obesity among U.S. adults, age 20-74

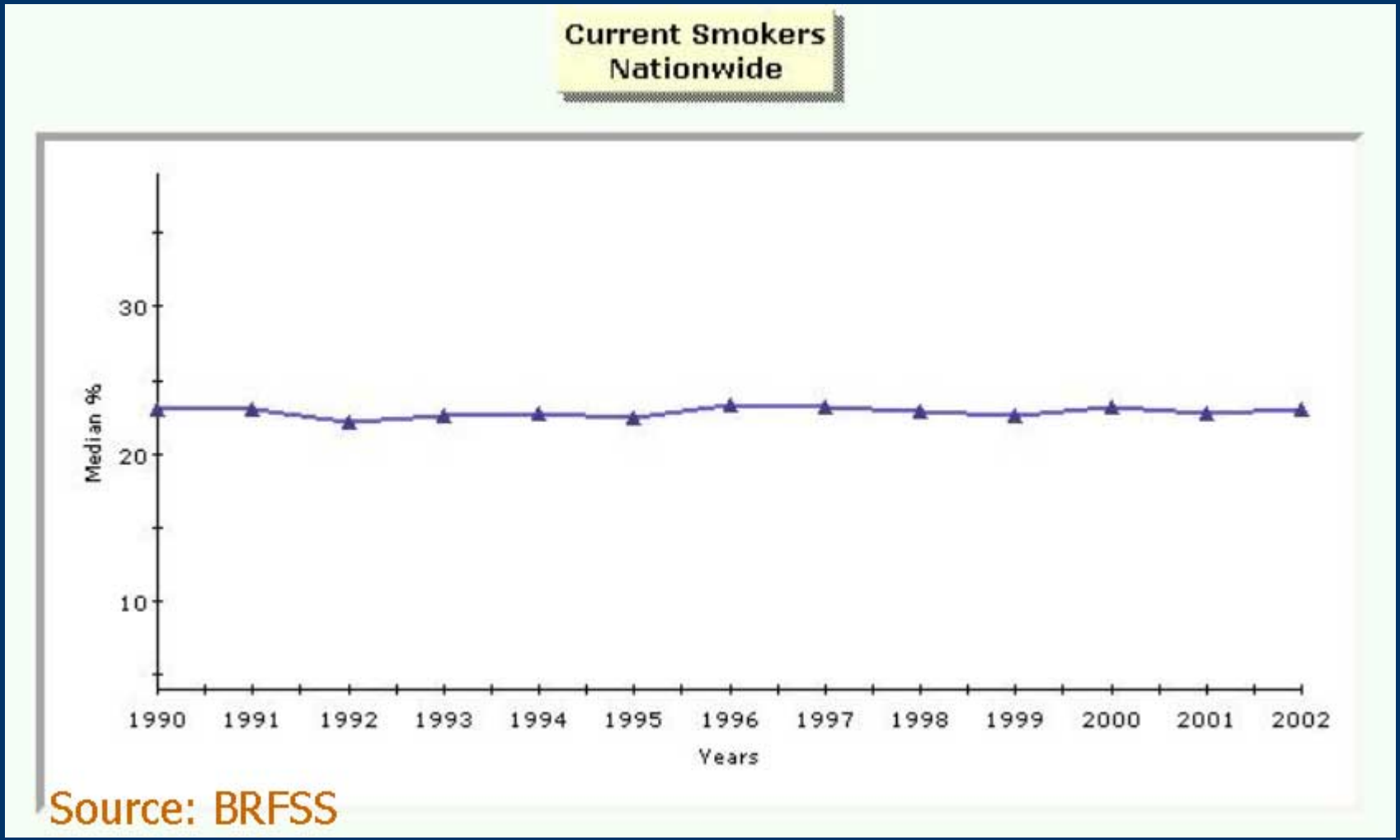
| | *NHANES II (1976-80)* | *NHANES III (1988-94)* | *NHANES (1999-2002)* |
|---|---|---|---|
| **Overweight or obese (BMI >=25.0)** | 47 | 56 | 65 |
| **Obese (BMI >=30.0)** | 15 | 23 | 31 |

# Prevention Efforts - Lack of Physical Activity

59% of adults do not engage in vigorous leisure-time physical activity lasting 10 minutes or more per week

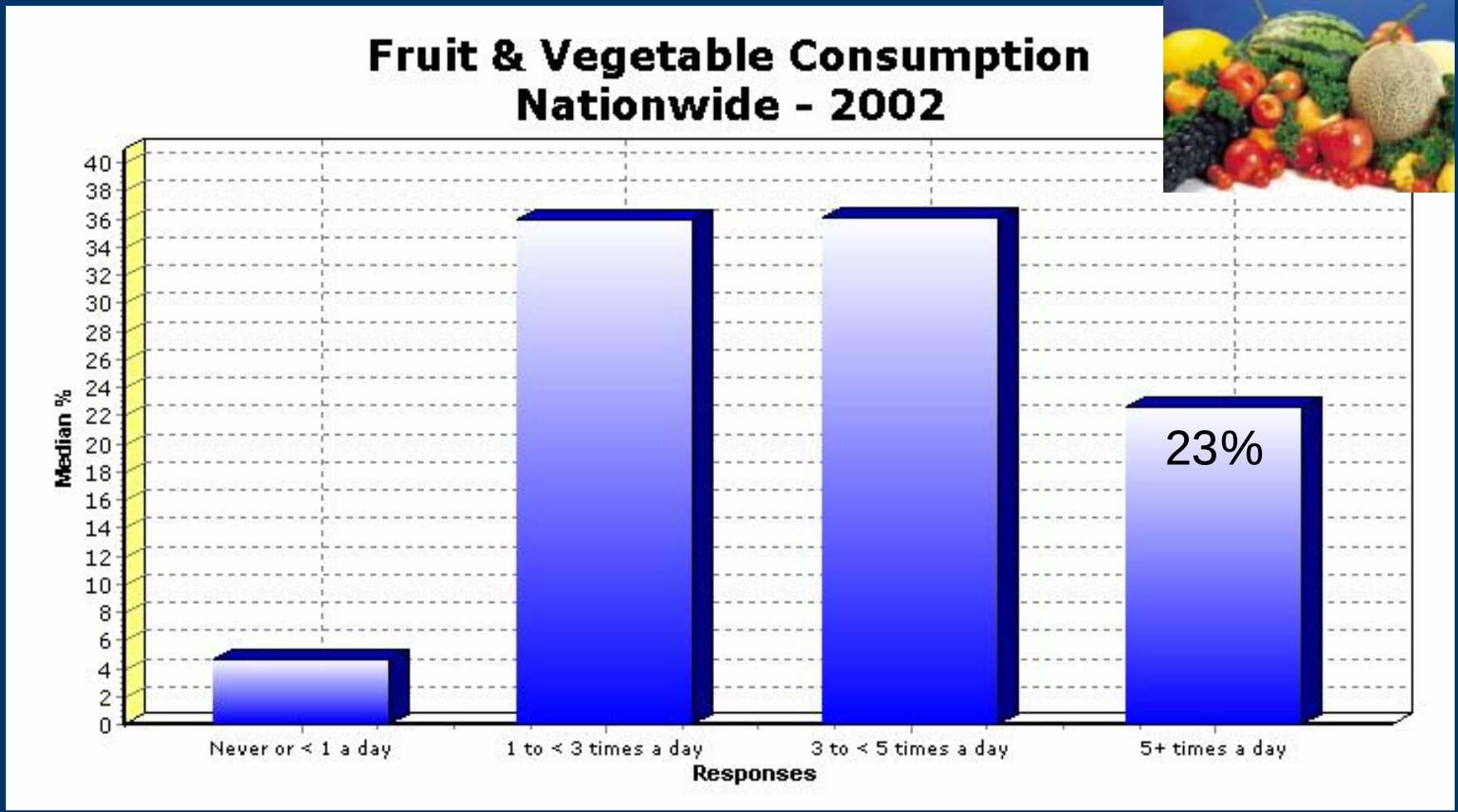
Source: NHIS, 2002

# Prevention Efforts - Smoking




Source: BRFSS

# Prevention Efforts– Poor Diet




Source: BRFSS

# Prevention Efforts– Colorectal cancer screening

- Only 45% of men and 41% of women aged ≥50 years had undergone a flexible sigmoidoscopy or colonoscopy within the previous 10 years or had used a FOBT home test kit within the preceding year
  CDC's 2000 NHIS

- Approximately 41.8 million average-risk persons aged ≥50 years have not been screened for colorectal cancer according to national guidelines
  CDC's National Survey of Endoscopic Capacity

# What is the added value of family history?

- One size fits all population approach to prevention has limits
- Augment with targeted and personalized prevention strategies focused on higher-risk families
- Awareness of familiar risk may be a motivating factor for behavior change and screening uptake
- Family-centered approaches to risk reduction may have longer impact
- Earlier or more frequent screening based on familial risk may be cost effective

# Goals of Family History Initiatives

- Increase awareness among the public and health professionals of the value of family history for disease prevention and health promotion
- Provide tools to gather information, assess risk, and guide prevention strategies; and educational materials to facilitate communication about familial risk between patients and providers
- Increase genomics and health literacy
- Prepare the public and health professionals for the coming era in which genomics will be an integral part of regular health care

# U.S. Surgeon General's Family History Initiative






# U.S. Surgeon General's Family History Initiative

- November 8, 2004
  - Formal announcement of the initiative
  - Release of My Family Health Portrait

My Family Health Portrait
A tool from the U.S. Surgeon General

- Thanksgiving Day, 2004

  First Annual National Family History Day

Your Family Health Portrait

File Edit Help

My Family Health Portrait
A tool from the U.S. Surgeon General

## Welcome to Your Family Health Portrait

Your Family Health Portrait allows you to create a personalized family health history based on information you provide about you and your family's experience with the leading diseases.

Your Family Health Portrait should only be used in consultation with a healthcare professional. It can be a valuable tool for discussion, risk assessment, and medical advice.

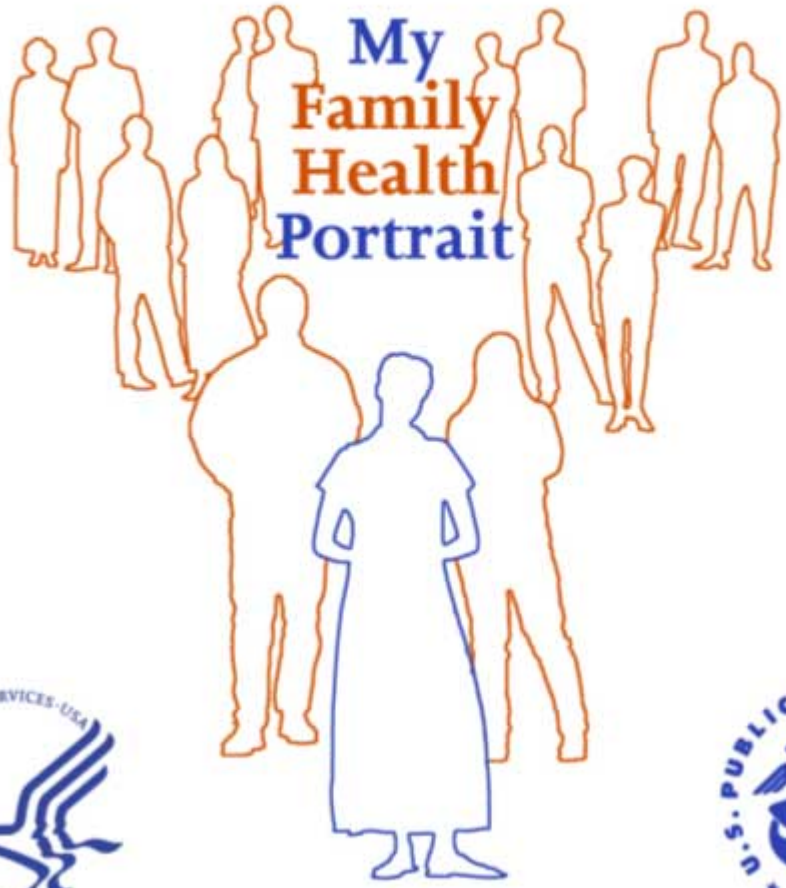
New Users Start Here ▶

Returning Users ▶

Information you provide is stored on your computer's hard drive and is only as secure as that drive. Please take appropriate precautions to protect sensitive information. For general questions about security and privacy, click here.

http://www.hhs.gov/familyhistory/

# U.S. Surgeon General's Family History Initiative




# La iniciativa de Historial Familiar del Cirujano General

# U.S. Surgeon General's Family History Initiative

1. My Family Health Portrait – new easy to use web-based tool

2. Resource packets for health departments and community groups

   - Fact sheets
   - FAQs
   - Case Studies
   - Web resources
   - Electronic and hard copies of FHx tools
   - Presentations
   - Brochures and posters

CDC Home | Search | Health Topics A-Z

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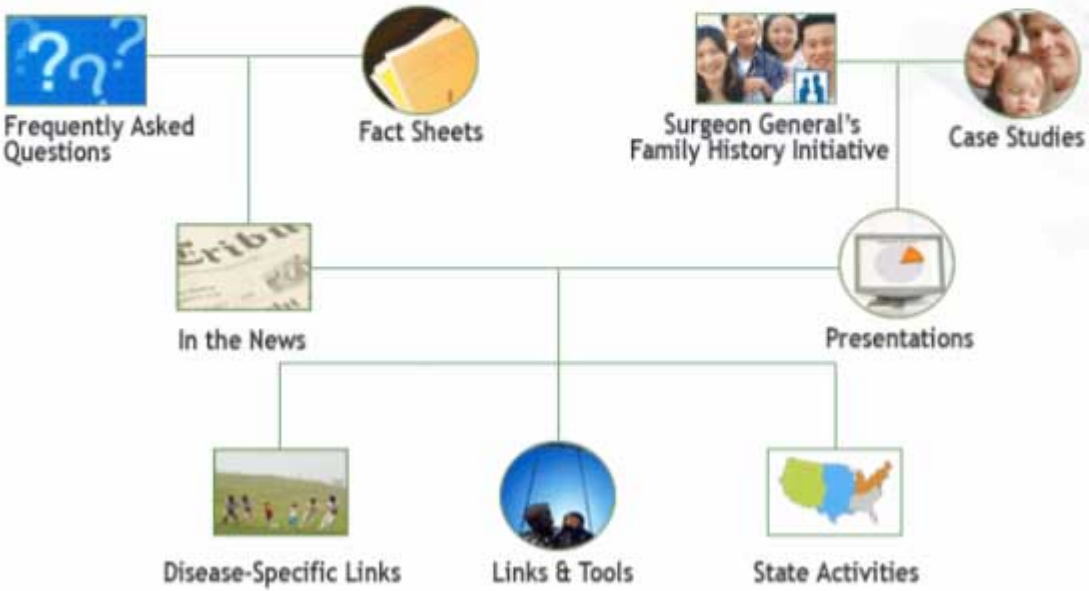
# Genomics and Disease Prevention

EVENTS | TRAINING | FUNDING | LINKS | SEARCH GENOMICS

home > general public > family history

## General Public


*Using Family History to Promote Health*




Top of page



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Family Healthware

*Using Family History to Promote Health*

## Welcome to Family Healthware

Family Healthware is a tool that collects information on your:

- lifestyle behaviors
- use of screening tests
- family history of six major diseases

and produces a personalized report that:

- analyzes your family history as a risk factor for disease
- recommends screening, lifestyle and other changes to improve your health.

Click below to learn about:

Using Family Healthware

Family history and health

Privacy policy

### New Users

Begin your Family Healthware assessment today...

Create My Account

### Returning Users

Username:

Password:

Go

Forgot your username or password?

Family Healthware is not designed to replace medical advice and discussions with a health professional. You should talk to your health professional before making a decision about your medical care.

# Incorporating family history into programs

- Collect family history data at state and local levels
  - BRFSS
  - Health interview surveys
  - Focus groups
- Include family history data in disease registries (cancer, birth defects)
- Increase family history awareness in the community
- Incorporate family history into prevention/risk reduction activities

# Family history is a risk factor for diseases throughout all stages of life

birth defects
blood disorders

diabetes
depression

Alzheimer's disease
osteoporosis

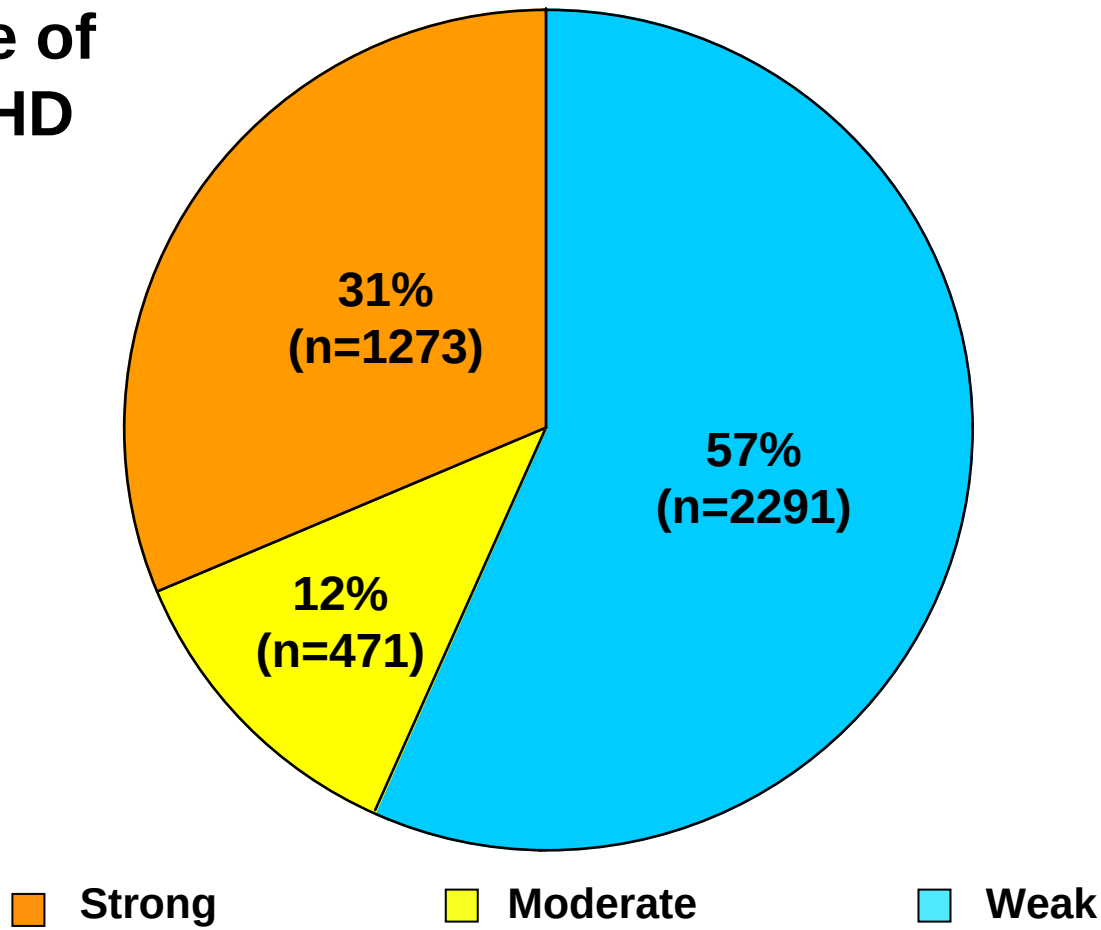
infants | children | adolescents | adults | older adults

asthma
autism

cancer
heart disease

# ❖ Establish disease-specific prevalence estimates of FHx

**Prevalence of Familial CHD**




Scheuner et al. Healthstyles 2003

# ❖ Develop and validate familial risk stratification algorithms

| | OR[a] | 95% CI |
|---|---|---|
| **Strong Familial Risk** n=1273 (31%); 1.86 criteria met per subject ***At least . . .*** | | |
| Two 1st deg early CHD, same lineage | **4.1** | **2.5-6.7** |
| One 1st deg early CHD + one 1st deg late CHD, same lineage | **2.6** | **1.6-4.1** |
| One 1st deg early CHD | **3.6** | **2.6-4.9** |
| Two 1st deg late CHD, same lineage | **2.5** | **1.4-4.4** |
| One 1st deg late CHD + one 2nd deg early CHD, same lineage | **2.4** | **1.6-3.7** |
| One 1st deg late CHD + two 2nd deg late CHD, same lineage | **2.6** | **1.6-4.3** |
| Two 2nd deg early CHD, same lineage | **3.3** | **2.3-4.6** |
| One 2nd deg early CHD + two 2nd deg late CHD, same lineage | **3.6** | **2.4-5.5** |
| **Moderate Familial Risk** n=471 (12%); 1.25 criteria met per subject ***Only . . .*** | | |
| One 1st deg late CHD + one 2nd deg late CHD, same lineage | **1.6** | **0.8-30** |
| Mother and father late CHD | **2.2** | **1.2-4.0** |
| One 1st deg late CHD | **2.1** | **1.5-2.9** |
| One 2nd deg early CHD + one 2nd deg late CHD, same lineage | **1.1** | **0.5-2.2** |
| Two 2nd deg late CHD, same lineage | **2.5** | **1.7-3.6** |
| **Weak Familial Risk** n=2291 (57%); 1.01 criteria met per respondent ***Only . . .*** | | |
| One 2nd deg early CHD (one or both sides of family) | **1.5** | **0.6-4.1** |
| One 2nd deg late CHD (one or both sides of family) | **0.9** | **0.3-3.0** |
| No family history of CHD | **1.0** | **(referent group)** |



Scheuner et al. Healthstyles 2003

- Determine if FHx modifies the association between disease and other risk factors

# Diabetes Risk Factors by Family History Risk Category

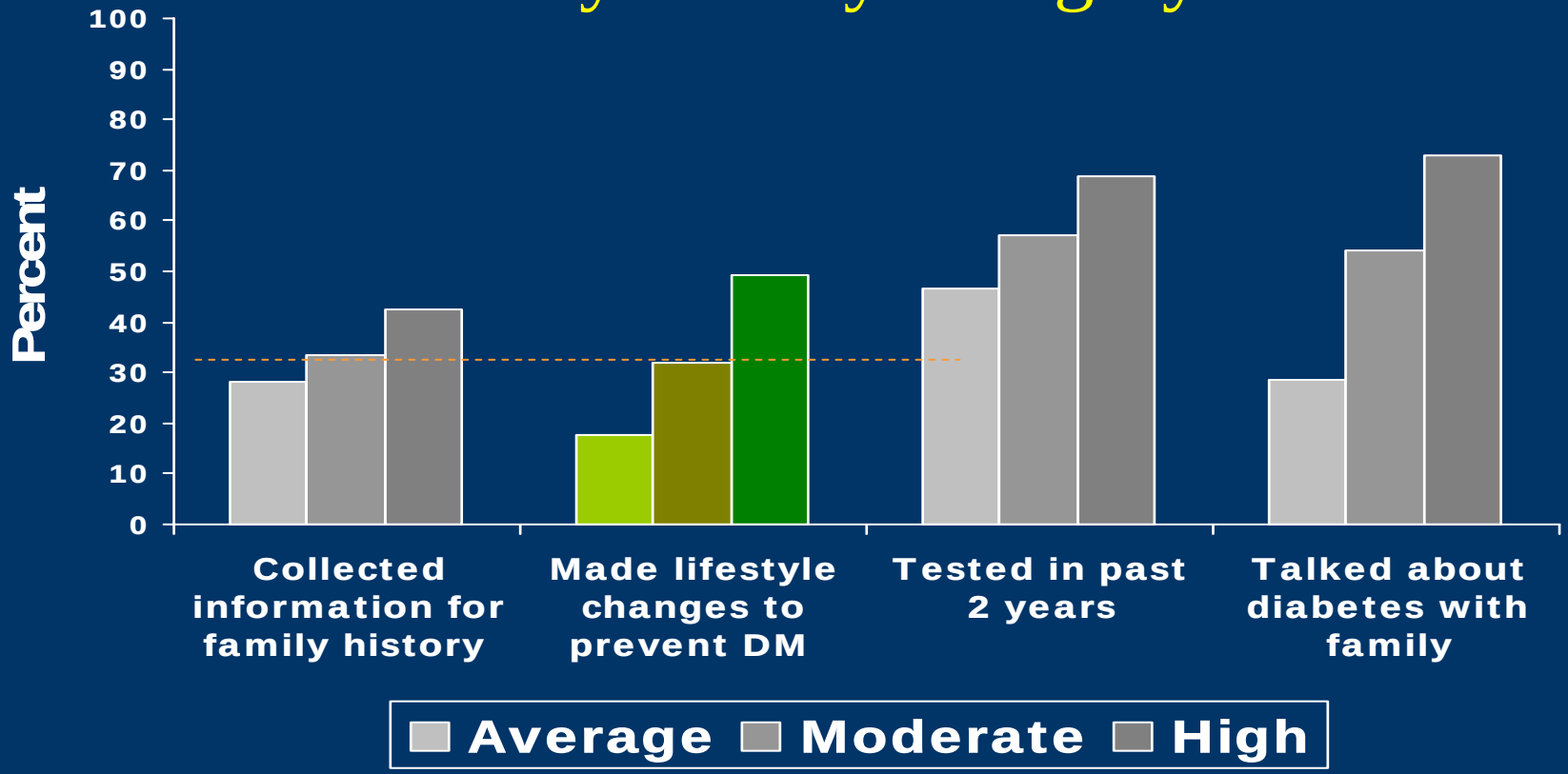
| Risk factors* | Average risk (n=2791) | Moderate risk (n=843) | High risk (n=711) |
|---|---|---|---|
| **Obesity (BMI >=30)** | 14% | 19% | 27% |
| **Did not meet exercise guidelines** | 62% | 63% | 60% |

*Mantel-Haenszel Chi square test for equal proportions significant at p <0.001 for all variables

Hariri et al. Healthstyles 2004

- Assess associations between familial risk and risk-reducing behaviors

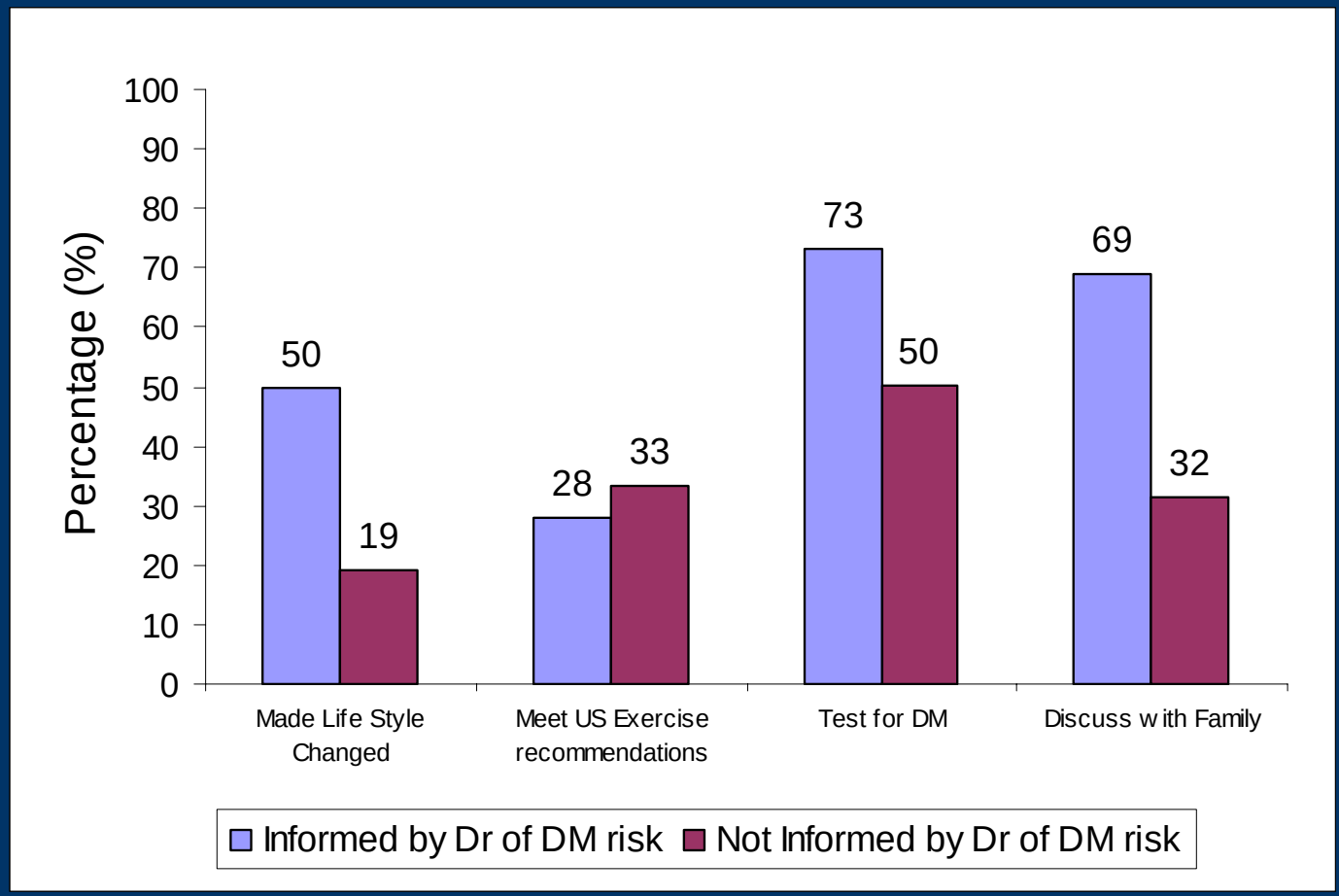
# Risk-reducing and Risk-aware Behaviors by Family History Category




Hariri et al. Healthstyles 2004

- Examine knowledge, attitudes, and practice of collecting family histories – individuals and clinicians

## Doctor informed respondent of familial DM risk by behaviors




Qureshi et al. Healthstyles 2004

# Family history data collection

- Need to standardize questions and modules

Have any of your blood relatives ever been diagnosed with asthma?

Yes No

Have any of your first degree relatives (mother, father, siblings, children) ever been diagnosed with asthma?

Yes No

How many of your first degree relatives were diagnosed with asthma?

One Two Three Four or more

# Family history data collection

## Family history of CHD example:

1. Have you ever been diagnosed by your doctor as having coronary heart disease (e.g., myocardial infarction, coronary bypass graft surgery or angioplasty)

2. Has your mother ever been diagnosed as having coronary heart disease?

3. Has your father ever been diagnosed as having coronary heart disease?

Yes, at or before aged 60 Yes, after age 60 NO DK

4. How many of your brothers and sisters have been diagnosed with coronary heart disease at or before age 60?

5. How many of your brothers and sisters have been diagnosed with coronary heart disease after age 60?

6. How many of your mother's relatives (her sisters, brothers and parents) were diagnosed with coronary heart disease at or before age 60?

7. How many of your mother's relatives (her sisters, brothers and parents) were diagnosed with coronary heart disease after age 60?

8. How many of your father's relatives (his sisters, brothers and parents) were diagnosed with coronary heart disease at or before age 60?

9. How many of your father's relatives (his sisters, brothers and parents) were diagnosed with coronary heart disease after age 60?

None One Two or more DK

# Increasing awareness about family history in the community

- Convene community presentation/discussions – churches, libraries, schools, hospitals, health fairs, etc
- Develop resource packets - videos, powerpoint presentations, case studies, fact sheets, family history tools, etc
- Partner with local companies (Olin Mills, Sears, Penny's, etc) to include family history themed materials in their studios.
- Develop materials for doctors offices, hospitals and clinics

# Increasing awareness about family history in the community

- Sponsor poster contest for students
- Develop continuing education modules for health dept personnel
- Write articles for local newspapers (include local case studies)
- Identify a champion to work with
- Your ideas???

# How can you collect your family history?

- Ask questions
- Talk at family gatherings
- Draw a family tree
- Write down the information
- Look at death certificates, family medical records, etc.

Sample slides

# What information do you need?

- Major medical conditions and causes of death
- Age when disease diagnosed and age at death
- Ethnic background
- Lifestyle factors like heavy drinking and smoking

*Example:*

Uncle Bill – smoked cigarettes since he was a teenager, had a heart attack at age 52

Sample slides

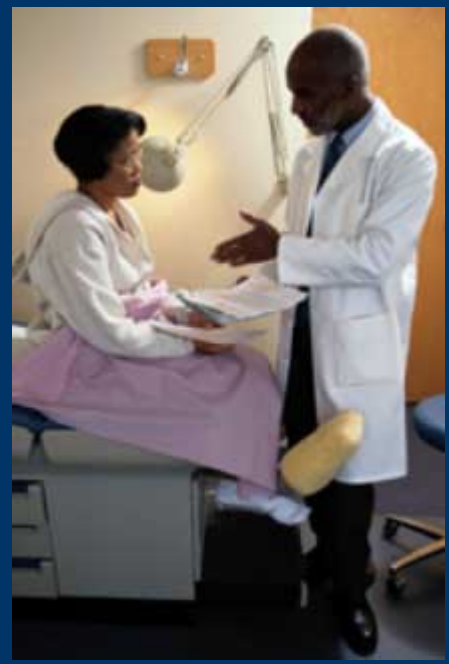
# What relatives should be included?

- you
- children
- siblings
- parents
- grandparents
- aunts and uncles
- nieces and nephews

Sample slides

# What should you do with the information?

- Organize the information
- Share it with your doctor
- Keep it updated
- Pass it on to your children



Sample slides

# What will your doctor do with the information?

- Determine your risk for disease based on:
  - Number of family members with the disease
  - The age when they were diagnosed
  - How you are related to the family member
- Consider other disease risk factors
- Recommend screening tests and lifestyle changes



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# Incorporate family history in prevention/risk reduction activities

Example - Assessment of BMI in schools:

- Identify affected sibships (families at highest risk i.e., those with more than one overweight child in the school system)
- Conduct assessment of additional risk factors and health problems including family history of chronic diseases associated with obesity (cardiovascular disease, diabetes, cancer)
- Work with high risk families to change their unhealthy behaviors and increase screening uptake. Engage local health departments, schools, YMCA's, etc.

# For more information

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Office of Genomics and Disease Prevention
Website: http://www.cdc.gov/genomics