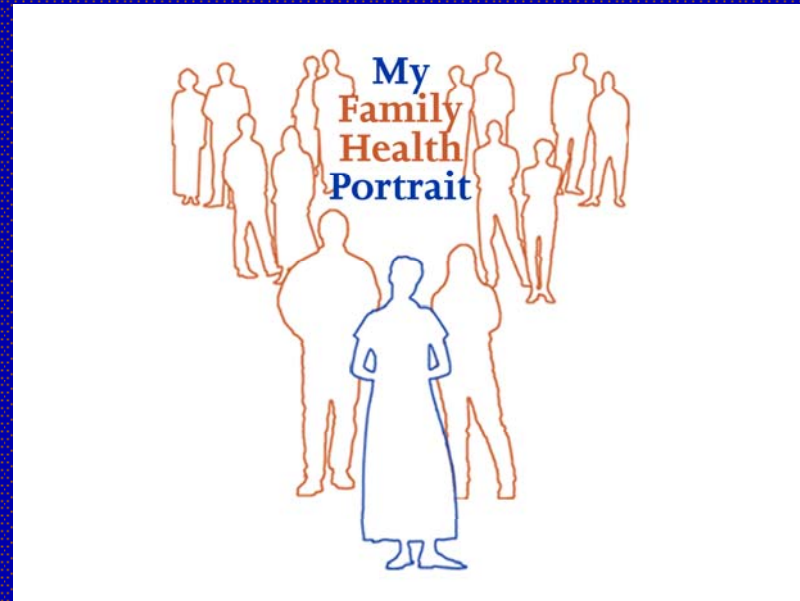


# The U.S. Surgeon General's Family History Initiative: Modeling collaboration, communication, and consumer outreach to improve health



Jean Jenkins PhD, RN  
September 13, 2006



# The U.S. Surgeon General's Family History Initiative: Collaboration



# Why Family History?

- Most diseases are due to interactions of multiple genes and environmental factors.
- Almost every patient has available today, a free, personalized tool that captures many of these interactions and can serve as the cornerstone for individualized disease prevention and health promotion.
- This valuable, free, and well-proven tool is the family history.

# Why Family History?

- Although we will gain important new genomic tools, family history will remain highly relevant for years.
- Family history helps predict risk for varied health concerns;
- Yet, many people are unaware of relatives' medical histories, and many health professionals underutilize this information in advising patients on how to maintain good health.

**"Why Now?"-to improve the  
public's health:  
Communication**

# Goals of the Surgeon General's Family History Initiative: Consumer Outreach

- Increase the American public's awareness of the importance of family history in health;
- To provide accessible, user-friendly methods (web-based & print) to collect and record family history to improve their health;
- Increase the awareness of health professionals about the importance of family history in disease prevention and health promotion;

# Goals of the Surgeon General's Family History Initiative

- Give health professionals tools to gather, evaluate, and use family history information; and to communicate with their patients about family history;
- Increase genomics and health literacy;
- Prepare both the American public and their health professionals for the coming era in which genomics will be an integral part of regular health care.

# The Surgeon General's Family History Initiative Launch

- November 8, 2004
  - Formal announcement of the Initiative
  - Release of My Family Health Portrait
- Thanksgiving Day, 2004
  - First Annual National Family History Day
- November 15, 2005 Press Conference
  - **Web-based Tool released!**



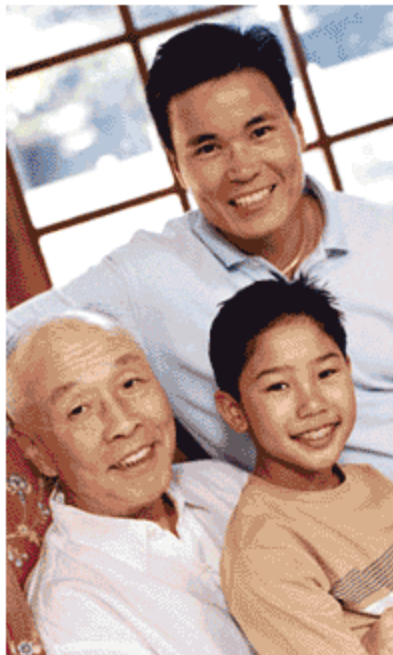
# My Family Health Portrait

A tool from the U.S. Surgeon General

**ENGLISH OR SPANISH**



Help with this page



## Welcome to My Family Health Portrait

**My Family Health Portrait** allows you to create a personalized family health history report from any computer with an Internet connection and an up-to-date Web browser. Information you provide creates a drawing of your family tree and a chart of your family health history. Both the chart and the drawing can be printed and shared with your family members or your healthcare professional. Used in consultation with your healthcare professional, your family health history can help you review your family's health history and develop disease prevention strategies that are right for you.

New users can click on **Create a Family History** to begin creating a personalized family health history. Returning users can click on **Load a Saved Family History** to edit or update an existing personalized family health history.

[Create a Family History](#)[Load a Saved Family History](#)

**My Family Health Portrait** has been tested on following browsers on Windows: Internet Explorer 5.0+, Netscape 7.0+ and Mozilla Firefox 1.0+. It has also been tested on the following browsers on Mac: Safari 1.3+, Netscape 7.0+ and Mozilla Firefox 1.0+. Internet Explorer 5.2 or lower on Mac is not a supported browser. To update your browser, visit the [Browser Update](#) page.

### Additional Information

Since **My Family Health Portrait** is Web-based, no additional software needs to be downloaded or installed. The health information you provide is stored only on your computer and not on a U.S. government server. You own the file and can choose what to do with it at any time.

With My Family Health Portrait, you can:



Address https://familyhistory.hhs.gov/selfInfo.cfm?

Go



Help with this page

## My Profile - Personal Information

Name:

Age:

Gender:  Male  Female

Weight (lbs.):

Height:  Feet  Inches

## Steps toward completing My Family Health Portrait

- Enter your personal information**
- Enter your health history
- Create family

## Health History for Sally [Me]

Name:

Gender:  Male  Female

Are you an identical twin?  Yes  No

Disease	Yes	No	Don't know	Age at first diagnosis
Heart Disease <a href="#">?</a>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	
Stroke <a href="#">?</a>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	
Diabetes <a href="#">?</a>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	At age 40-49 <input type="button" value="v"/>
Colon Cancer <a href="#">?</a>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	Select age: In infancy Before age 20 At age 20-29 At age 30-39 At age 40-49 At age 50-59 60 and older Diagnosis age unknown
Breast Cancer <a href="#">?</a>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	
Ovarian Cancer <a href="#">?</a>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	

[?](#) [Disease Definitions](#)

Additional Diseases (Optional): [?](#) [Help for Additional Diseases](#)


## Steps toward completing My Family Health Portrait

- Enter your personal information
- Enter your health history**
- Create family





[← Back to My Family](#)






[Help with this page](#)

## Health History for James [Father]

Name:

Is this person still living?  Yes  No  Unknown

Is your father an identical twin?  Yes  No

Disease	Yes	No	Don't know	Age at first diagnosis
Heart Disease 	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	
Stroke 	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	
Diabetes 	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	
Colon Cancer 	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="text" value="60 and older"/>
Breast Cancer 	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	

 [Disease Definitions](#)

Additional Diseases (Optional):  [Help for Additional Diseases](#)


## Health History for Family Members

- [Sally \[Me\]](#)
- [Carol \[Mother\]](#)
- [Jean \[Mother's Mother\]](#)
- [Carl \[Mother's Father\]](#)
- [Father]**
- [Vivian \[Father's Mother\]](#)
- [Theodore \[Father's Father\]](#)
- [Jennifer \[Daughter 1\]](#)
- [Deana \[Daughter 2\]](#)

[← Back to My Family](#)



[Go to My Family >](#)

## Congratulations!

**You have successfully created a new family health history!**


You may now proceed to the **My Family** page, by clicking the **Go to My Family** button in the top right corner. If you are a new user and need help with the My Family page, please go to **Help with this page**, which is included on every page.

[Help](#) | [Glossary](#) | [FAQs](#) | [Accessibility](#) | [Privacy and Security Policy](#) | [About My Family Health Portrait](#)



## My Family

<a href="#">Sally [Me]</a>	<div style="width: 100%; background-color: green;"></div>	*
<a href="#">Carol [Mother]</a>	<div style="width: 100%; background-color: green;"></div>	*
<a href="#">Jean [Mother's Mother]</a>	<div style="width: 75%; background-color: green;"></div>	*
<a href="#">Carl [Mother's Father]</a>	<div style="width: 75%; background-color: green;"></div>	*
<a href="#">James [Father]</a>	<div style="width: 100%; background-color: green;"></div>	*
<a href="#">Vivian [Father's Mother]</a>	<div style="width: 100%; background-color: green;"></div>	*
<a href="#">Theodore [Father's Father]</a>	<div style="width: 100%; background-color: green;"></div>	*
<a href="#">Jennifer [Daughter]</a>	<div style="width: 100%; background-color: green;"></div>	<a href="#">Delete</a>
<a href="#">Deana [Daughter]</a>	<div style="width: 100%; background-color: green;"></div>	<a href="#">Delete</a>

 **Note:** The percent of green in the progress bars is a rough indicator of how much of the information has been entered for each relative.

\* You can't delete yourself, your parents or your grandparents.

## Actions:

[View Reports \(family tree drawing, health history chart\)](#)

[Add Family \(aunts, uncles, etc.\)](#)

[Edit My Profile \(age, height, weight, etc.\)](#)

 [Save My Health Information to My Computer](#)

[Save My Health Information as Another Relative \(for a parent, a child, or sibling, etc.\)](#)

[Start Over \(create a new history, or load a saved history\)](#)

**My Family Health Portrait - Chart Report**  
Sally - November 14, 2005

My 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.

Age: 45  
Height: 5' 4"  
Weight: 160  
Body Mass Index: 27.4

	Heart Disease	Stroke	Diabetes	Colon Cancer	Breast Cancer	Ovarian Cancer	Additional Diseases
<b>Sally [Me]</b>	No	No	Yes, At age 40-49	No	No	No	
<b>Carol [Mother]</b>	No	No	Yes, At age 50-59	No	No	No	Osteoarthritis [60 and older]
<b>Jean [Mother's Mother]</b>	No	No	Yes, At age 50-59	No			
<b>Carl [Mother's Father]</b>	Yes, 60 and older					N/A	
<b>James [Father]</b>	No	No	No	Yes, 60 and older	No	N/A	
<b>Vivian [Father's Mother]</b>	No	No	No	No	No	No	Blood cancer [At age 30-39]
<b>Theodore [Father's Father]</b>	Yes, 60 and older	No	No	No	No	N/A	Emphysema [At age 50-59]
<b>Jennifer [Daughter]</b>	No	No	No	No	No	No	Asthma [Before age 20]
<b>Deana [Daughter]</b>	No	No	No	No	No	No	

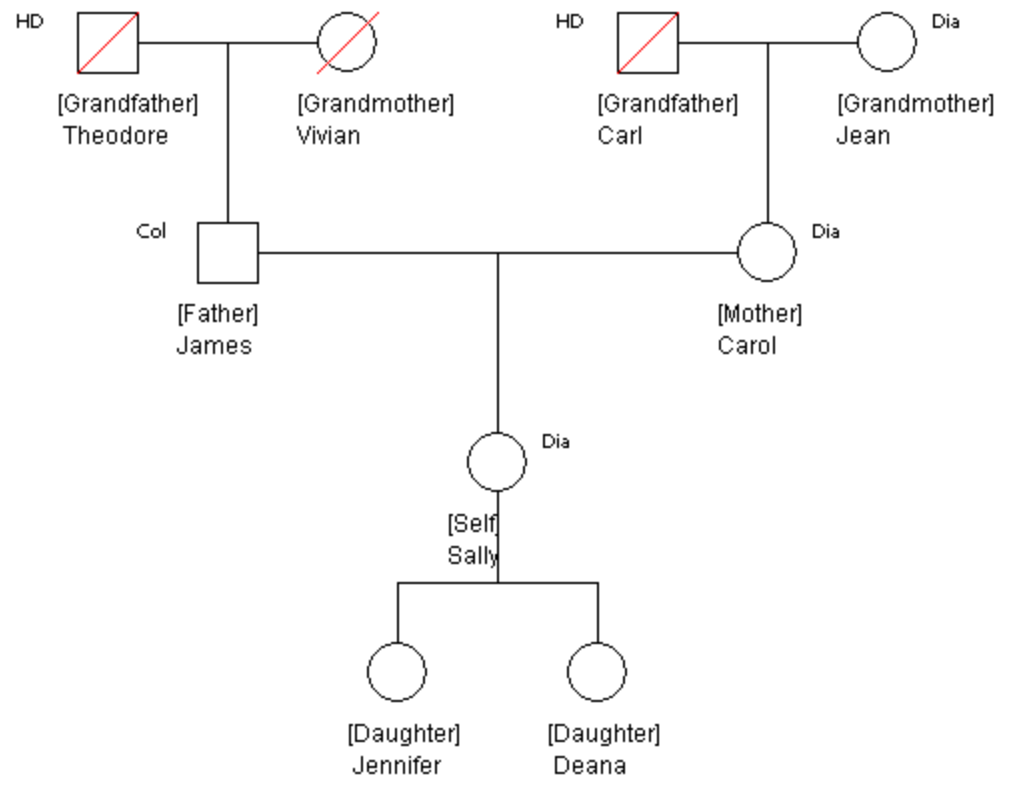


\* You will need [Adobe Acrobat Reader](#) to print the Drawing Report

### My Family Health Portrait - Drawing Report

Sally - November 14, 2005

<input type="checkbox"/> - Male Family Member	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> - Family Members with a History of Disease	
<input type="checkbox"/> - Female Family Member	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> - Deceased Family Member	
HD - Heart Disease	Str - Stroke	Dia - Diabetes
Col - Colon Cancer	BrC - Breast Cancer	OvC - Ovarian Cancer





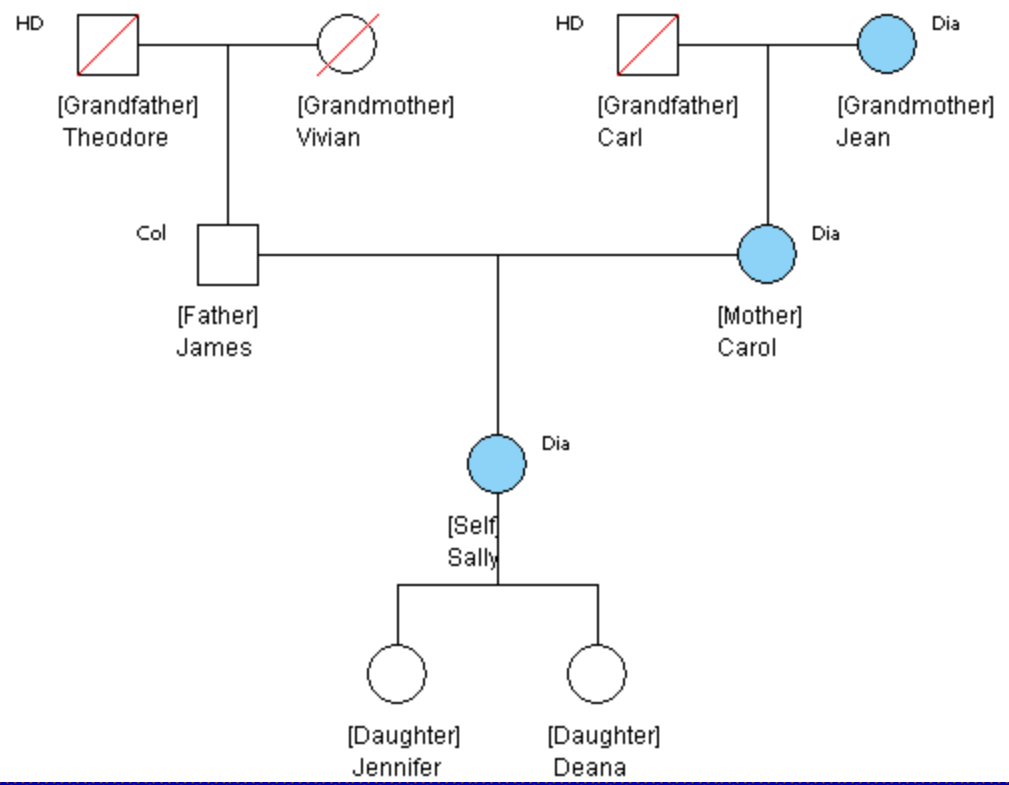
\* You will need [Adobe Acrobat Reader](#) to print the Drawing Report

### My Family Health Portrait - Drawing Report

Sally - November 14, 2005

Highlighted disease: Diabetes

<input type="checkbox"/> - Male Family Member	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> - Family Members with a History of Disease	
<input type="checkbox"/> - Female Family Member	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> - Deceased Family Member	
HD - Heart Disease	Str - Stroke	Dia - Diabetes
Col - Colon Cancer	BrC - Breast Cancer	OvC - Ovarian Cancer





## Add Family

Only add family members that are biological (blood) relatives (not adopted or step relatives). For extended family members, add the parents before you add the children. For example, add your aunts and uncles before adding your cousins.

Family Members	Number of people entered	Number of people to add
Daughters	2	<input type="text" value="0"/>
Sons	0	<input type="text" value="0"/>
Sisters	0	<input type="text" value="0"/>
Brothers	0	<input type="text" value="0"/>
Half Sisters	0	<input type="text" value="0"/>
Half Brothers	0	<input type="text" value="0"/>
Father's Sisters (Aunts)	0	<input type="text" value="0"/>
Father's Brothers (Uncles)	0	<input type="text" value="0"/>
Mother's Sisters (Aunts)	0	<input type="text" value="0"/>
Mother's Brothers (Uncles)	0	<input type="text" value="0"/>
Nieces (Siblings' Daughters)	0	<input type="text" value="0"/>
Nephews (Siblings' Sons)	0	<input type="text" value="0"/>
Female Cousins	0	<input type="text" value="0"/>
Male Cousins	0	<input type="text" value="0"/>





[← Back to My Family](#) [Help with this page](#)

## Save My Data as Another Relative

The **Save My Data as Another Relative** function allows you to create a file centered on one of your relatives instead of yourself. You can then give the file to that relative so that they can create their own family health history without having to start from scratch. For example, you could save your data centered around a daughter. When she loads the file the only information she will need to enter is her personal information (weight, height) and relatives that aren't part of your Family Health Portrait (e.g., her mother and her mother's parents). Please refer to the instructions below to save your data as another relative.

### Save My Data as Another Relative instructions- for Internet Explorer users on Windows

Read all of the instructions before you start because you will not be able to view the instructions after you begin.

1. Select a relative from the **Relative** drop-down menu and click the **Go!** button.

The Relative drop-down menu is below the instructions.

2. Click the **Save** button.

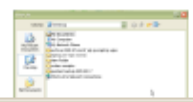
Do NOT click the **Open** button or the **Cancel** button.



Figure 2 (Click to enlarge image)

3. Select the folder for the file to be saved into.

Choose a file name. You can either choose the preset filename (**myFamilyHistory-for-relative.htm**) or type in another name for the



This is a new window. Please [close this window](#) to return to the "My Family Health Portrait" tool.

## Help Topics

[About Help](#)

[Welcome to My Family Health Portrait](#)

✓ [Load a Saved Family History](#)

[Personal Information](#)

[Health History \[Me\]](#)

[Create Family](#)

[Health History \[Relative\]](#)

[My Family](#)

[Add Family \(Aunts...\)](#)

[Save My Health Info to My Computer](#)

[Save My Health Info as Another Relative](#)

[View Reports](#)

[Drawing Report](#)

[Chart Report](#)

## Help for Load a Saved Family History

Clicking the **Load a Saved Family History** button on the **Welcome to My Family Health Portrait** page takes you to the **Load a Saved Family History** page. On the Load a Saved Family page, there is a space that looks like a text box, a **Browse** button and a **Load my File** button. Though the space before the Load my File button looks like a text box, it is highly recommended that you do not type any text into that space unless you know for sure the exact file location. Typing text with anything other than the exact path of the file location and clicking the Load button will not load the file.

**Note:** For those who use the **Safari** Web browser on Macintosh operating systems, you will not see any space that resembles a text box. You will only see a **Choose File** button and an **Load my File** button. Clicking on the **Choose File** button will perform the same action as the Browse button would on other browsers.

You will not be able to open a health history from the downloadable Windows version of My Family Health Portrait using the Web version. Files created from the downloadable windows version can only be opened using the downloadable Windows version. This is the reason the downloadable Windows version will still be available.

### Loading a File

To begin loading a previously saved file from the Load a Saved Family History page, follow these steps:

1. Click the **Browse** button to open a **File Upload** dialog box.  
Safari users: You will see a **Choose File** button instead of a Browse button.
2. With the File Upload dialog box open, select your saved file and click the **Open** button to close the dialog box.  
Make sure that the file you selected is the same file as the file you last saved and ends with an .htm or .html.
3. Click the **Load my File** button to finish the process.

**Note:** You can also load a previously saved file by manually locating the file on your computer or from a disk and double-clicking on the file, if you find that easier.

This is a new window. Please [close this window](#) to return to the "My Family Health Portrait" tool.

# Since the launch of the Initiative on November 8, 2004

- The Initiative has been highlighted in more than 1000 media stories
- The web-based version has been downloaded over 160,000 times
- The print version of the tool (available in English or Spanish) has been requested 85,000 times

# To obtain the “My Family Health Portrait” tool:

- 1) Download the web- based tool from <https://www.hhs.gov/familyhistory>
- 2) Download the PDF of the print tool from <http://www.hhs.gov/familyhistory>
- 3) Order a free copy of the print version through the HRSA Information Center at 1-888-Ask HRSA or [www.ask.hrsa.gov](http://www.ask.hrsa.gov)

# Family History

- Knowledge of a positive family history does not always translate to improvement in
  - Accuracy/reliability of information (stigma)
  - Sharing of information to healthcare providers(HCP) and other family members
  - Utilization of information by the family/HCP
  - Screening recommendation follow-up
  - Risk-reducing lifestyles

# Hopes and Fears

Main concern of consumer:

What can be done to improve the  
outcome of my health?

*Awareness, interest,  
access, outcomes,  
decisions, fears of  
discrimination*

# Policy and Process

- Federal/State protection
- Access to services
- Family relationships
- Recognition of importance of health promotion and disease prevention

[www.nchpeg.org](http://www.nchpeg.org)

- **Online family history newsletter**
  - Eight issues posted (30,000 copies)
  - Challenges: core competencies, slide set
- **OTHER RESOURCES**
  - Packet of materials for community healthcare providers