



II. Appendices

A. Education and Outreach

Appendix 1A. Letter to the Hospital Community from Dr. Gary Gottlieb, Brigham and Women's Hospital President

Brigham and Women's Hospital's Executive Management Group provided the FHP with their full support, including a letter of support to the hospital community from Hospital President Gary Gottlieb. Dr. Gottlieb's letter was emailed to all BWH staff and was also posted on the FHP's intranet site.

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1A. Letter to the Hospital Community from Gary Gottlieb



BRIGHAM AND
WOMEN'S HOSPITAL



HARVARD
MEDICAL SCHOOL

Office of the President

75 Francis Street
Boston, MA 02115

Gary L. Gottlieb, M.D., M.B.A.
President,
Brigham and Women's Hospital

November 1st 2005

Dear BWH Community,

Brigham and Women's Hospital is known around the world as an innovative medical community with a passion that surrounds its mission's focus on caring, teaching and research. BWH's treasured history embraces an enthusiastic spirit of discovery, and, once again, our hospital has the opportunity to build on that formidable foundation. We have been given the unique opportunity to be in the national spotlight and take another step forward in the advancement of medicine.

In this spirit, I would like to introduce and encourage you to learn more about **Brigham and Women's Hospital Family History Project**. This project represents an exciting opportunity for all BWH employees to help shape the future of health care and, at the same time, promote your own health and that of your family. This will be a chance for you to work closely and collaboratively with your personal care provider and to better understand your own medical history.

The BWH Family History Project will give you the tools to organize your health information into a family tree, using the U.S. Surgeon General's "My Family Health Portrait." You can find the form to fill out at <http://familyhistory.hhs.gov>

The information you gather about your family medical history is your personal information that you may wish to share with medical professionals. The Surgeon General's hope is that you will do this to empower your physician to provide you the best in health care. The family medical history you share with your doctor will remain private and will not be provided to anyone else unless you choose to do so.

The BWH Family History Project begins this month. This is a voluntary effort. You do not have to participate if you do not wish, but I hope you will because this is a free opportunity to promote your own health and the health of your family.

If you have questions about the project please visit our Intranet site to view "[Frequently Asked Questions](#)" and an email for you to ask other questions that might not be addressed.

Here are just a couple of examples.

Why is BWH participating in this project?

A: A family history can enrich the information about your health background, and working with your own doctor, you can make decisions together about screenings or other prevention efforts for specific conditions that run in your family. This is valuable information for all of our employees to know. This is the first time that an employer has participated in such a project of national scope, and the BWH community, with its history of participating in internationally respected research studies, such as the Nurses' Health Study and the Women's Health Project, understands the leadership role it can play by engaging in this project.

What happens to the family medical history information I collect when I use the U.S. Surgeon General's 'My Family Health Portrait' tool?

A: The family medical history information is your private health history. You do not need to share it with anyone unless you so choose. We encourage you to share it with your personal physician to assist your physician in providing you the best healthcare possible.

Please join me at a Brigham and Women's hospital-wide meeting on Monday, Nov. 7, at 2 p.m. in the Bornstein Amphitheater to offer more information and answer your questions about the BWH Family History Project.

Thank you.

Sincerely,

Gary Gottlieb, MD, MBA
BWH President

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Appendix 2A. Family History Project Questions and Answers

With the launch of the BWH Family History Project, FHP staff and advisory board members created a document to answer frequently asked questions about the project. This document was emailed to all Brigham and Women's Hospital employees along with Dr. Gottlieb's "Letter to the Hospital Community" supporting the project and was also posted on the Family History Project's intranet site. In addition, copies of this document were always available during employee outreach and data entry sessions in the FHP Interactive Center.

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2A. Family History Project Questions and Answers

Brigham and Women's Frequently Asked Questions

1.) What is Brigham and Women's Family History Project?

A: The BWH Family History Project, organized by the newly formed BWH Biomedical Research Institute's Center for Integrative Genetic Medicine, will give employees the tools to voluntarily collect and organize, for their own private purposes, a family health history, with a level of detail that is usually not included in the medical record. The integration of family medical history into your medical care can assist your health care provider in making informed decisions about screening tests and preventive measures that could save your life. The BWH Family History Project will evaluate the obstacles to gathering family medical histories and will seek an understanding of what patients and providers do with the family medical history information, evaluating how it can best assist in patient care. Furthermore, this project will help to build the educational and information technology infrastructure needed to improve this area of health care.

2.) Why is BWH participating in this project?

A: There is growing evidence that a detailed and accurate family medical history can improve the chances that you (and your health care provider) will better understand your potential health risks and the opportunities to plan for a healthy life. Many professional medical groups, such as the American Medical Association, recognize the importance of a complete family medical history and are now calling for improvements in the way that patients and their health care providers collect and organize their information. In August 2005, the National Institutes of Health (NIH), through its National Human Genome Research Institute's (NHGRI) Education and Community Involvement Branch, selected Brigham and Women's Hospital to create a model program and to develop the necessary supportive materials to educate and engage a health care community in the use of family history in health care. This is the first time that an employer has participated in such a project of national scope, and the BWH community, with its history of participating in internationally-respected research studies, such as the Nurses' Health Study and the Women's Health Initiative, understands the leadership role it can play by engaging in this project.

3.) Why should I participate in this project?

A: You should participate in the BWH Family History Project because it has the potential to improve the health care that you and your family may need. It is hoped that you will view this opportunity to complete a family medical history, either with your family in your own home, or in a supportive setting in which there are project staff available to assist you as needed in the taking of your health history. Participation in the BWH Family History Project is yet another example of a benefit of being a BWH employee. The U.S. Surgeon General, Dr. Richard H. Carmona, said it best, "Knowing your family's history can save your life."

4.) What happens to the family medical history information I collect when I use the U.S. Surgeon General's "My Family Health Portrait" tool?

A: The family medical history information is your private health history. You do not need to share it with anyone unless you so choose. We encourage you to share it with your personal physician to assist him or her in providing you the best health care possible.

2A. Family History Project Questions and Answers

5.) How do I participate? Where do I find the information?

A: Visit <http://familyhistory.hhs.gov>. The site will soon include a printable version and a Spanish version. Watch for updates on This Week @ BWH.

6.) What if I have questions? Whom should I ask?

A: Starting in November, there will be a number of ways to answer all of your questions. Information sites will be located throughout the hospital where project staff can answer your questions. Questions can also be answered by e-mailing familyhistoryproject@partners.org or calling 617-525-4777. This number is a voice mail only line with voice mailboxes in English, Spanish and French Creole. Staff can also provide expert advice and guidance to those who are interested in discussing their history with a genetic counselor or medical geneticist.

7.) What about the privacy of my health information and that of my family members?

A: Goals of the BWH Family History Project do not include the gathering of the family health history of participants. The information that you gather about your family's health history is your private information and you will control the information. A goal of this project will be to survey employees and staff and review responses about the following information: why people choose to participate or not participate, and what participants did with the information they generated (e.g., was it shared with a health care provider, and did it make a difference in an individual's health care). We hope that you will fill out the surveys so that we can learn how to improve this process.

8.) If I share family history information with my physician, will it be protected?

A: You should be aware that the inclusion of family history information in individual patient's medical records is not something new, and family history information has the same safeguards in place to protect it, as do all of your medical records. Groups representing medical professionals, such as the American Medical Association and consumer advocacy groups like the Genetic Alliance, are amongst those who believe that placing more complete family history data into the hands of your health care providers will result in a net benefit for individuals who choose to take these steps.

9.) What if I choose not to participate?

A: You are free to choose not to participate. The staff of the BWH Family History Project, however, will be available to assist anyone who wishes to participate during the course of the next 12 months, so that if you initially decline but later change your mind, based on the positive experience of friends or co-workers, you may participate at a later date.

10.) I understand that over the next several months, there will be individuals who are assisting in this project who will ask me to participate in a survey. How will I know that these people are connected to the project?

A: Our BWH Intranet site will soon have a list of all our project staff, and they all will have BWH identification badges when you meet them.

11.) How long does it take to fill out the Surgeon General's Family History Tool?

A: It should take about 10-20 minutes for the initial completion of the tool. However, recording your family medical history as completely and accurately as possible will usually entail doing a little

2A. Family History Project Questions and Answers

extra homework, such as talking to your relatives about their medical problems or the medical problems of family members who are deceased. After initial completion of the Family History Tool, you can update it wherever you filled in "I don't know" or where an error may have been made.

12.) Will BWH give me time from my responsibilities to fill out the necessary form?

A: Yes, your supervisors will be encouraged to provide you with 10-20 minutes to complete this document. You must arrange for this time in advance at a mutually convenient time.

13.) What if I do not have access to a computer? Can I still participate in the BWH Family History Project with the U.S. Surgeon General's "My Family Health Portrait" tool?

A: BWH is committed to offering online access to BWH employees who need a computer to fill out the Family Health Portrait. For individuals who are unfamiliar with using a computer, project staff will be available for assistance. The sites and times for computer availability will be posted around the hospital. Soon, the U.S. Surgeon General's office will provide printable version of the tool, which can be completed and mailed back to the project office.


14.) Who is funding this project?

A: The National Institutes of Health has awarded Brigham and Women's Hospital the only grant in the country available for this type of family history demonstration project, and the BWH Center for Integrative Genetic Medicine under the auspices of the BWH Biomedical Research Institute also supports this project. Both groups believe this project will provide groundbreaking information that will improve your medical care.

15.) How long will this project last?

A: The BWH Family History Project begins in November 2005 and will be completed by November 2006. November was chosen because Thanksgiving Day has been designated as "National Family History Day" in the United States as many individuals will have the opportunity on that day to discuss and better understand their family's health history. Brigham and Women's Family History Project will cover two Thanksgiving holidays, but family history information can be collected throughout the project period and beyond. Gathering your family history can be a one-time exercise or a lifelong family project.

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*Appendix 3A. Photograph of BWH FHP's
“Interactive Center”*

Project team members procured space within a high foot-traffic area in the hospital for the opening of our “Interactive Center”. This Interactive Center provided an area for FHP staff to assist employees in the creation of their family health portrait. Internet connection within the Interactive Center was made available to the FHP, and laptop computers with privacy screens were utilized during individual data entry sessions. FHP customized CD-Rs were distributed to each employee who visited the Interactive Center; these CD-Rs allowed participants to record and store one’s personal family health history. Employees were reassured in this way that their personal family health history information was not stored on the FHP laptop computers. The weekly hours of operation for the Interactive Center were posted on the FHP intranet site and on a large signpost in front of the Interactive Center. Staffing of the Interactive Center included FHP staff and volunteers.

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3A. Photograph of BWH FHP's "Interactive Center"



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Appendix 4A. BWH FHP Outreach Materials

FHP staff, in conjunction with graphic designers, developed outreach materials for the promotion of the project throughout the hospital. These materials included:

- [1] Family History Project Informational Brochure – Distributed to employees (two pages)
 - [2] Family History Project Poster #1 – Displayed at various locations throughout the hospital and satellites
 - [3] Family History Project Poster #2 – Displayed at various locations throughout the hospital and satellites
 - [4] Family History Project Deposit Survey Poster – Displayed at survey drop-off sites
 - [5] Materials Used in Promoting Project:
 - a. Top Center – Tabletop project information signs
 - b. Center – CD-R used to save family history
 - c. Bottom Left and Right – Buttons distributed to employees
 - [6] Project Staff Member with Informational Stand – Set up prior to events to advertise project.
 - [7] Family History Project Balloon – Used at media and various project events
 - [8] Family History Project Banner – Used at media and various project events
 - [9] Laptop Computer – One of three laptop computers purchased for the project. Used by employees to go online to the “My Family Health Portrait” site.
 - [10] National Coalition for Health Professional Education in Genetics Poster – Displayed at National Coalition for Health Professional Education in Genetics (NCHPEG) Conference, February 2 -3, 2006
 - [11] PowerPoint Presentation to New Employees – Given weekly to the 25-50 new hospital employees at a required orientation program.
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4A1. Family History Project Informational Brochure



BRIGHAM AND
WOMEN'S HOSPITAL
Family History Project



"Knowing Your Family's History Can Save Your Life."

THE U.S. SURGEON GENERAL
DR. RICHARD H. CARMONA



BRIGHAM AND
WOMEN'S HOSPITAL
Family History Project

Room 455 NRB
77 Avenue Louis Pasteur
Boston, MA 02115



4A1. Family History Project Informational Brochure

BRIGHAM AND WOMEN'S HOSPITAL (BWH) is proud to be the first workplace in the country to offer all of its employees a formal support structure for gathering and organizing their family health history. This initiative, known as the BWH Family History Project (BWH FHP), will give any interested BWH employee the necessary tools to voluntarily collect and organize their family history.

It is known that accurate and detailed information about one's family history can help health care providers make specific recommendations for your healthcare. We hope that many of the BWH participants will consider sharing the information that they gather with their health care providers, however, that choice is entirely up to each employee.

There is broad support at BWH for this Project, because it is believed that along with the potential benefit to each participant's health, we can learn from this Project how to improve family history collecting methods so that this area of healthcare can be improved for all Americans.

El hospital Brigham and Women (BWH) se siente orgulloso de ser el primer lugar de trabajo en el país que ofrece a todos sus empleados un sistema formal donde pueden reunir y organizar la historia de salud de su familia. Esta iniciativa, conocida como Proyecto para historial familiar (BWH FHP), dará a cualquier empleado del Brigham, las herramientas necesarias para recopilar y organizar su historial familiar.

Es establecido que, información detallada y precisa del historial médico de la familia puede ayudar a los médicos a hacer recomendaciones específicas para su salud. Nos gustaría ver muchos participantes del hospital Brigham and Women's compartir esta información con sus médicos, pero esta decisión es exclusivamente del empleado.

El BWH está apoyando este proyecto ya que además de los posibles beneficios para la salud de los participantes aprenderemos cómo mejorar los métodos que utilizamos para conseguir información sobre el historial de salud de familias y en general ayudar a mejorar la salud para todos los americanos.

"Conocer su historia médica familiar le puede salvar la vida."

DEL SURGEON GENERAL DE EE.UU.
DR. RICHARD H. CARMONA

FAQs ABOUT THE BWH FHP

1. What is done with my family history information?

You may choose to share this information with your health care provider and/or family members, but you do not have to share it with anyone. The BWH FHP does not seek to capture, analyze, or store the family history information.

2. Where can I find more information about the BWH FHP?

You can visit the BWH intranet site at www.bwhpikenotes.org for more information about the BWH FHP. You will also find a list of all the Project's staff at this site. Questions about the BWH FHP may be directed to Project staff by telephone [617-525-4746] or by email [FamilyHistoryProject@partners.org].

3. How long does it take to complete a family history?

"My Family Health Portrait" is the easy to use family tree drawing tool from the United States Surgeon General that we will be encouraging participants to use. Most participants in this voluntary Project should be able to complete their family history in 10-20 minutes.



My Family Health Portrait

A tool from the U.S. Surgeon General

Preguntas y respuestas sobre BWH FHP

1. ¿Qué hacen con la información del historial médico de mi familia?

Puede compartir esta información con su médico o con miembros de su familia, si así lo desea, pero no tiene obligación de compartir esta información con nadie más. El BWH FHP no tiene ninguna intención de analizar ni almacenar la información relacionada con el historial médico de su familia.

2. ¿Dónde puedo conseguir más información sobre BWH FHP?

Puede visitar la página de Internet del BWH al www.bwhpikenotes.org para más información acerca del BWH FHP y para obtener la lista del personal que trabaja en este proyecto. Si tiene preguntas sobre BWH FHP, puede llamar al 617-525-4746 ó mandar un correo electrónico a FamilyHistoryProject@partners.org.

3. ¿Cuánto tardaría en completar el historial médico de mi familia?

Recomendamos a los participantes que utilicen la herramienta del árbol genealógico diseñado por el Cirujano general de los Estados Unidos, conocida como "My Family Health Portrait." La mayoría de los participantes en este proyecto voluntario podrán completar su historial familiar entre 10 a 20 minutos.



Mi retrato de salud familiar

una herramienta del Surgeon General de EE.UU.

4A2. Family History Project Poster #1



History in the Making.

By participating in the Brigham and Women's Hospital Family History Project, BWH employees will be making history in this model program which is the first in the nation.

Using the "My Family Health Portrait," employees can create a family history to share with your personal care physician and to better understand your own medical history. Find out how to create your family history through the BWH intranet at

www.bwhpikenotes.org.



BRIGHAM AND
WOMEN'S HOSPITAL
Family History Project

My Family is Making History.



BRIGHAM AND
WOMEN'S HOSPITAL
Family History Project

Join BWH in a unique opportunity to advance national medicine. Through the **Brigham and Women's Hospital Family History Project**, all BWH employees can help shape the future of health care and promote your own health and that of your family.

Using the U.S. Surgeon General's "My Family Health Portrait," employees can create a family history to share with your personal care physician and to better understand your own medical history. Learn how to create your family history through the BWH intranet at www.bwhpikenotes.org.

4A4. Family History Project Deposit Survey Poster



4A5. Materials Used in Promoting Project



4A6. Project Staff Member with Informational Stand



4A7. Family History Project Balloon




4A8. Family History Project Banner



4A9. Laptop Computer



4A11. PowerPoint Presentation to New Employees



The Brigham and Women's Hospital Family History Project

Karen Holbrook, MS, CGC and
Mike Murray, MD
Genetics Division, Department of Medicine
Brigham and Women's Hospital

BWH Family History Project Plan

- Provide tools for all BWH employees to complete family health history (<https://familyhistory.hhs.gov>)
- Participating employees *completely control* their own information.
- Those BWH employees who wish can deliver their family health history information to their providers. Patients and doctors agree that family health history is important information for keeping people healthy.

Doesn't my doctor already have my "Family Health History"?

Average office visit for family practitioner = 16 minutes

Average time to take a detailed and complete family history = 15-20 minutes

Participating in this Project allows you and your doctor to spend more time focused on what to do about the family health history and less time gathering and organizing the history.


Doesn't my doctor already have my "Family Health History"?

Average office visit for family practitioner = 16 minutes

Average time to take a detailed and complete family history = 15-20 minutes

Participating in this Project allows you and your doctor to spend more time focused on what to do about the family health history and less time gathering and organizing the history.

The Surgeon General's Tool




Welcome to My Family Health Portrait

The new Web-based My Family Health Portrait allows you to create a personalized family health history report. Information you provide is used to create a listing of family members with their health history for major diseases and a drawing of your family tree.

Create a family history Load a saved family history

Please note: If you used the downloadable Windows version of the Family History tool, and saved your family history, the file will not be able to load on the Web-based tool.

If you are a new user of the Web-based tool, click on Create a family history to begin creating a personalized family health history. If you are a returning user of the Web-based tool, click on Load a saved family history to select your existing profile.



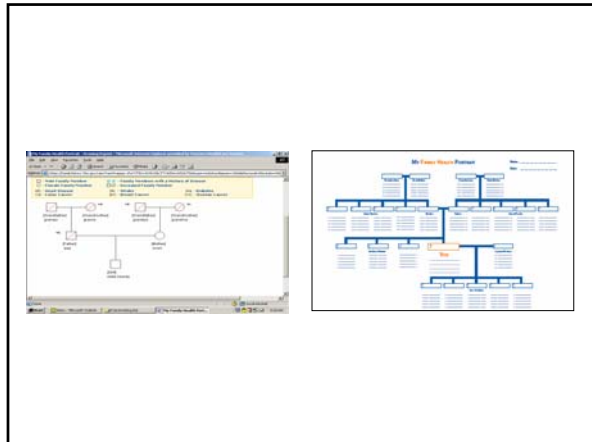
My Family Health Portrait

Retrato de Salud de mi Familia

THE SURGEON GENERAL'S FAMILY HISTORY INITIATIVE

LA INICIATIVA DE HISTORIAL FAMILIAR DEL CIRUJANO GENERAL

4A11. PowerPoint Presentation to New Employees



BWH Family History Project

HOW DO I PARTICIPATE?
WHERE DO I FIND THE INFORMATION?

- More information can be found at <http://www.bwhpikenotes.org/FamilyHistoryProject/Introduction.asp>.

BWH Family History Project

WHAT IF I HAVE QUESTIONS? WHOM SHOULD I ASK?

- Information sites at various locations in the hospital with Project staff who can answer your questions.
- Questions can be directed to Project staff by phone (617-525-4777) or email (familyhistoryproject@partners.org).
- When requested, the Project staff will provide expert advice and guidance to those who are interested in having questions answered by a genetic counselor or medical geneticist.

BWH Family History Project

HOW LONG DOES IT TAKE TO FILL OUT THE SURGEON GENERAL'S FAMILY HISTORY TOOL?

- It should take about 10-20 minutes for the initial completion of the tool.

WILL BWH GIVE ME TIME FROM MY RESPONSIBILITIES TO FILL OUT THE NECESSARY FORM?

- Yes, your supervisors will be encouraged to provide you with 10-20 minutes to complete this document. You must arrange for this time in advance at a mutually convenient time.

BWH Family History Project

WHAT IF I DO NOT HAVE ACCESS TO A COMPUTER? CAN I STILL PARTICIPATE?

- BWH is committed to offering online access to BWH employees who need a computer to fill out the Family Health Portrait. For individuals who are unfamiliar with using a computer, Project staff will be available for assistance. The sites and times for computer availability will be posted around the hospital.

Participation Surveys

What we hope to learn:

- How to make it more user friendly
- How to make it more useful for patients
- How to make it more useful for healthcare providers

Appendix 5A. BWH FHP Media Coverage

BWH's Public Affairs department was instrumental in spreading the word about the launch of the BWH FHP, with summaries of the project appearing in their weekly electronic email to all BWH staff and in the weekly hospital newsletter, *BWH Bulletin*. The Public Affairs department also facilitated an interview for Michael Murray, MD with Boston's local Fox news network November 23, 2005. The project generated significant media coverage in the Boston area and on a national level.

BWH Family History Project National News Stories

[1] From HHS/NHGRI following November 15, 2005 Press Conference:

<http://www.genome.gov/17515539>

[2] From NIH News following November 15, 2005 Press Conference:

<http://www.nih.gov/news/pr/nov2005/nhgri-15.htm>

[3] From AMN Healthcare, week of December 5, 2005:

<http://www.amnhealthcare.com/Features.asp?ArticleID=14602>

[4] From WPIX-TV (WB11.com) New York:

<http://wb11.empowereddoctor.com/story.php?id=686>

[5] From Kansas City InfoZine November 30, 2005:

<http://www.infozine.com/news/stories/op/storiesView/sid/11660/>

BWH Family History Project Local News Stories

[1] From the Harvard University Gazette newspaper February 2, 2006:

<http://www.news.harvard.edu/gazette/2006/02.02/09-family.html>

[2] From Massachusetts Hospitals: Continuing Commitment to Patient Safety and High Quality Care February 1, 2006:

<http://www.patientsfirstma.org/advance/06-02-01.cfm#11>

[3] From BWH Public Affairs November 15, 2005:

<http://www.brighamandwomens.org/publicaffairs/Newsreleases/U.S.%20Surgeon%20General%20Urges%20Americans.asp>



BWH Family History Project Internet News Stories

[1] From Healthcare IT News November 15, 2005:

<http://www.healthcareitnews.com/story.cms?id=3989>

[2] From dLife (Diabetes News) November 15, 2005:

http://www.dlife.com/dLife/do/ShowContent/diabetes_news/news_archive_november_2005/diabetes_newsarticle111505_us_surgeon_general_urges_americans_to_know_their_family_health_history.html

[3] From Senior Journal.com November 23, 2005:

<http://www.seniorjournal.com/NEWS/Features/5-11-23-FamilyHealthHistory.htm>

Other media related items...

[1] *Boston Herald* newspaper: *(Wish)boning up on family health: Docs urge Thanksgiving chat to learn history of illness*

By **Jessica Heslam** Wednesday, November 16, 2005

[2] *Fox25* television live interview with Michael Murray, MD and David Wade: November 22, 2005

[3] *WBUR* (National Public Radio) interview with Michael Murray, MD and Martha Bebinger: June 12, 2006

BWH Bulletin (weekly newsletter for and about the people of BWH: see attached newsletters)

[1] November 11, 2005: "Family History Project Kicks Off" (page 1)

[2] November 18, 2005: "Family History Initiative Launched Nationally at BWH" (page 1)

[3] November 25, 2005: "Know Your History: Thanksgiving is National Family Health History Day" (page 1)

[4] December 9, 2005: "BWH Family History Project in Full Swing" (page 2)

[5] January 20, 2006: "Mailroom Staff Completes Their Family Medical Histories" (page 4)

www.bwhpikenotes.org

November 11, 2005

BWH Bulletin

FOR AND ABOUT THE PEOPLE OF BRIGHAM AND WOMEN'S HOSPITAL

Twenty minutes to complete your medical family tree could save your life and empower you and your family to get the best health care possible. That's the root of the Brigham and Women's Family History Project, a year-long initiative launched Monday. The U.S. Surgeon General tapped BWH to be the first employer in the U.S. to encourage employees to voluntarily complete the "My Family Health Portrait" tool.

On an individual level, this tool could ensure participating members of the BWH family receive the most appropriate health care from their primary care physician. On a national and worldwide level, BWH's participation in this project

(Cont. on p. 4)

Reminder: Respecting Our Mission Hill Neighbors

Brigham and Women's Hospital is the only clinical care institution in the Longwood Medical Area that directly abuts the Mission Hill neighborhood. BWH has a responsibility to be a good corporate neighbor in addition to providing the best health care to

(Cont. on p. 2)

FAMILY HISTORY PROJECT KICKS OFF

Drs. Cynthia Morton and Michael Murray are leading the Brigham and Women's Family History Project.

AMMP Awards Eight Scholarships

When Linda Clay completes her bachelor's degree in human services at Cambridge College, she plans to adopt a little girl. "I always wanted to have a girl," said Clay, practice secretary for Brigham Internal Medicine Associates and mother of three grown sons. "It's only fair that I finish my last two years of school first."

The BWH Association of Multicultural Members of Partners (AMMP) helped Clay pay for her education through its annual scholarship program. Last

(Cont. on p. 3)



The AMMP scholarship recipients are, front from left, Dennis A. Dean II, Rosilia Gomez-Barranco, Amy Belyea, Sasha Dubois, Linda Clay, Ruth Capella and Jeanette Merren. Elizabete DeMoura is not pictured. During last week's ceremony, they were joined by, back row, Kate Walsh, Dr. Gary Gottlieb and Robin Vann Ricca.

BWH Bulletin

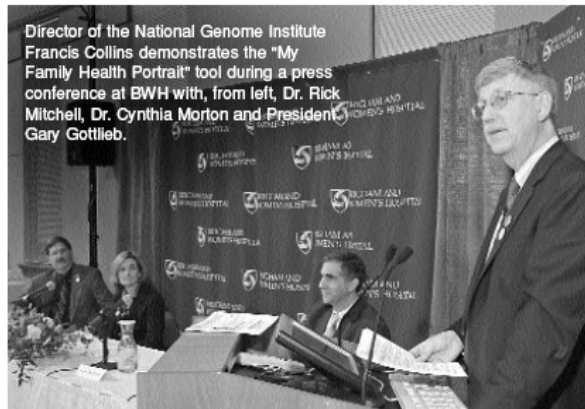
FOR AND ABOUT THE PEOPLE OF BRIGHAM AND WOMEN'S HOSPITAL

Family History Initiative Launched Nationally at BWH

Francis Collins, MD, PhD, director of the National Human Genome Research Institute, came to Francis Street this week for the national public launch of the U.S. Surgeon General's "My Family Health Portrait" and to announce BWH's leadership role in piloting the updated Web-based tool—an initiative that may contribute to reshaping the future of health care and strengthening personalized medicine.

"We're delighted to have such a remarkable institution be the first out of the gate," said Collins, who joined BWH President Gary Gottlieb, MD, MBA, Cynthia Morton, PhD, and Rick Mitchell, MD, PhD, for the public unveiling in Carrie Hall on Tuesday. "This project offers all of us a chance to make medicine more personalized."

The Brigham and Women's Family History Project kicked off within the BWH community last week. Employees who choose to participate will record their family health histories using "My



Director of the National Genome Institute Francis Collins demonstrates the "My Family Health Portrait" tool during a press conference at BWH with, from left, Dr. Rick Mitchell, Dr. Cynthia Morton and President Gary Gottlieb.

Family Health Portrait." Participants are encouraged to share with their primary care providers this information, which will help them receive the best health care possible and could even save their life or the life of a family member. (Cont. on p. 4)

SEE INSERT FOR NOMINATION FORMS



Nominations Now Available for Thomson Leadership Award, Compassionate Care Scholars

Nominations are now being accepted for two recognition awards originating from the remembrance and impression of one of BWH's most treasured leaders—the late Dennis Thomson, who was widely known by his peers as "the conscience of BWH." The seventh annual Dennis Thomson Leadership Award and Compassionate Care Scholar Awards will be presented at an awards ceremony March 30, 4 p.m., in Bornstein Family Amphitheater. The nomination deadline for both the leadership award and scholarships is Jan. 6.

From 1991 to 1998, Thomson served as BWH's director and then vice president of Public Affairs, overseeing all internal communications and external media outreach. Thomson died Nov. 10, 1998, following a battle with cancer. He was 49. Months later, hospital leadership and Thomson's colleagues initiated a leadership award and

(Cont. on p. 3)

On My Own Time



Garth Meikle of Biomedical Engineering pieces together intricate puzzles in his spare time. Find out about the hobbies of other BWHers on p. 3.

INSIDE **Plenty of December Holiday Happenings. Calendar, page 4.**

www.bwhpikenotes.org

November 25, 2005

BWH Bulletin

FOR AND ABOUT THE PEOPLE OF BRIGHAM AND WOMEN'S HOSPITAL

KNOW YOUR HISTORY

Thanksgiving is National Family Health History Day

Rick Mitchell, MD, PhD, a BWH cardiovascular pathologist, beat colon cancer earlier this year, but there's a 50 percent chance he passed the cancer-causing gene to his children, Matt, 19, and Becky, 17. That's why Mitchell is arming his family with the knowledge to prevent the disease and maintain good health through the Brigham and Women's Family History Project.

"I was very lucky to be diagnosed early because the cancer could be removed before it spread," Mitchell said. "But I don't want my kids to rely on luck. I want them to get early screening and preventive care that will give them their best chance to fight any cancer before it can bring them down." (Cont. on p. 2)



From left, Rick, Diane, Matt and Becky Mitchell at their Natick home with their golden retrievers, Cassie, Chayenne and Montana.



BWH Doctors Join the "Tour de Brain"

The brain power of Gary Gottlieb, MD, MBA, BWH president; Dennis Selkoe, MD, BWH neurologist and founder of the Partners Program of Excellence in Alzheimer's and Neurodegenerative Diseases; and Martin A. Samuels, MD, BWH chair of Neurology, is coming soon to a theater near you. The three lent their expertise to the new Partners-produced IMAX® film, "Wired to Win: Surviving the Tour de France," which premieres at the Museum of Science on Dec. 1.

The film, funded in part by a grant from the National Science Foundation, is the centerpiece of a Partners initiative to draw young people to the complex world of science. It's a unique

(Cont. on p. 2)

BWH, BWPO Receive Nesson Award

Partners Community HealthCare, Inc. (PCHI) awarded BWH and the Brigham and Women's Physician Organization with a Nesson Award for Excellence in recognition of the "Plan and Promise" program. The program aims to reduce preventable hospitalizations for patients with chronic disease by emphasizing individualized patient education and improving patients' access to timely care. The program helps patients self-manage their care by emphasizing the importance of calling their physicians in a timely manner when not feeling well.

The Nesson Awards are named for H. Richard Nesson, MD, PCHI's founder and the former president of Partners HealthCare. The awards are bestowed annually to PCHI physicians and groups who exemplify his commitment to improving care.

"PCHI was founded with a commitment to improve both the quality and efficiency of patient care," PCHI CEO Thomas Lee, MD, said. "The leadership at both Brigham and Women's Hospital and its physician organization, through programs



From left, Allen Kachalia, MD, Joanne Hogan, RN, MS, and Allen Smith, MD, are joined by Ted Nesson, son of PCHI founder H. Richard Nesson, MD, at PCHI's annual meeting.

like this one to reduce preventable admissions, is helping to make that vision a reality."

BWH Family History Project in Full Swing

With the Family History Project on their minds, about 100 BWH employees gathered Dec. 1 for the return visit of Francis Collins, MD, PhD, director of the National Human Genome Research Institute. Collins, who visited BWH in November for the public launch of the U.S. Surgeon General's "My Family Health Portrait" tool, returned to BWH to answer questions and demonstrate the Web-based tool.

Collins joined Michael Murray, MD, clinical chief in the Division of Genetics; Cynthia Morton, PhD, director of Cytogenetics; Kate Walsh, chief operating officer; Karen Holbrook, Family History Project manager; and John Lew, director of employment services, to answer questions about the Family History Project.

For more information on the project, visit www.bwh-pikenotes.org or access the "My Family Health Portrait" tool directly at <http://familyhistory.hhs.gov>



From left, panelists Michael Murray, Karen Holbrook, Francis Collins, Kate Walsh, Cynthia Morton and John Lew answer questions about the Family History Project.

BT Cash Out Deadline Dec. 24

BWH employees are required to take off or cash out a minimum number of benefit time (BT) hours each calendar year. Refer to your paycheck for your BT taken and BT requirement. Employees have through Dec. 24 to meet the annual requirement. For those who do not meet their annual requirement, the difference will be transferred from BT to extended sick leave (ESL).

Cash out guidelines:

- Cash out is limited to twice per calendar year

- Employees must maintain a benefit time balance of twice scheduled hours
 - Cash out is in increments of 20 hours
 - Hours cashed out count toward your annual BT requirement
 - Cash out forms are available in the Human Resources forms section on Pike Notes at :
<http://www.bwhpikenotes.org/HumanResourcesBenefits/HumanResourceBenefits.asp>
- Contact your HR generalist if you have any questions.

Mailroom Staff Completes Their Family Medical Histories

The Mailroom is the first department at BWH where all staff completed their family histories with the U.S. Surgeon General's "My Family Health Portrait" Web-based tool. BWH Family History Project staff held two sessions with Mailroom staff to answer questions about the tool and help employees complete their family histories online. Now, all Mailroom participants have copies of their family medical histories saved on CD, which they may choose to share with their primary care doctors, helping them to get the best care possible. "It was both fun and informative," Ann Haley, Mailroom manager, said.

Family History Project staff are available to meet with departments and groups to answer questions about the project and provide assistance in using the tool. If you would like to set up a meeting, e-mail Karen Holbrook, project coordinator, at khholbrook1@partners.org. Visit www.bwhpikenotes.org/family-historyproject/introduction.asp for more information.



Front left, the Family History Project's Anne Coakley and Karen Holbrook, and front right, Sigrid Tishler, join Mailroom staff who completed their family medical histories, including back from left, Ellen Adams, Curly Green, Ann Haley, Dennis Christofi, James Crowley, Mary Gray-Skerritt, Gayle Muehlberger, Sonya Leonard; front, Sean Suarez (center) and Wilma Stanley.

A Home Away From Home

Hospitality Homes Provides Housing for Families of Boston Patients

(Cont. from p. 1)

apartments – the apartment in which Barry Haber would stay while his wife underwent surgery in June 2004.

"Having the apartment was a wonderful experience in a bad situation," Barry said. After spending days by Diane's side in the hospital, he would return to the solitude of the Commonwealth Avenue apartment, cook meals in the kitchen and watch movies. "I had a nice place to stay, laundry in the building and a grocery store nearby," he said. The apartment building also houses an exercise room and a swimming pool, and building staff were so moved by the program that they inspired Wingate Management to assume payment of the apartment's cable bill.

The apartments are a "home away from home," said Chris Collins, director of Patient Access Services and board member for Hospitality Homes. "Families who stay there have a sense of being at home. They're able to cook meals themselves and have

other members of their family stay with them to provide support. Their presence is a vital part of the healing process for the patient."

Families like the Habers, who have stayed with host families or in the apartments, are grateful, according to Marianne Duddy, executive director of Hospitality Homes. "The most powerful feedback is when someone says, "Without this program, my family member could not have accessed lifesaving treatment available only in Boston," she said. "The living costs make it impossible for many."

"The Schuster Family continually supports Brigham and Women's Hospital," Collins said, "This goes a step beyond; it helps the whole Boston health care community."

For more information, visit www.hosp.org ♦

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**BRIGHAM AND
WOMEN'S HOSPITAL**

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Appendix 6A. Multi-lingual Translations of “My Family Health Portrait”

The US Surgeon General’s tool was made available in both English and Spanish. In an effort to reach a larger population, the Brigham and Women’s Hospital Family History Project worked with the Hospital’s Interpreter Services Department and an outside translation company to translate the “*My Family Health Portrait*” paper tool into Portuguese, French, Chinese, and Polish for use by non-English speaking employees. These four languages were chosen based upon those non-native English-speaking groups with significant numbers of employees at BWH. Adobe software was used to edit the paper tool PDF into the same format as the original English and Spanish versions made available through the Department of Health and Human Services (HHS). Paper copies of the foreign language versions of “My Family Health Portrait” were available during employee outreach and data entry sessions in addition to being posted on the Family History Project intra-and internet sites. Following are the PDF documents of “*My Family Health Portrait*” as translated into:

[1] English

[2] Spanish

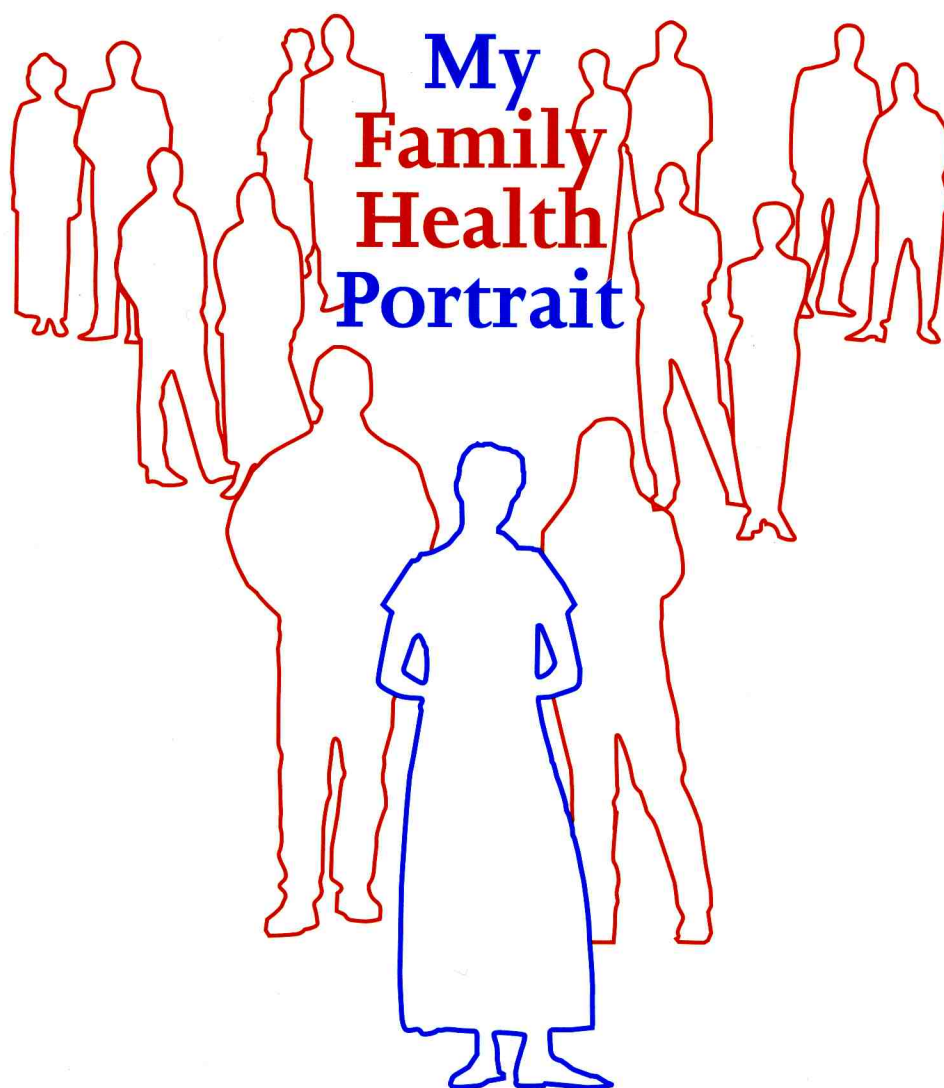
[3] French

[4] Portuguese

[5] Polish

[6] Chinese

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**THE SURGEON GENERAL'S
FAMILY HISTORY INITIATIVE**

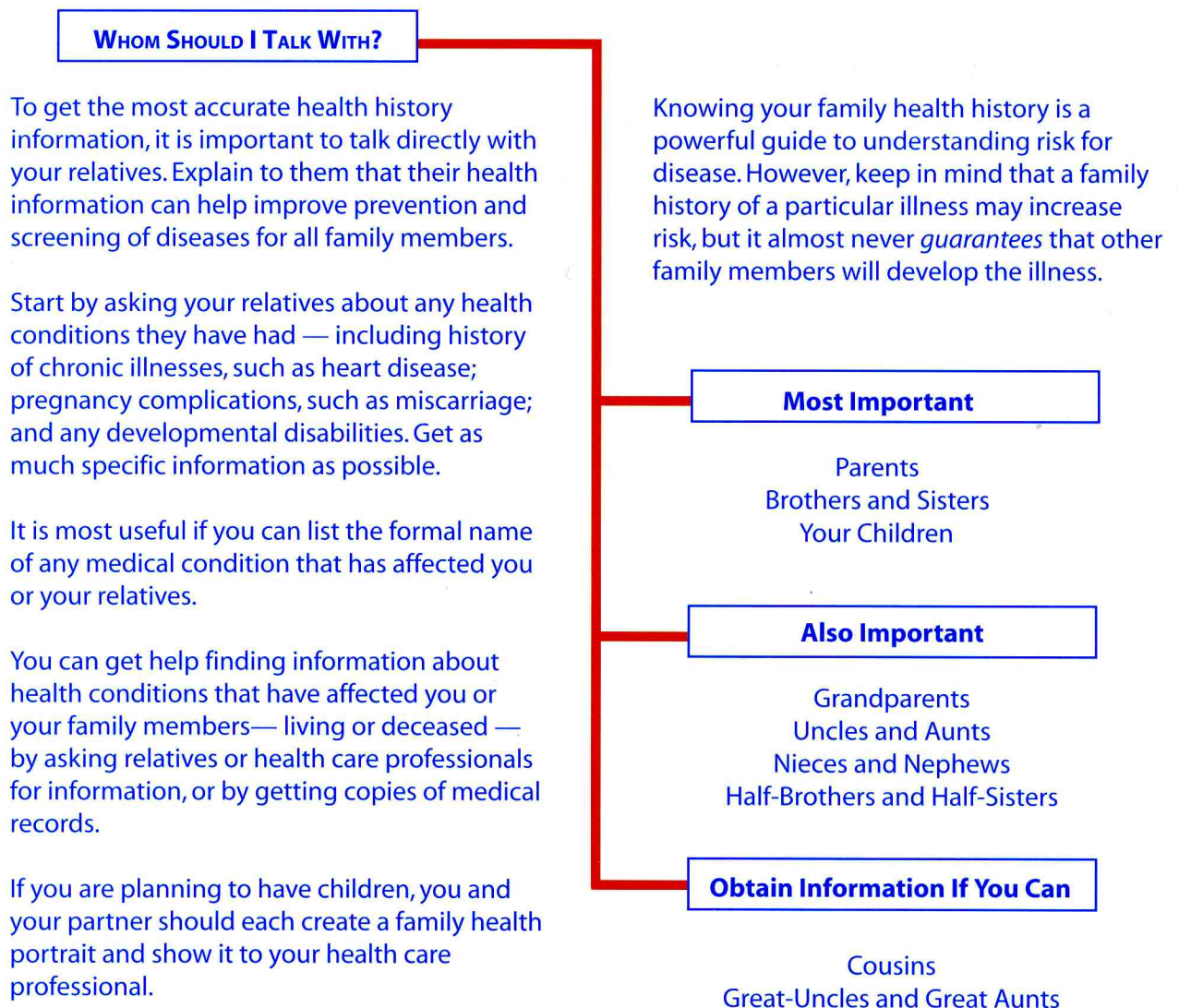
THE SURGEON GENERAL'S FAMILY HISTORY INITIATIVE

HOW TO CREATE MY FAMILY HEALTH PORTRAIT

The Surgeon General has launched a national initiative to encourage all American families to learn more about their family health histories.

Knowing your family's medical history can save your life.

With a copy of your family health history, you and a health care professional can individualize your care to prevent and screen for conditions for which you may be at higher risk. Family events, such as Thanksgiving or family reunions, offer a great chance to gather the information for "My Family Health Portrait."



How Do I Fill Out The Form?

"My Family Health Portrait," located to the right, will help you collect and organize your family information. No form can reflect every version of the American family, so use this chart as a starting point and adapt it to your family's needs.

First, write each of your relatives' names in the designated boxes and circle whether they are male (M) or female (F). On the next line, write the name of any health conditions they have had. If you know the age at which they were diagnosed with a condition, write that in parentheses after the condition. For example: "diabetes (diagnosed - age 37)."

If family members have died, write "deceased" and the age at which they died. For example: "heart attack (deceased - age 63)."

For twins, write "twin" on the first line for both individuals. If the twins are identical, write "identical twin" on the first line for both.

If your family includes half brothers or half sisters, write "half brother" or "half sister" on the

first line and note "different father" or "different mother" on the next line.

Some conditions are more common in people with a shared background or ancestry. It is important to record the ancestry of your relatives and be as specific as possible. For example, if you know that your grandmother is Hispanic and her family comes from Mexico, write "Mexican" underneath her name. Likewise, if your family is from Africa, Asia, Europe or South America, note the country they came from, if possible.

Once you complete "My Family Health Portrait," take it to your health care professional so that he or she can better individualize your health care. Be sure to make a copy for your records and update it as circumstances change or you learn more about your family's health history.

Congratulations on taking this step toward a longer, healthier life! "My Family Health Portrait" can be an effective way to improve your health — today and in the future.

CUT OUT AND ADD TO CHART AS NEEDED

<div data-bbox="268 1256 544 1317"><p>M F</p></div> <hr/> <hr/> <hr/> <hr/>	<div data-bbox="668 1256 944 1317"><p>M F</p></div> <hr/> <hr/> <hr/> <hr/>	<div data-bbox="1064 1256 1340 1317"><p>M F</p></div> <hr/> <hr/> <hr/> <hr/>
<div data-bbox="268 1659 536 1720"><p>M F</p></div> <hr/> <hr/> <hr/> <hr/>	<div data-bbox="668 1659 936 1720"><p>M F</p></div> <hr/> <hr/> <hr/> <hr/>	<div data-bbox="1064 1659 1348 1720"><p>M F</p></div> <hr/> <hr/> <hr/> <hr/>

My FAMILY HEALTH PORTRAIT

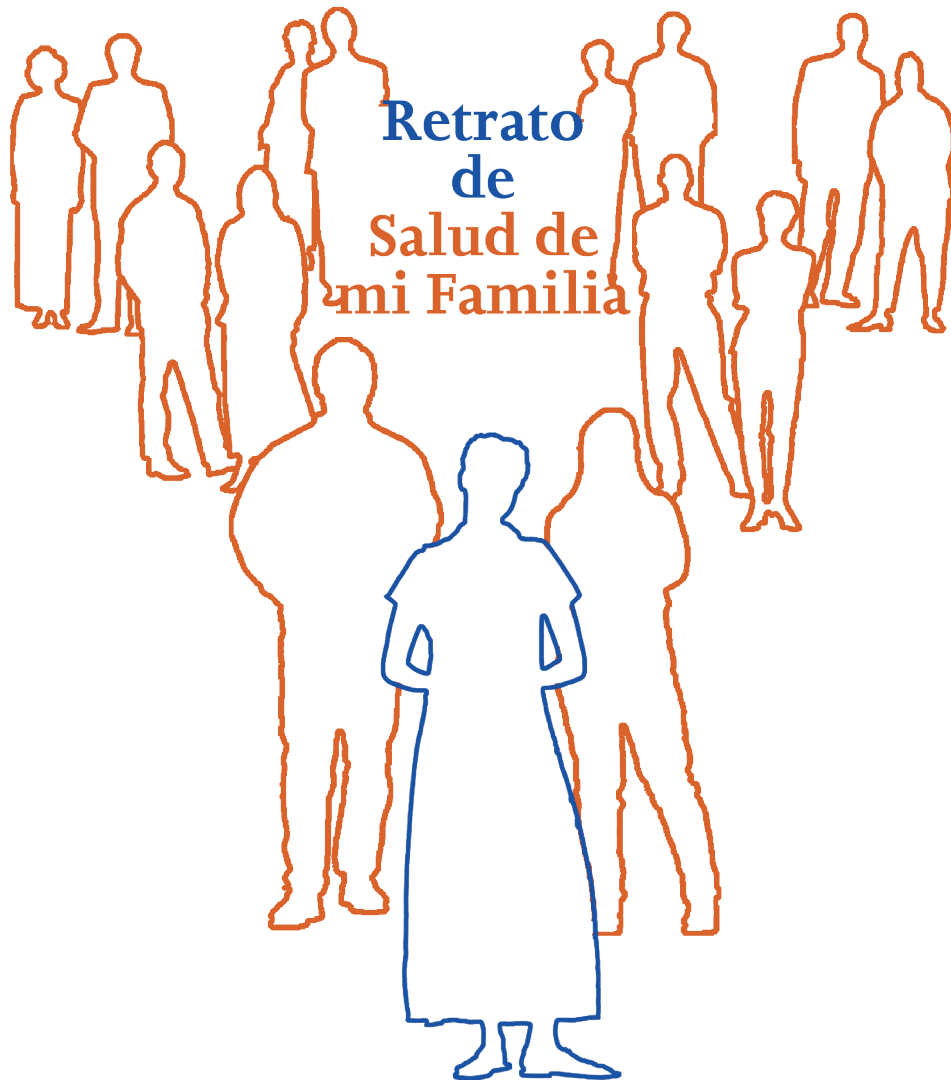
Name: _____

Date: _____

The diagram is a family tree structure with the following components:

- Grandmother** (left side, top): Two boxes, each with a gender indicator (M/F) and four lines for notes.
- Grandfather** (right side, top): Two boxes, each with a gender indicator (M/F) and four lines for notes.
- Aunts/Uncles** (left side, middle): Three boxes, each with a gender indicator (M/F) and four lines for notes.
- Mother** (right side, middle): One box with a gender indicator (M/F) and four lines for notes.
- Father** (left side, middle): One box with a gender indicator (M/F) and four lines for notes.
- You** (center): One large box with a gender indicator (M/F) and four lines for notes.
- Spouse/Partner** (right side, bottom): One box with a gender indicator (M/F) and four lines for notes.
- Brothers/Sisters** (left side, bottom): Two boxes, each with a gender indicator (M/F) and four lines for notes.
- Your Children** (right side, bottom): Three boxes, each with a gender indicator (M/F) and four lines for notes.

[2] Spanish



**LA INICIATIVA DE HISTORIAL FAMILIAR
DEL CIRUJANO GENERAL**

LA INICIATIVA DE HISTORIAL FAMILIAR DEL CIRUJANO GENERAL

[2] Spanish

¿CÓMO CREAR EL RETRATO DE SALUD DE MI FAMILIA

El Cirujano General ha lanzado una iniciativa nacional para alentar a las familias estadounidenses a informarse mejor sobre los historiales de salud de sus familias.

El conocer el historial médico de su familia puede salvarle la vida.

Con una copia del historial de salud de su familia, usted y un profesional de la salud pueden individualizar su cuidado y realizar controles para detectar condiciones médicas de las que puede correr un riesgo mayor. Los eventos familiares, como las reuniones del Día de Acción de Gracias (Thanksgiving) o las reuniones de la familia, ofrecen una gran oportunidad de recoger la información para el "Retrato de Salud de mi Familia".

¿Con quién debo hablar?

Para obtener la información más exacta sobre el historial de salud, es importante que hable directamente con sus familiares. Explíqueles que su información de salud puede contribuir a mejorar la prevención y los controles de detección de enfermedades para todos los miembros de la familia.

En primer lugar, pregunte a sus parientes acerca de cualquier condición de salud que hayan tenido, incluido el historial de enfermedades crónicas, como las enfermedades cardíacas, complicaciones del parto, por ejemplo, aborto espontáneo, y cualquier discapacidad relacionada con el desarrollo. Obtenga tanta información específica como le sea posible.

Sería muy útil si usted pudiese indicar el nombre formal de cualquier condición médica que le haya afectado a usted o a sus parientes.

Puede obtener ayuda para obtener información sobre condiciones de salud que le hayan afectado a usted o a sus parientes (vivos o fallecidos) solicitando información a los parientes o a los profesionales de la salud, o consiguiendo copias de los expedientes médicos.

Si está planeando tener hijos, usted y su compañero o compañera deberán crear, cada uno, un retrato de salud familiar y mostrárselo a su profesional de la salud.

El conocer su historial de salud familiar es un arma poderosa para entender los riesgos de enfermedades. Sin embargo, tenga en cuenta que el historial familiar de una enfermedad determinada puede aumentar el riesgo pero casi nunca garantiza que otros miembros de la familia van a contraer la enfermedad.

Los más importantes

Padres
Hermanos y hermanas
Sus hijos

También importantes

Abuelos
Tíos y tías
Sobrinos y sobrinas
Medios hermanos y hermanas

Obtenga información, si es posible

Primos
Tíos y tías abuelas

¿CÓMO RELLENO EL FORMULARIO?

El "Retrato de Salud de mi Familia" le será útil para recoger y organizar la información de salud referente a su familia. Ningún formulario puede reflejar todas las versiones de la familia estadounidense, por lo cual le recomendamos utilizar este esquema como punto de partida y adaptarlo a las necesidades de su familia.

En primer lugar, escriba los nombres de cada uno de sus parientes en las casillas indicadas, y marque con un círculo si la persona es de sexo masculino (M) o femenino (F). En la línea siguiente, escriba el nombre de las condiciones médicas que han tenido. Si sabe la edad a la que se les diagnosticó determinada condición médica, escriba esa información entre paréntesis después de la condición. Por ejemplo, "diabetes (diagnosticada a los 37 años)".

Si determinado miembro de la familia ha fallecido, ponga "fallecido" y la edad a la que la persona murió. Por ejemplo: "ataque cardíaco (fallecido a los 63 años)".

Si se trata de mellizos, escriba "mellizo" en la primera línea para ambas personas. Si los mellizos son gemelos, escriba "mellizo gemelo" en la primera línea para ambas personas.

Si su familia incluye medios hermanos o hermanas, escriba "medio hermano" o "media hermana" en la primera línea y ponga "diferente padre" o "diferente madre" en la línea siguiente.

Algunas condiciones médicas son más comunes entre las personas que comparten un origen o ascendencia. Es importante registrar la ascendencia de sus parientes, y hacerlo de la manera más específica posible. Por ejemplo, si sabe que su abuela es hispana y que su familia proviene de México, escriba "Mexicana" debajo de su nombre. De la misma forma, si su familia es de África, Asia, Europa o América del Sur, escriba el país del que provienen, si es posible.

Una vez que haya completado el "Retrato de Salud de mi Familia", lléveselo a su profesional de la salud para que pueda individualizar mejor su cuidado médico. Haga una copia para guardar en sus registros y actualizarla si cambian las circunstancias o si obtiene más información sobre el historial de salud de su familia.

¡Felicitaciones por dar este paso hacia una vida más larga y más sana! El "Retrato de Salud de mi Familia" puede ser un elemento eficaz para mejorar su salud, ahora y en el futuro.

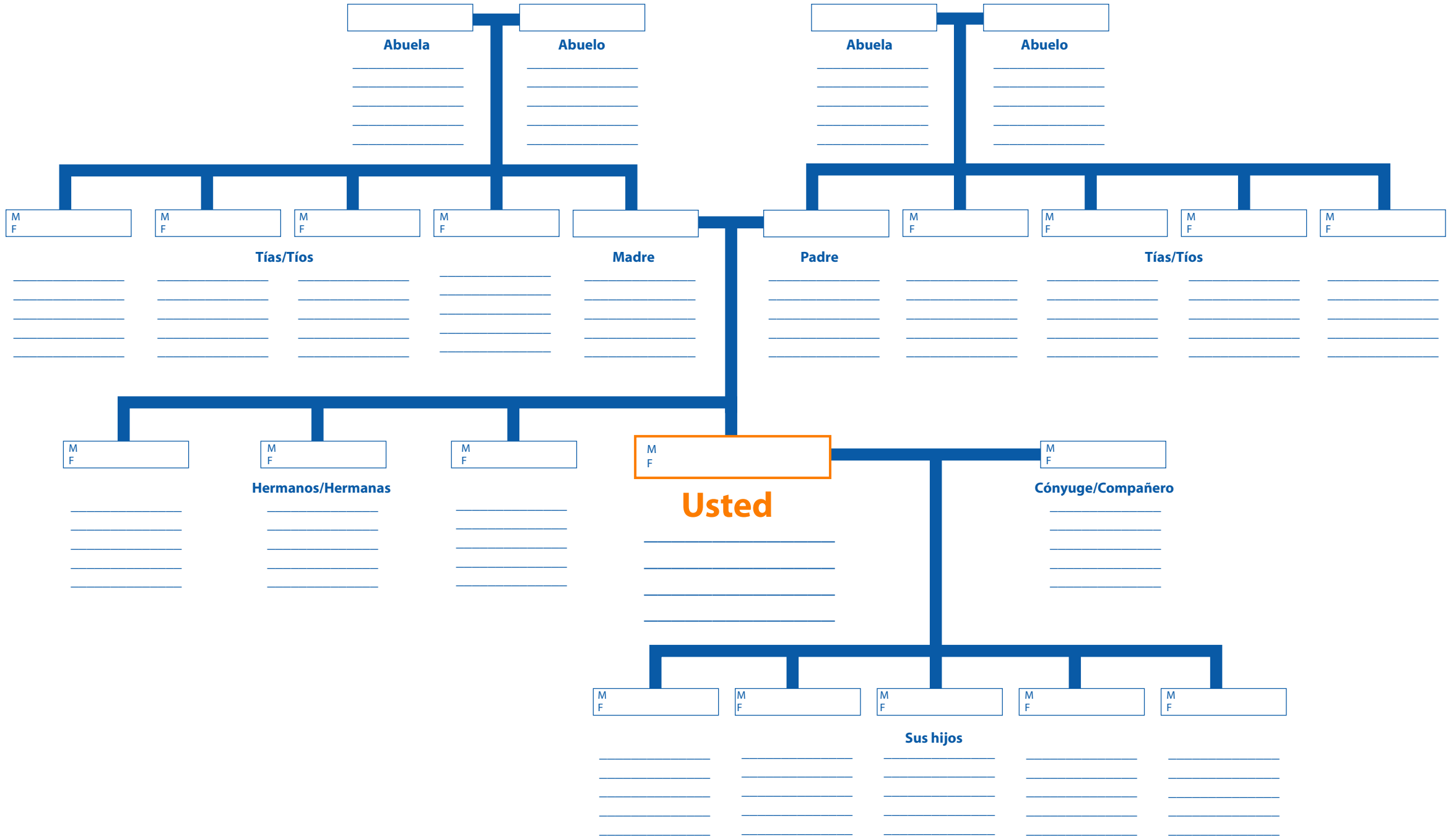
RECORTAR Y AGREGAR A LA TABLA SEGÚN LAS NECESIDADES

M F	M F	M F
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

RETRATO DE SALUD DE MI FAMILIA

Nombre: _____

Fecha: _____



[3] French

**BRIGHAM & WOMEN'S HOSPITAL
FAMILY HISTORY PROJECT**



**INITIATIVE DU CHIRURGIEN GÉNÉRAL
SUR L'HISTOIRE DE LA FAMILLE**

**Pour Créer Un Portrait de Santé de Famille En Ligne
Visitez:**

www.hhs.gov/familyhistory/

[3] French Initiative de l'Histoire de la famille du Chirurgien Général Comment Créer le Portrait de Santé de Ma Famille

Le Chirurgien Général a lancé une initiative nationale encourageant toutes les Familles Américaines à apprendre d'avantage sur l'histoire de santé de leur famille.

Connaître l'histoire médicale de votre famille peut sauver votre vie.

Avec une copie de l'histoire de santé de votre famille, vous et un professionnel de soins de santé pouvez individualiser vos soins prévenir et déceler les conditions pour lesquelles vous seriez prédisposé et courriez un plus grand risque. Les événements tels que Thanksgiving, les reunions de famille, offrent une bonne occasion pour assembler des informations pour le "Portrait de Santé de Ma Famille."

A Qui Devrais-je parler?

Pour recueillir les informations les plus précises sur l'histoire de santé de votre famille, il est important de parler directement aux membres de votre famille. Expliquez-leur que l'information au sujet de leur santé peut aider à améliorer la prévention et la détection de maladies pour tous les membres de la famille.

Commencez à vous informer auprès de vos parents des différentes conditions de santé dont ils souffrent ou qu'ils ont souffert — incluant l'histoire des maladies chroniques, telles que les maladies cardiaques; des complications lors des grossesses, tel que avortement spontané; et n'importe quelle handicap au niveau du développement. Compilez autant d'information spécifique que possible.

C'est encore plus utile si vous pouvez obtenir une liste formelle des noms des différentes conditions médicales qui vous ont affectées ainsi que vos parents.

Vous pouvez trouver de l'aide dans la recherche d'information au sujet des conditions qui vous ont affectées ainsi que les membres de votre famille— vivants ou décédés — en questionnant vos parents ou les professionnels des soins de santé, ou bien en réclamant des copies des dossiers médicaux.

Si vous projetez d'avoir des enfants, vous et votre partenaire devriez créer chacun un portrait de santé de votre famille et le montrer à votre médecin traitant.

Connaître l'histoire de santé de sa famille est un guide puissant pour comprendre les risques qu' on court de développer une maladie. Cependant, il faut garder à l'esprit que l'histoire d'une maladie particulière dans une famille peut augmenter le risque de développer cette maladie, mais jamais ne constitue une garantie que d'autres membres de la famille la développeront.

Le Plus Important

Parents
Frères et Soeurs
Vos enfants

Aussi Important

Grand-parents
Oncles et Tantes
Nieces et neveux
Demi-Frères et Demi-Soeurs

Obtenir des Informations si vous pouvez

Cousins
Grand-Oncles et Grand-Tantes

[3] French

La forme "portrait de santé de ma famille vous aidera à collecter et à organiser les informations concernant votre famille. Il n'y a aucune forme qui puisse refléter toutes les versions de la famille américaine, alors, utilisez cette forme comme un point de départ et adaptez-la aux besoins de votre famille.

D'abord, écrivez le nom de chacun de vos parents dans la boîte désignée à cet effet, encerclez selon qu'il soit homme (M) ou femme (F). Puis, sur la prochaine ligne inscrivez la liste de toutes les conditions médicales qu'ils ont eues. Si vous connaissez l'âge auquel le diagnostic a été fait écrivez cela entre parenthèse tout de suite après la maladie. Par exemple: "diabète (diagnostiqué à l'âge de 37 ans)"

Si les membres de la famille sont décédés, écrivez décédés et l'âge auquel ils sont morts. Par exemple: "crise cardiaque (décédé à l'âge de 63 ans)."

Si ce sont des jumeaux, écrivez "jumeau" sur la première ligne pour les deux individus. Si les jumeaux sont identiques, écrivez "jumeaux identiques" sur la première ligne pour les deux individus.

Si votre famille comprend des demi-soeurs et des demi-frères, écrivez "demi-soeurs et demi- frères" sur la première ligne et noter de "Père différent" ou de "mère différente" sur la ligne suivante.

Certaines conditions sont plus courantes chez des personnes de même parentée et ayant des ancêtres communs. C'est très important de retracer les souches des ancêtres de vos parents et être aussi spécifique que possible. Par exemple si vous savez que votre grand-mère est espagnole et que sa famille vient du Mexique, écrivez "mexicaine" sous son nom. De même, si votre famille vient de l'Afrique, de l'Asie, de l'Europe ou de l'Amérique du Sud notez le pays de leur origine.

Une fois que vous auriez achevé le "Portrait de santé de ma famille" apportez- le à votre médecin pour qu'il puisse mieux individualiser vos soins de santé. Assurez-vous de garder une copie pour vos archives et faites une mise à jour aussi souvent que les circonstances changent ou si vous apprenez d'avantage au sujet de l'histoire de santé de votre famille.

Félicitations de ce que vous ayez décidé de choisir une vie plus longue et une meilleure santé. "Le Portrait de santé de ma famille" peut être un moyen efficace d'améliorer votre santé — aujourd'hui et dans le futur.

Découpez et ajoutez au dossier si nécessaire.

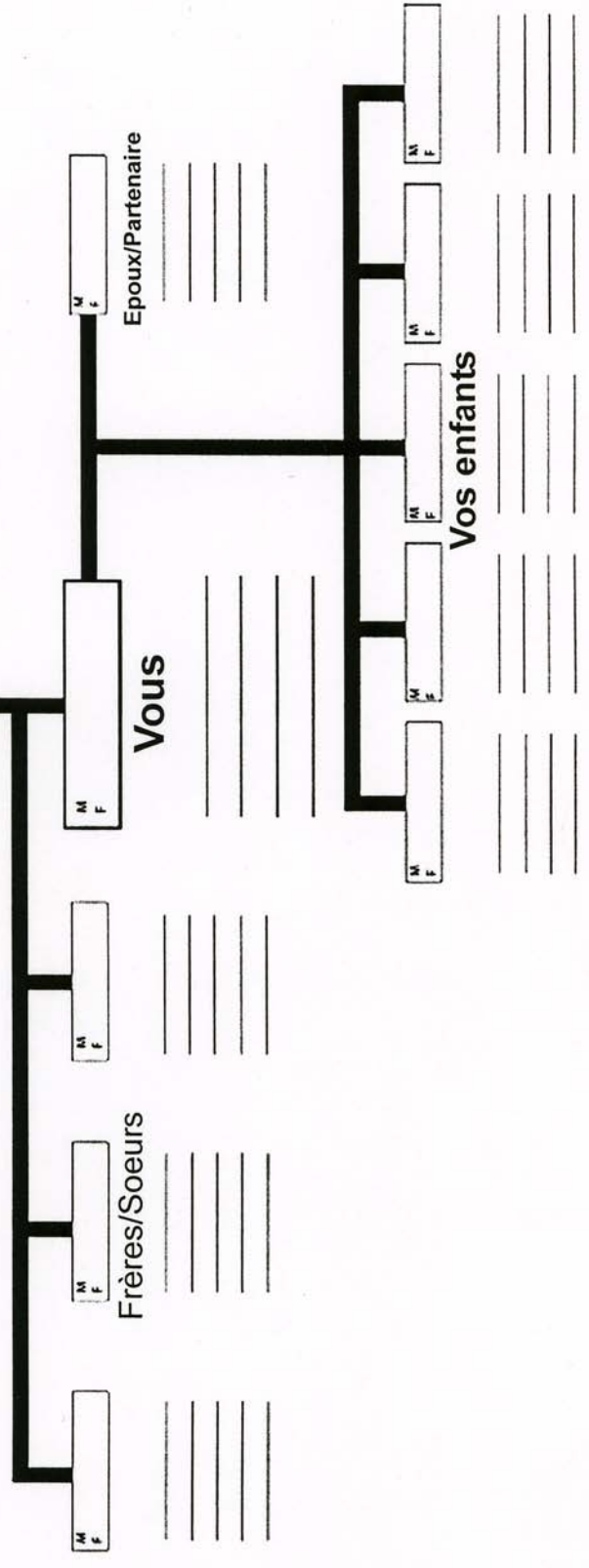
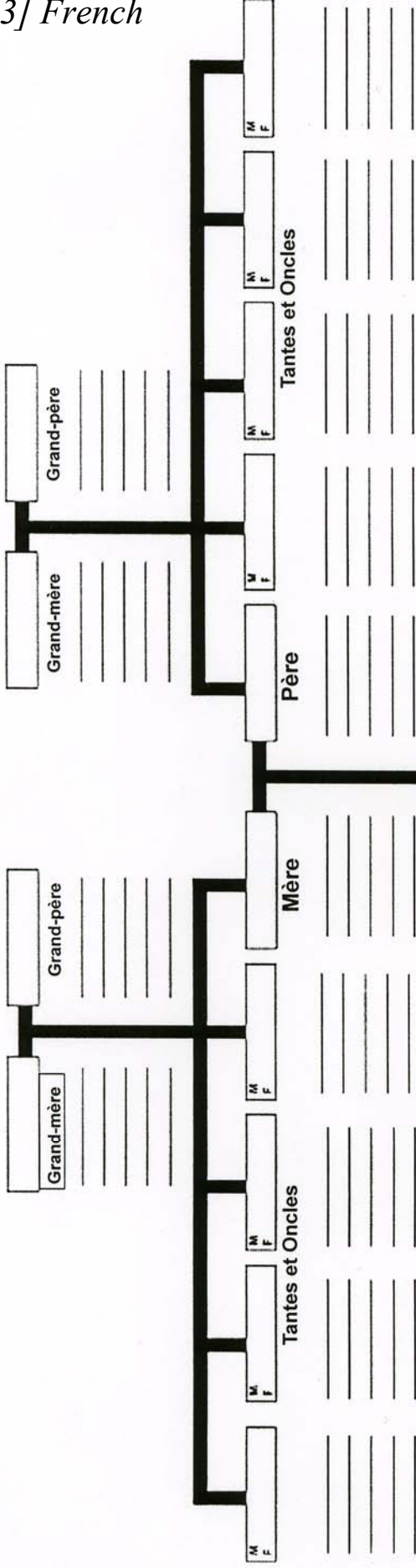
<div data-bbox="224 1241 521 1308"> <p>M F</p> </div> <div data-bbox="240 1402 505 1598"> <p>_____ _____ _____ _____</p> </div>	<div data-bbox="656 1241 953 1308"> <p>M F</p> </div> <div data-bbox="672 1402 937 1598"> <p>_____ _____ _____ _____</p> </div>	<div data-bbox="1084 1241 1382 1308"> <p>M F</p> </div> <div data-bbox="1101 1402 1365 1598"> <p>_____ _____ _____ _____</p> </div>
<div data-bbox="212 1682 509 1749"> <p>M F</p> </div> <div data-bbox="228 1843 493 2039"> <p>_____ _____ _____ _____</p> </div>	<div data-bbox="644 1682 941 1749"> <p>M F</p> </div> <div data-bbox="660 1843 925 2039"> <p>_____ _____ _____ _____</p> </div>	<div data-bbox="1094 1682 1391 1749"> <p>M F</p> </div> <div data-bbox="1110 1843 1375 2039"> <p>_____ _____ _____ _____</p> </div>

Le Portrait de Sante de Ma Famille

Nom: _____

Date: _____

[3] French



Découpez et ajoutez au dossier si nécessaire.

M
F

[4] Portuguese **BRIGHAM & WOMEN'S HOSPITAL**
FAMILY HISTORY PROJECT



Iniciativa de História Clínica Familiar
do Surgeon General

PARA CRIAR UM RETRATO DE SAÚDE DA FAMÍLIA NA INTERNET
ENTRE EM:

www.hhs.gov/familyhistory/

Iniciativa de História Clínica Familiar do Surgeon General para Criar Retrato de Saúde da minha Família

O Surgeon General, autoridade máxima de saúde pública nos Estados Unidos, lançou uma iniciativa nacional para persuadir todas as famílias americanas a procurar saber mais informações sobre a história clínica de todos os membros da família.

A sua vida pode ser salva se souber a história clínica de sua família.

Tendo uma cópia da história clínica de sua família, pode ajudar um profissional de saúde a personalizar os cuidados/tratamento de que necessita, ou para prevenção, e fazer os exames de rastreio para certas doenças de maior risco para si. Acontecimentos familiares, tais como reuniões familiares ou Dia de Ação de Graças (Thanksgiving) são boas oportunidades para recolher informação para o “Retrato de Saúde da minha Família”.

COM QUEM DEVO FALAR?

Para obter informações mais corretas possível, é importante que fale diretamente com os seus familiares. Explique-lhes que a informação sobre a saúde deles pode ser útil para melhorar a prevenção e rastreio de doenças para todos os membros da família.

Comece por perguntar aos seus familiares sobre qualquer doença que tenham tido- inclusive doenças crónicas, tais como doenças cardíacas; complicações durante gravidez, tais como aborto espontâneo; e quaisquer problemas durante o crescimento. Obtenha informação de forma mais específica possível.

Será mais útil se poder escrever o nome médico de qualquer doença que você ou a sua família tenham tido.

A melhor maneira de obter informação sobre doenças suas ou de seus familiares- vivos ou mortos- é perguntado os familiares ou profissionais de saúde, ou pedindo cópias de arquivos médicos.

Se estiver planejando ter filhos, você e seu companheiro/a devem criar um retrato de família e mostrá-lo ao seu profissional de saúde.

Saber a história clínica de sua família é um guia poderoso para a compreensão do risco para doença. Contudo, lembre-se que a existência de uma determinada doença na família pode aumentar o risco, mas quase nunca *garante* que outros membros da família possam vir a ter a doença.

Mais Importantes

Mãe e Pai
Irmãos e Irmãs
Os seus filhos

Também Importantes

Avós e avôs
Tios e Tias
Sobrinhas e Sobrinhos
Meios-Irmãos e Meias-Irmãs

Se Puder Obtenha Informação

Primos e primas
Tios-Avôs e Tias-Avós

[4] Portuguese

O formulário de “Retrato de Saúde da minha Família” vai ajudá-lo a recolher e organizar informações sobre a sua família. Nenhum formulário pode representar todas as versões da família americana, assim sendo use este diagrama como ponto de partida e adapte-o de acordo com a sua família.

Primeiro, escreva o nome de cada um dos seus familiares nos blocos designados e marque com um círculo se forem machos (M) ou fêmeas (F). Na linha seguinte, escreva o nome de qualquer problema de saúde que tenham tido. Se souber a idade que tinham quando foram diagnosticado com a doença, escreva entre parênteses depois do nome da doença. Por exemplo: “diabetes (diagnosticado(a) - idade 37).”

No caso dos familiares que já morreram, escreva “falecido(a)” e a idade que tinham quando faleceram. Por exemplo: “ataque cardíaco (falecido(a) - idade 63).”

Para gêmeos, escreva “gêmeo(a)” na primeira linha para ambas as pessoas. Caso os gêmeos sejam idênticos, escreva “gêmeo(a) idêntico(a)” na primeira linha para ambos(as).

Se na sua família existirem meios-irmãos ou meias-irmãs, escreva “meio-irmão” ou “meia-irmã” na primeira linha e anote “pai diferente” ou “mãe diferente” na linha seguinte.

Algumas doenças são mais comuns entre pessoas com os mesmos antecedentes ou antepassados. É importante que registre os antepassados dos seus familiares e seja o mais específico possível. Por exemplo, se souber que a sua avó é hispana e a família dela é oriunda do México, escreva “Mexicana” por baixo do nome dela. Da mesma maneira, se a sua família for oriunda da Africa, Asia, Europa ou America do Sul, escreva o país de origem, se for possível.

Depois de completar o “Retrato de Saúde da minha Família,” leve-o ao seu profissional de saúde para que ele ou ela possa personalizar melhor os seus cuidados/tratamento de saúde. Mantenha os dados do seu arquivo médico em dia, fazendo as mudanças conforme for obtendo mais informações sobre a história clínica da sua família, e guarde uma cópia para si.

As nossas felicitações por ter dado este passo rumo a uma vida mais longa e mais saudável! O “Retrato de Saúde da minha Família” pode ser uma maneira eficaz de melhorar a sua saúde — hoje e no futuro.

Copie e acrescente conforme for precisando

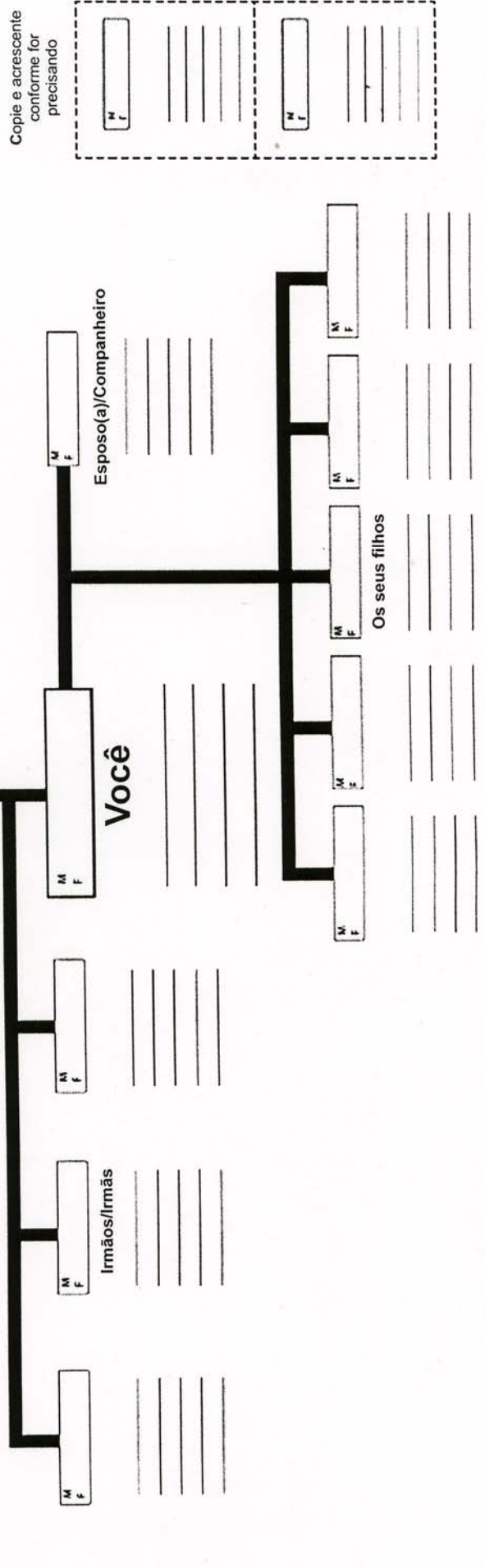
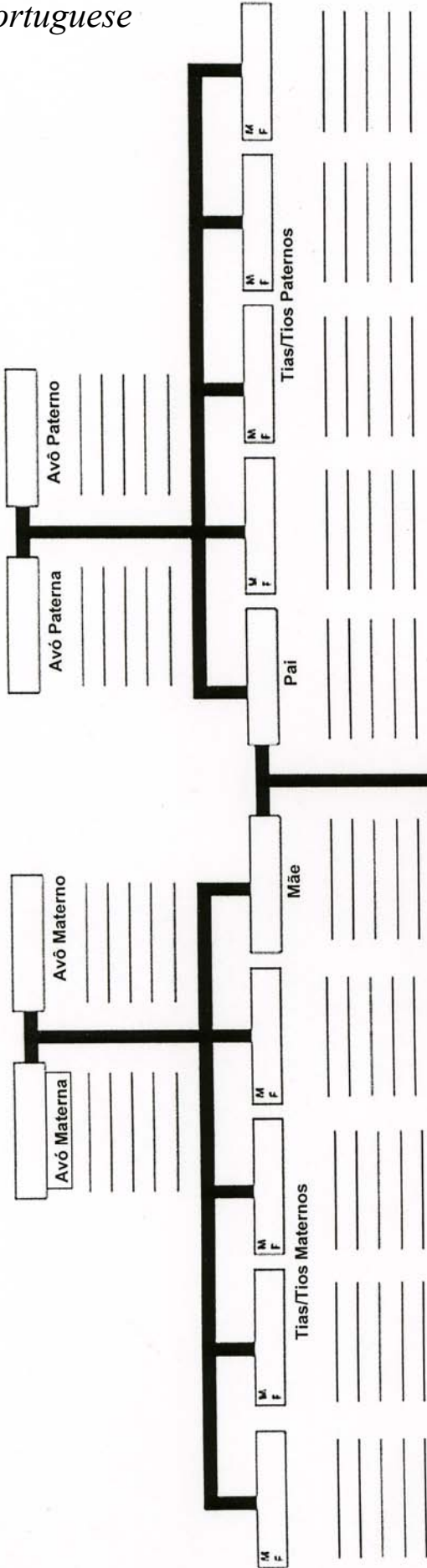
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[4] Portuguese

Nome: _____

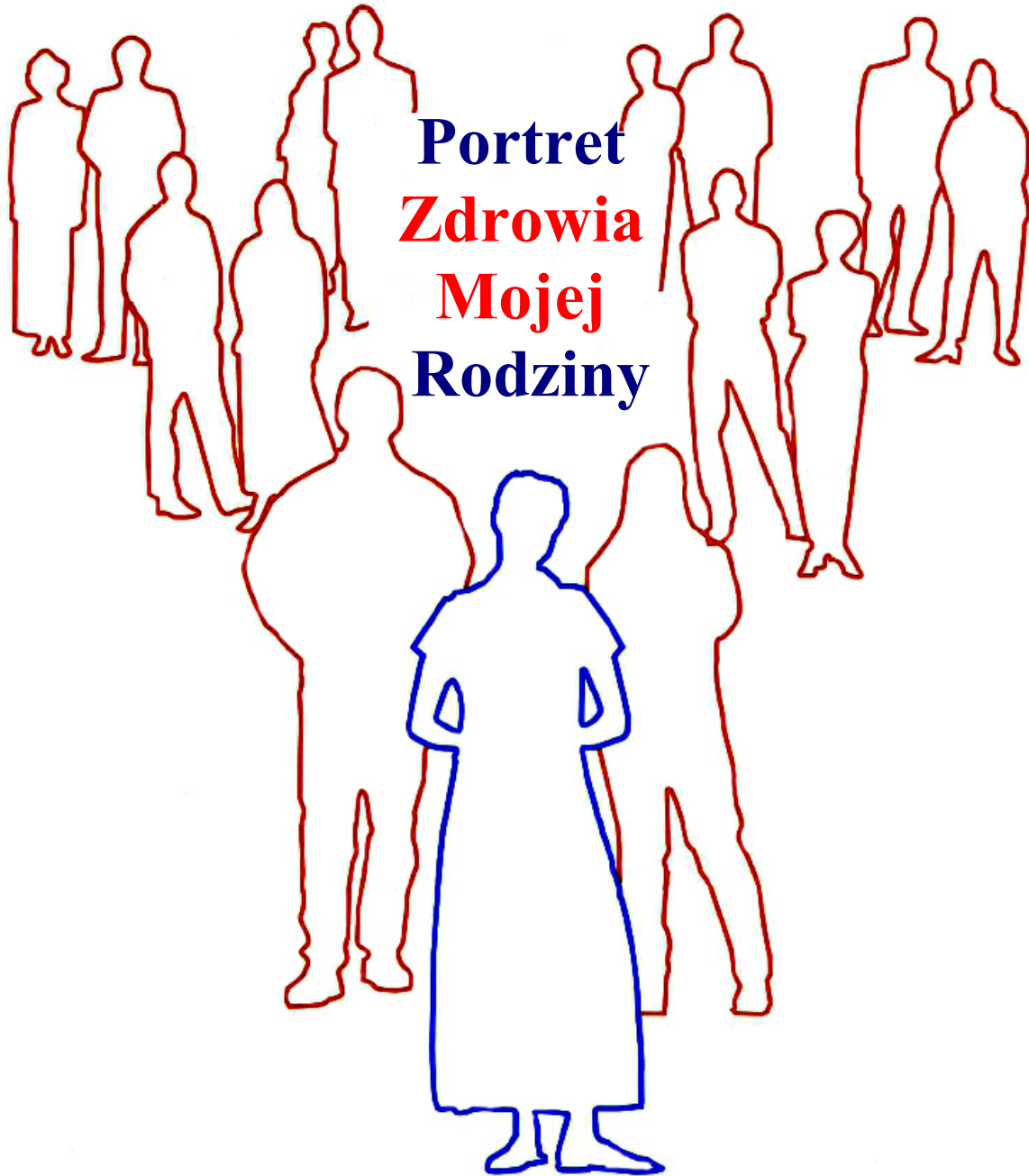
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Retrato de Saúde da minha Família



Copie e acrescente conforme for precisando

Two dashed boxes for additional family members, each containing a small 'M F' box and several horizontal lines for notes.



**Portret
Zdrowia
Mojej
Rodziny**

**INICJATYWA NACZELNEGO LEKARZA
STANÓW ZJEDNOCZONYCH W SPRAWIE
HISTORII ZDROWIA RODZINY**

Brigham and Women's Hospital Family History Project

JAK NALEŻY WYPEŁNIĆ FORMULARZ?

Formularz „Portret zdrowia mojej rodziny” umożliwia zebranie i uporządkowanie informacji o swojej rodzinie. Żaden formularz nie jest w stanie objąć każdego wariantu rodziny amerykańskiej, dlatego więc przedstawiony wykres służy jako punkt wyjścia, który należy dostosować do potrzeb danej rodziny.

Po pierwsze w wyznaczonych kwadratach należy wpisać imiona i nazwiska wszystkich członków rodziny i zaznaczyć, czy są mężczyznami (M) czy kobietami (K). W następnym wierszu należy wyszczególnić wszystkie choroby, na które chorowali. Jeżeli zna Pan(i) wiek, w którym zdiagnozowano daną chorobę, proszę podać go w nawiasie po nazwie choroby, np.: „cukrzyca (zdiagnozowana – w wieku 37 lat)”.

Jeżeli członek rodziny nie żyje, należy wpisać „zmarł” oraz wiek, w którym nastąpiła śmierć, np.: „zawał (zmarł - w wieku 63 lat).”

W przypadku bliźniąt należy wpisać w pierwszym wierszu „bliźniak” przy obu osobach. Jeżeli bliźnięta są jednojajowe, należy w pierwszym wierszu wpisać „bliźnięta jednojajowe”.

Jeżeli Pana(i) rodzina obejmuje rodzeństwo przyrodnie, należy w pierwszym wierszu wpisać

„przyrodni brat” lub „przyrodnia siostra”, a w następnym wierszu odpowiednio „inny ojciec” lub „inna matka”.

Niektóre choroby występują częściej u osób z tego samego środowiska lub o wspólnym pochodzeniu. Dlatego tak ważne jest, aby podać pochodzenie swoich krewnych i jak najwięcej szczegółów. Przykładowo, jeżeli wie Pan(i), że babcia jest Latynosem, a jej rodzina pochodzi z Meksyku, należy pod jej nazwiskiem napisać „Meksykanka”. Podobnie, jeżeli rodzina pochodzi z Afryki, Azji, Europy lub Ameryki Południowej, należy w miarę możliwości podać kraj pochodzenia.

Po wypełnieniu formularza „Portret zdrowia mojej rodziny” należy zabrać go do swojego lekarza, który odpowiednio zindywidualizuje opiekę medyczną. Radzimy zrobić kserokopię zgromadzonych materiałów, które należy uaktualniać wraz ze zmianą okoliczności lub poznawaniem nowych danych na temat historii zdrowia rodziny.

Gratulujemy! Formularz to krok naprzód w kierunku dłuższego i zdrowszego życia! „Portret zdrowia mojej rodziny” może być skutecznym sposobem na poprawę stanu zdrowia – zarówno dzisiaj, jak i w przyszłości.

ODCIĄĆ I DODAĆ DO WYKRESU W RAZIE POTRZEBY

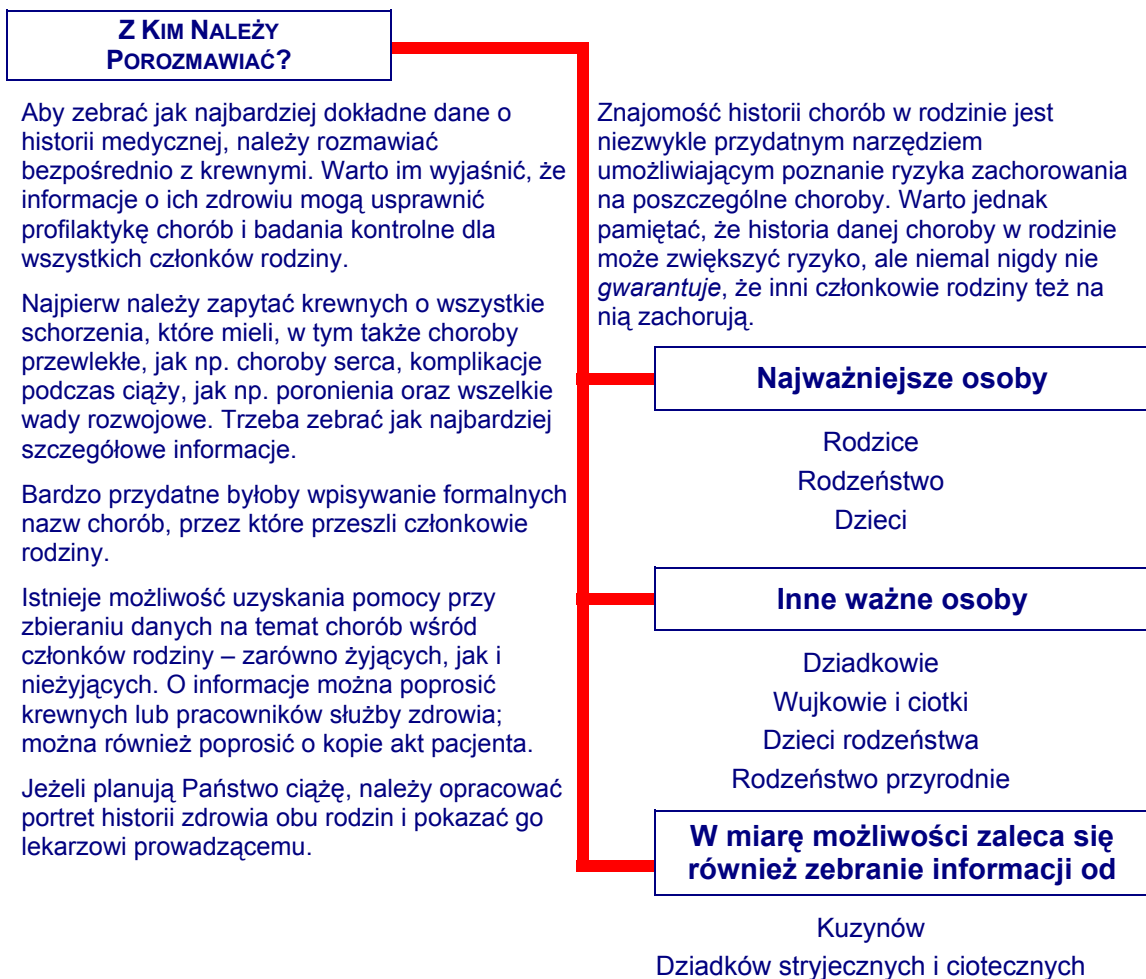
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INICJATYWA NACZELNEGO LEKARZA STANÓW ZJEDNOCZONYCH W SPRAWIE HISTORII ZDROWIA RODZINY JAK OPRACOWAĆ PORTRET HISTORII **ZDROWIA SWOJEJ** RODZINY?

Naczelny Lekarz Stanów Zjednoczonych wprowadził ogólnokrajową inicjatywę zachęcającą wszystkie amerykańskie rodziny do dokładnego poznania swojej historii zdrowia.

Znajomość medycznej historii swojej rodziny może ocalić życie.

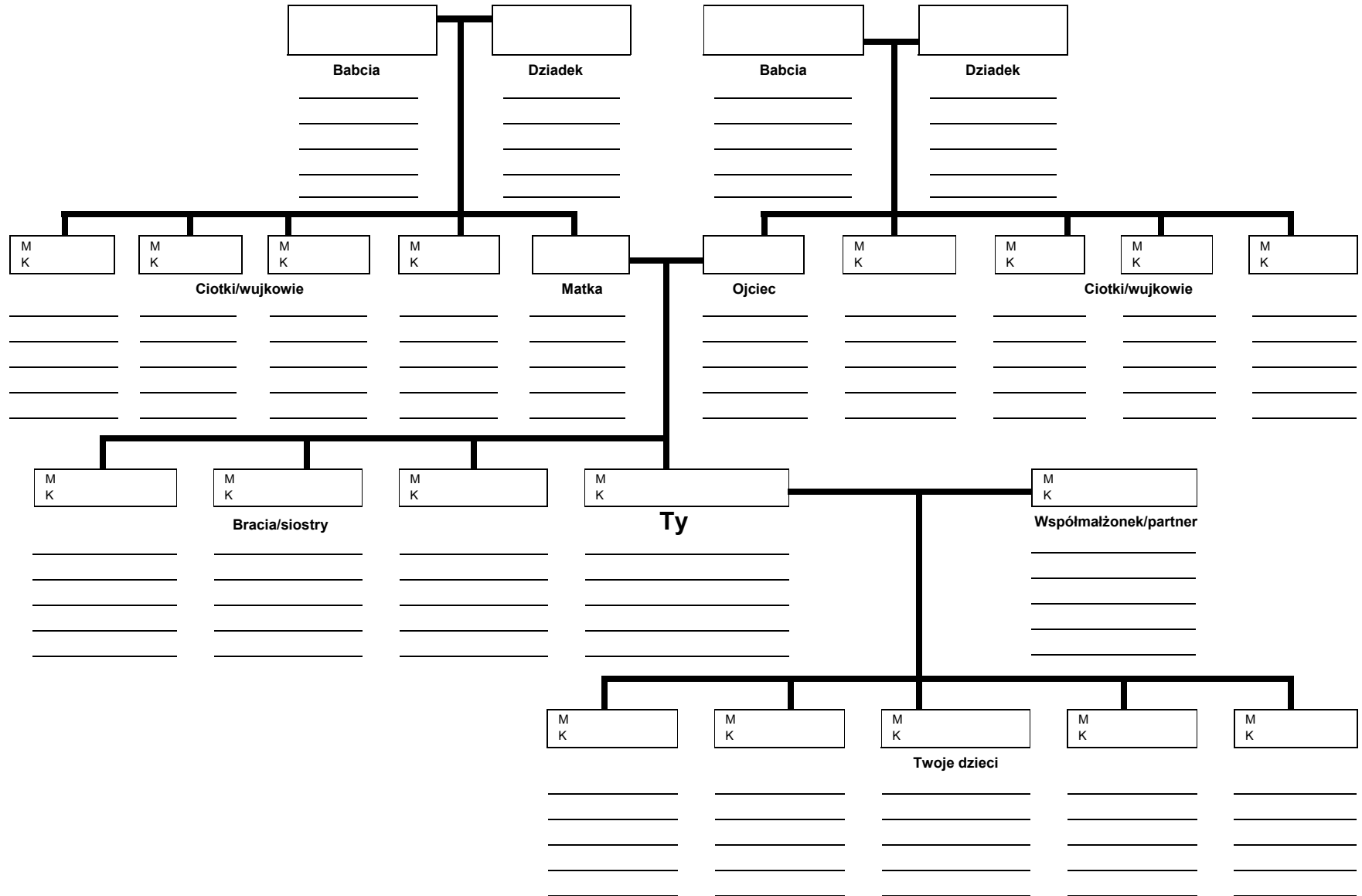
Przy użyciu egzemplarza historii zdrowia Pana(i) rodziny pracownicy służby zdrowia mogą zindywidualizować opiekę medyczną, wykonując badania kontrolne i zapobiegając chorobom, których wystąpienie obarczone jest większym ryzykiem. Spotkania rodzinne, przykładowo podczas Świąta Dziękczynienia lub zjazdów rodzinnych, stanowią świetną okazję do zebrania informacji na potrzeby „Portretu zdrowia mojej rodziny”.



PORTRET ZDROWIA MOJEJ RODZINY

Imię i nazwisko: _____

Data: _____



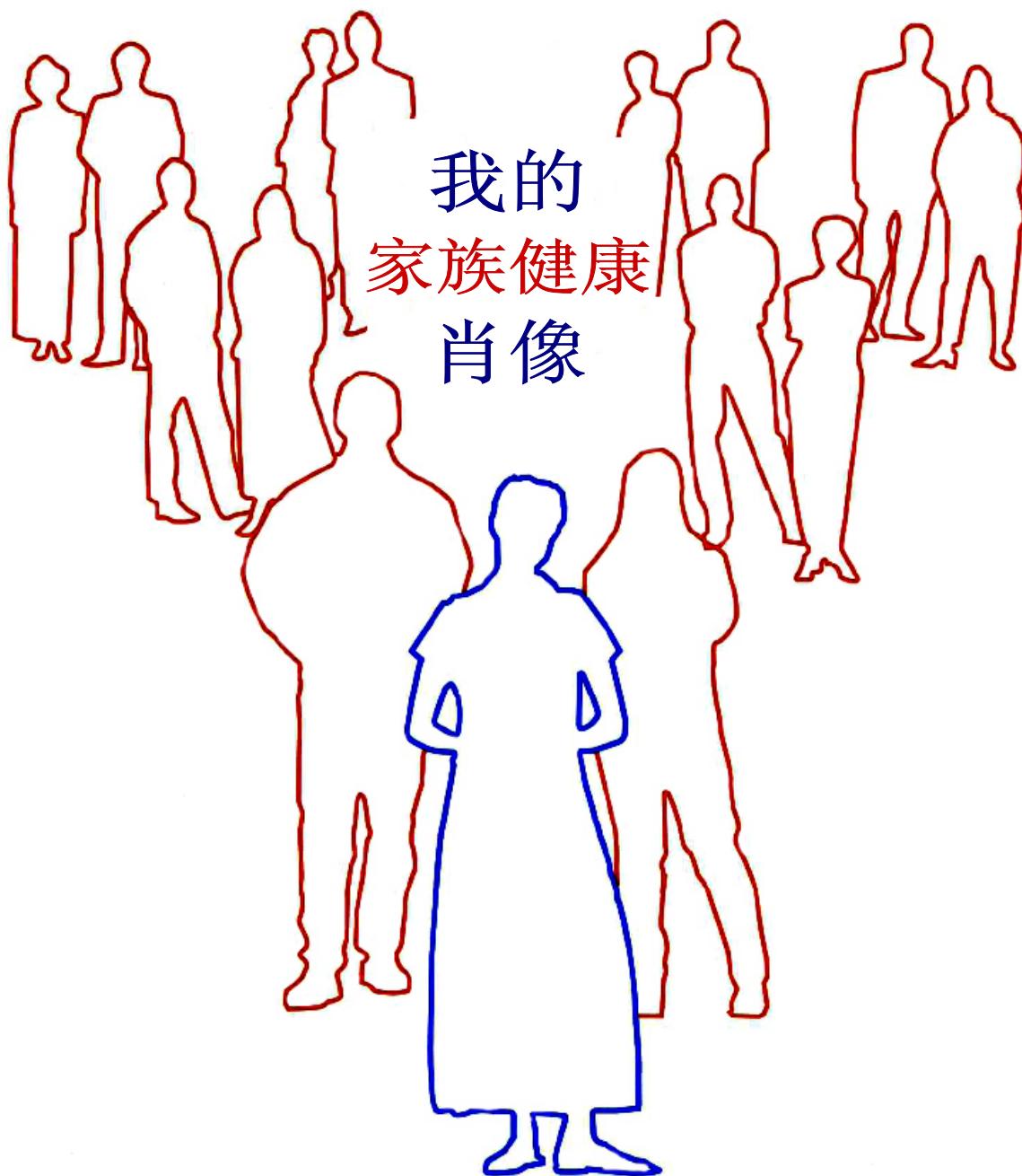
[5] Polish

**Aby przygotować portret zdrowia rodziny w internecie,
należy wejść na stronę:**

www.hhs.gov/familyhistory/

www.brighamandwomens.org/familyhistory/

Listopad 2004



我的
家族健康
肖像

卫生署长的
家族史方案

我该如何填写该表格？

“我的家族健康肖像”表格将帮助您收集和整理您家族的信息。没有表格能够反映美国人家族的所有形式，因此请将本表格作为起点，并按照您家族的需要进行调整。

首先，请在指定的方框内填写您每一位亲属的姓名，并用画圈表示他们是男性（男）或女性（女）。在下一行填写他们曾患有的任何疾病的名称。如果您知道他们被诊断患病的年龄，请将此年龄填写在该疾病后面的括号内。例如：“糖尿病（诊断 - 37岁）”。

如果家族成员已过世，写下“过世”及死亡时的年龄。例如：“心脏病发作（过世 - 63岁）”。

如果是双胞胎，请在两个人的第一行写下“双胞胎”。如果是同卵双胞胎，请在两个人的第一行写下“同卵双胞胎”。

如果您的家族中包括同母异父或同父异母的兄弟姊妹，请在第一行写下“同母异父或同父异母兄

弟”或“同母异父或同父异母姊妹”，并在下一行注明“异父”或“异母”。

有一些疾病在背景或血缘相同的人士中更常见。因此尽可能详细地记录您亲属祖籍很重要。

例如，如果您知道自己的祖母是西班牙裔，她的家族来自墨西哥，请在她的名字下面写上“墨西哥裔”。同样，如果您的家族来自非洲、亚洲、欧洲或南美洲，请在可能的情况下，注明他们来自哪个国家。

一旦完成“我的家族健康肖像”，请将它交给您的医疗服务专业人员，以便他/她能更好地按照您的个人情况对您进行保健服务。请一定为您的记录制作一份副本，并在情况发生变化或您对自己家族健康史了解更多时对该副本进行更新。

祝贺您由此迈向更长寿、更健康的生活！“我的家族健康肖像”可以有效地改善您当前和未来的健康。

按照需要剪切并添加表格

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卫生署长的家族史方案 如何建立我的**家族健康**肖像

美国卫生署长发起了一项全国性方案，旨在鼓励所有的美国家庭加深对自己家族健康史的了解。

了解自己家族的病史可以挽救您的生命。

有了一份您家族的健康史，您和医疗服务专业人员就可以按照您个人的情况调整您的医疗服务，以预防和筛检您可能具有较高风险的疾病。家族活动（例如感恩节或家族聚会）提供了收集“我的家族健康肖像”所需信息的绝佳机会。

我应该与谁交谈？

为了得到健康史最准确的信息，直接与您的亲属交谈非常重要。向他们解释他们的健康信息可以帮助所有的家族成员改善对疾病的预防和筛检。

从询问您的亲属曾患过任何疾病开始 — 包括慢性疾病史，比如心脏病；妊娠并发症，比如流产；以及任何的发育不健全。获得尽可能多的详细信息。

如果您能列出您或您的亲属曾患过的任何疾病之正式名称，则作用最大。

您可以通过询问亲属或医疗服务专业人员或获取医疗记录副本，来帮助找到关于影响您或您家族成员的疾病的信息。

如果您计划生育孩子，您和您的伴侣应该建立各自的家族健康肖像，并出示给你们的医疗服务专业人员。

了解您的家族健康史是理解疾病风险强有力的指南。然而，请记住，家族中有某个特定疾病的病史可能会增加患病风险，但它并不意味着其他家族成员一定会患此病。

最重要的成员

父母
兄弟姊妹
您的孩子

也很重要的成员

(外)祖父母
(舅)叔(姨)姑
侄儿，侄女，外甥和外甥女
同父异母和同母异父的兄弟姊妹

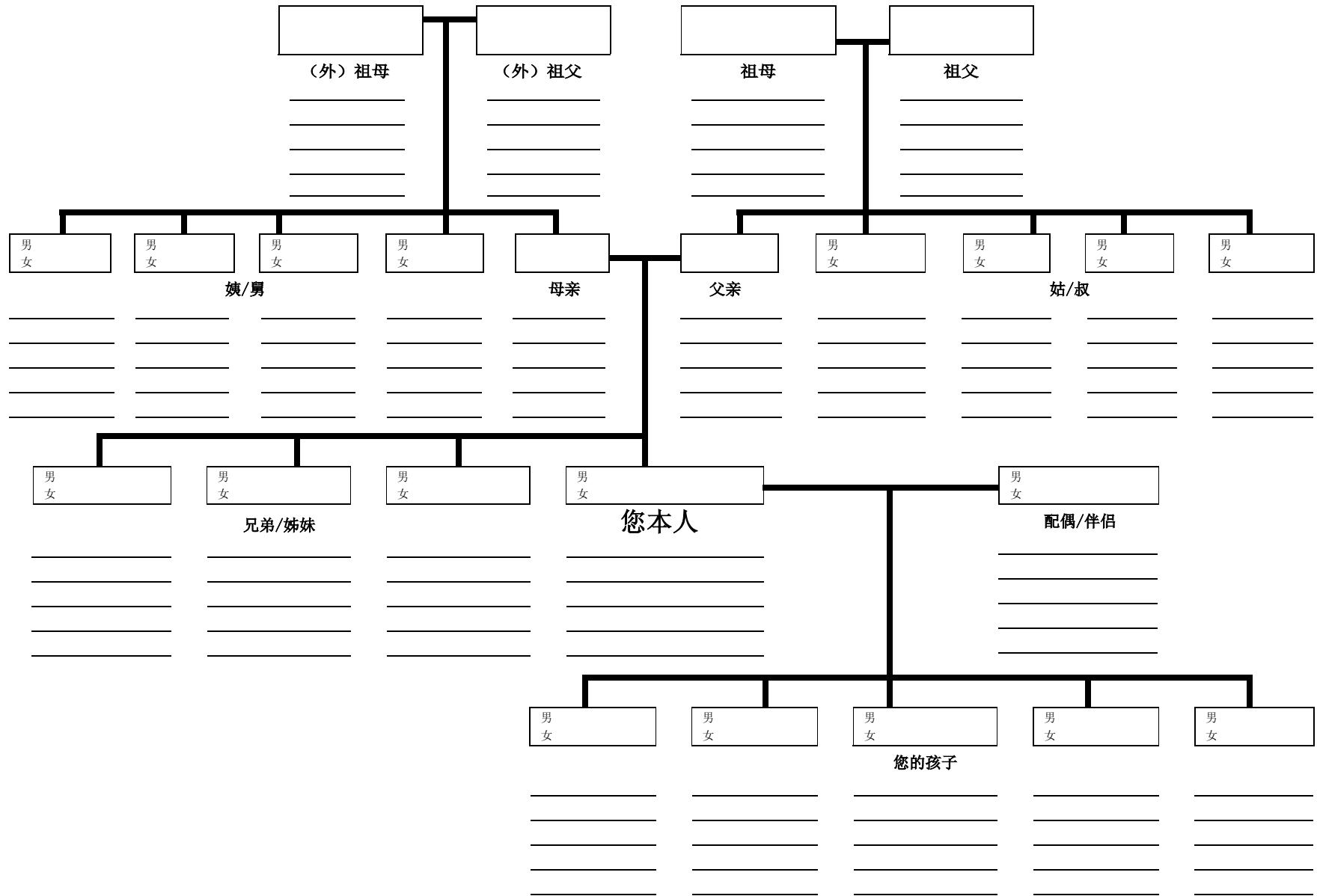
如果可能，获取以下人员的信息

表(堂)兄弟和表(堂)姐妹
祖伯叔、祖舅爷、祖姑母、祖姨婆

我的家族健康肖像

姓名: _____

日期: _____



[6] Chinese


如要在线建立家族健康肖像
请前往：

www.hhs.gov/familyhistory/

www.brighamandwomens.org/familyhistory/

2004年11月

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*Appendix 7A. Press Release for the Chinese
Language Translation of “My Family Health
Portrait”*

The release of the Chinese version of the paper tool caught the attention of the media.

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7A1. Press Release for the Chinese Translation of "My Family Health History"



NEWS

For Immediate Release
Monday, September 25, 2006

Contact: Jessica Podlaski
(617) 534-1603
jpodlaski@partners.org

BWH Extends Family Health History Tool to Chinese-Speaking Employees and Individuals Worldwide

Boston – September 25, 2006 – [Brigham and Women's Hospital](#) (BWH) has launched a Chinese version of the [U.S. Surgeon General's "My Family Health Portrait"](#) on its website to assist its diverse workforce of 12,000 and support individuals worldwide who are interested in organizing their family's health history. The [BWH Family History Project](#), funded by the National Human Genome Research Institute's Education and Community Involvement Branch, now has its tool publicly available on the hospital's website in Chinese, Polish, Portuguese, French, Spanish and English.

"We are giving our employees the opportunity to uncover their family's health history, and share this information with their family and doctors," said Michael Murray, MD, director of the BWH Family History Project and clinical chief of the hospital's Genetics Division. "In doing this, we hope to create an online resource for people around the world."

The National Human Genome Research Institute selected BWH in the fall of 2005 as the first academic medical center to pilot this tool. The BWH Family History Project developed as a voluntary and confidential service open to all hospital employees. Since November, the hospital has been collecting survey data from participating employees to better understand how people use their health history and how this tool can be improved.

"This fall we plan to work with patients to incorporate their family's comprehensive health history into their electronic medical records," said Murray. Health experts believe that a thorough family health history can be used to improve medical decision-making and subsequent patient care.

"For instance, if three of your family members have had breast cancer and you've added this information to your record, then your doctor might suggest an alternative screening strategy to reduce your risk of developing this disease," said Murray.

For more information about The BWH Family History Project, or to access the web-based tool in English or Spanish, visit the hospital's website or click [here](#). To download a PDF of the tool in other languages including Chinese, click the links below:

[Chinese](#)
[Polish](#)

7A1. Press Release for the Chinese Translation of "My Family Health History"

[Portuguese](#)

[French](#)

BWH is a 747-bed nonprofit teaching affiliate of Harvard Medical School and a founding member of Partners HealthCare System, an integrated health care delivery network. BWH is committed to excellence in patient care with expertise in virtually every specialty of medicine and surgery. The BWH medical preeminence dates back to 1832 and today that rich history in clinical care is coupled with its national leadership in quality improvement and patient safety initiatives, dedication to educating and training health care professionals, and strength in biomedical research. With \$370M in funding and more than 500 research scientists, BWH is an acclaimed leader in clinical, basic and epidemiological investigation - including the landmark Nurses Health Study, Physicians Health Studies, and the Women's Health Initiative. For more information visit www.brighamandwomens.org.

7A. Press Release for the Chinese Translation of "My Family Health Portrait"

BWH 将美国卫生署长的“我的家族健康肖像”提供给讲中文的员工和世界各地的人士

波士顿 – 2006 年 9 月 29 日 – [Brigham and Women's Hospital](#) (BWH) 已经在其网站上启动了[美国卫生署长的“我的家族健康肖像”](#)中文版，以协助其 12,000 名多元化的员工，并支持世界各地有意建立自己家族健康史的人士。该项 [BWH 家族史计划](#)是由国家人类基因组研究所 (National Human Genome Research Institute) 的社区参与分部 (Community Involvement Branch) 资助。现在该计划的工具已列在医院的网站上供公众使用，语言有中文、波兰文、葡萄牙文、法文、西班牙文和英文。

BWH 家族史计划的主管及医院遗传学部的临床主任，医学博士 Michael Murray 说：“我们给与员工机会，让他们发掘自己家族的健康史，并将这一信息与其家族和医师分享。通过这样做，我们希望为世界各地的人们建立一个在线资源。”

国家人类基因组研究所于 2005 年秋季选择 BWH 作为试点该工具的首个城市教学医疗中心。BWH 家族史计划作为一项自愿和保密的服务建立，向医院员工开放。自 11 月以来，医院已经从参与的员工处收集了调查数据，以更好地了解人们是如何使用其家族健康史的，以及如何改善该工具。

Murray 说：“这个秋天我们计划与病人一起工作，将他们的家族全面健康史纳入其电子病历中。”医学专家认为完整的家族健康史，可以用来改善医师的决策以及病人的后续治疗。

“例如，如果您的家族成员中有三位曾患有乳腺癌，而且您将这一信息添加入了您的病历，那么，您的医师可能会建议一种替代筛检策略，以降低您患该疾病的风险，” Murray 这样说道。

要了解更多关于 BWH 家族史计划的信息，或是要获取基于网络的英文或西班牙文工具，请访问医院的网站或单击[这里](#)。要下载其他语言，包括中文在内，的该工具的 PDF 文件，请单击下面的链接：

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[波兰文](#)

[葡萄牙文](#)

[法文](#)

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*Appendix 8A. Worldwide Media Coverage of
BWH Family History Project*

Project staff was also able to regularly monitor the numbers of media visitors to the internet sites.

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8A. Worldwide Media Coverage of BWH Family History Project



**BRIGHAM AND
WOMEN'S HOSPITAL**

My Family Health Portrait

Media Hits: January 2005 - June 2007

Date	Outlet	Outlet Type	Headline
2/18/2005	WBZ-TV	Television station	"The New Family Tree"
11/12/2005	The Sun News	Newspaper	"Healthful Advice"
11/16/2006	Boston Herald	Newspaper	"Docs: Talk turkey - and health history - at the dinner table"
11/15/2005	The NIH Record	Magazine	"U.S. Surgeon General Urges Americans to Know Their Family Health History"
11/15/2005	WebHire.com	Online	"U.S. Surgeon General Urges Americans to Know Their Family Health History"
11/15/2005	EurekaAlert!	Online, trade/science	"U.S. Surgeon General Urges Americans to Know Their Family Health History"
11/21/2005	WTOC-TV	Television station	"Valuable Information about your Health"
11/23/2005	Senior Journal	Online, consumer	"Calling on all Americans to know their family history"
11/21/2005	Boston Globe	Newspaper	"Brigham staff to track family medical history"
11/26/2005	WTNH-TV	Television station	"Creating a family medical history"
12/1/2005	Kansas City infoZine	Online, consumer	"U.S. Surgeon General Urges Americans to Know Their Family Health History"
12/2/2005	UAB Health System	Online, trade/medical	"U.S. Surgeon General Urges Americans to Know Their Family Health History"
12/5/2005	Managed Care Weekly Digest	Newsletter - online	"MEDICAL HISTORY; U.S. Surgeon General urges Americans to know their family health histories"
12/5/2005	Health & Medicine Week	Newsletter - online	"MEDICAL HISTORY; U.S. Surgeon General urges Americans to know their family health histories"
12/6/2005	Science Letter	Newsletter - online	"MEDICAL HISTORY; U.S. Surgeon General urges Americans to know their family health histories"
12/6/2005	Life Science Weekly	Newsletter - online	"MEDICAL HISTORY; U.S. Surgeon General urges Americans to know their family health histories"

8A. Worldwide Media Coverage of BWH Family History Project

12/8/2005	Hospital & Nursing Home Week	Newsletter - online	"MEDICAL HISTORY; U.S. Surgeon General urges Americans to know their family health histories"
12/9/2005	Surgery Litigation & Law Weekly	Newsletter - online	"MEDICAL HISTORY; U.S. Surgeon General urges Americans to know their family health histories"
12/9/2005	Medicine & Law Weekly	Newsletter - online	"MEDICAL HISTORY; U.S. Surgeon General urges Americans to know their family health histories"
12/9/2005	MD Week	Newsletter - online	"MEDICAL HISTORY; U.S. Surgeon General urges Americans to know their family health histories"
12/9/2005	Genomics & Genetics Weekly	Newsletter - online	"MEDICAL HISTORY; U.S. Surgeon General urges Americans to know their family health histories"
12/10/2005	Obesity, Fitness & Wellness Week	Newsletter - online	"MEDICAL HISTORY; U.S. Surgeon General urges Americans to know their family health histories"
2/1/2006	Hospitals & Health Networks	Magazine, trade/industry	"Family Portraits"
2/2/2006	Harvard University Gazette	Newspaper	"Brigham pilot program connects people with family histories"
2/5/2006	University Affairs	Magazine	"Brigham pilot program connects people with their family histories"
8/15/2006	The Sampson Independent	Newspaper	"Genetic testing what's so great about knowing your fate?"
8/15/2006	Belfast Telegraph	Newspaper	"Genetic testing what's so great about knowing your fate?"
8/23/2006	Irish Independent	Online, news	"Family fortunes"
11/1/2006	PR Newswire	Wire Service	"Can We Talk? Americans Urged to Start the Conversation About Their Family Medical History"
11/1/2006	Yahoo!	Online, news	"Can We Talk? Americans Urged to Start the Conversation About Their Family Medical History"
11/1/2006	Forbes	Magazine - online	"Can We Talk? Americans Urged to Start the Conversation About Their Family Medical History"
11/15/2006	States News Service	Government	"New Family Health History Projects Focus on Alaska Native, Appalachian Communities"
11/16/2006	National Institutes of Health	Online, trade	"New Family Health History Projects Focus on Alaska Native, Appalachian Communities"

8A. Worldwide Media Coverage of BWH Family History Project

11/16/2006	Kansas City infoZine	Online, consumer	"Know Your Family Health Histories, Acting Surgeon General Urges Americans"
11/20/2006	USA Today	Newspaper	"Know your family history"
11/21/2006	KARE-TV	Television station	"Know your family history"
11/22/2006	MediLexicon	Online, trade	"Americans Urged To Know Their Family Health Histories By Acting Surgeon General"
12/4/2006	Boston Herald	Newspaper	"Med History Often Elusive to Adoptees"
12/4/2006	Managed Care Weekly Digest	Newsletter - online	"GENETICS & GENOMICS; New family health history projects focus on Alaska Native and Appalachian communities"
12/5/2006	Health Risk Factor Week	Newsletter - online	"GENETICS & GENOMICS; New family health history projects focus on Alaska Native and Appalachian communities"
12/5/2006	Disease Prevention Week	Newsletter - online	"GENETICS & GENOMICS; New family health history projects focus on Alaska Native and Appalachian communities"
12/6/2006	Physician Law Weekly	Newsletter - online	"GENETICS & GENOMICS; New family health history projects focus on Alaska Native and Appalachian communities"
12/6/2006	Genetics & Environmental Health Week	Newsletter - online	"GENETICS & GENOMICS; New family health history projects focus on Alaska Native and Appalachian communities"
12/7/2006	State & Local Health Law Weekly	Newsletter - online	"GENETICS & GENOMICS; New family health history projects focus on Alaska Native and Appalachian communities"
12/7/2006	Hospital Law Weekly	Newsletter - online	"GENETICS & GENOMICS; New family health history projects focus on Alaska Native and Appalachian communities"
12/7/2006	Hospital & Nursing Home Week	Newsletter - online	"GENETICS & GENOMICS; New family health history projects focus on Alaska Native and Appalachian communities"
12/7/2006	Genetics & Environmental Business Week	Newsletter - online	"GENETICS & GENOMICS; New family health history projects focus on Alaska Native and Appalachian communities"
12/8/2006	MD Week	Newsletter - online	"GENETICS & GENOMICS; New family health history projects focus on Alaska Native and Appalachian communities"

8A. Worldwide Media Coverage of BWH Family History Project

12/8/2006	Genomics & Genetics Weekly	Newsletter - online	"GENETICS & GENOMICS; New family health history projects focus on Alaska Native and Appalachian communities"
12/9/2006	Genetics & Environmental Law Weekly	Newsletter - online	"GENETICS & GENOMICS; New family health history projects focus on Alaska Native and Appalachian communities"
12/9/2006	Law & Health Weekly	Newsletter - online	"GENETICS & GENOMICS; New family health history projects focus on Alaska Native and Appalachian communities"
12/10/2006	Preventative Medicine Week	Newsletter - online	"GENETICS & GENOMICS; New family health history projects focus on Alaska Native and Appalachian communities"
12/10/2006	Hospital Business Week	Newsletter - online	"GENETICS & GENOMICS; New family health history projects focus on Alaska Native and Appalachian communities"
12/10/2006	Disease Risk Factor Weekly	Newsletter - online	"GENETICS & GENOMICS; New family health history projects focus on Alaska Native and Appalachian communities"
12/1/2006	Hospital Network.com	Online, trade	"New Family Health History Projects"
Spring 2006	WBUR	Radio station	"Report by Martha Bebinger"
6/15/2007	WHDH-TV	Television station	"Family Ties"
6/22/2007	WRC-TV	Television station	"Web Site Helps Track Family Medical History"
6/22/2007	WIS-TV	Television station	"Health Alert Family history"

Total Hits: 59
Broadcast Outlets: 8
Print Outlets: 11
Other Outlets: 40

Appendix 9A. BWH FHP Intra- and Internet websites

The BWH FHP staff developed both intra- and internet websites to provide interested employees and the general public with more information about the project and family health history collection. The websites were promoted and advertised throughout the hospital by project staff and volunteers and again through the help of the Public Affairs Department.

“Screen Shots” of Websites:

[1] **US Surgeon General’s Family History Website** – [\[https://familyhistory.hhs.gov/\]](https://familyhistory.hhs.gov/) “My Family Health Portrait”

[2] **BWH FHP Internet Website** – [\[http://www.brighamandwomens.org/familyhistory\]](http://www.brighamandwomens.org/familyhistory) “Family History Project Page”

[3] **BWH Intranet Page – Pike Notes** – [\[www.brighamandwomens.org/feature_nov052.asp\]](http://www.brighamandwomens.org/feature_nov052.asp) not accessible outside the hospital, expanded launch in March 2006 includes Family History “success stories”

[4] **BWH Gene Talk** – [\[http://genetalk.bwh.harvard.edu\]](http://genetalk.bwh.harvard.edu) includes family history information, links to other sites, and foreign language versions of Family History Tools

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9A1. U.S. Surgeon General's Family History Website

The screenshot shows a Mozilla Firefox browser window displaying the homepage of the My Family Health Portrait website. The browser's address bar shows the URL <https://familyhistory.hhs.gov/>. The website header features the title "My Family Health Portrait" and the subtitle "A tool from the U.S. Surgeon General". Navigation links for "Additional Information", "Help with this page", and "en Español" are visible. The main content area is titled "Welcome to My Family Health Portrait" and includes a graphic of a diverse group of people. The text explains that the tool allows users to create a personalized family health history report from any computer with an Internet connection and an up-to-date Web browser. It further states that the information provided creates a drawing of a family tree and a chart of family health history, which can be printed and shared. Two prominent buttons are displayed: "Create a Family History" and "Load a Saved Family History", separated by the word "OR". A footer note mentions compatibility with most browsers and operating systems, and provides links to a compatibility statement, downloadable software, and a hard copy paper form.

My Family Health Portrait - Home Page - Mozilla Firefox

File Edit View History Bookmarks Tools Help

<https://familyhistory.hhs.gov/> Google

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

[Additional Information](#) [Help with this page](#) [en Español](#)

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.

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

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.

My Family Health Portrait is compatible with most browsers and operating systems. Please see our [compatibility statement](#) for more information. For users who prefer alternative versions of My Family Health Portrait, the [downloadable software version](#) and [hard copy paper form](#) are available.

Done familyhistory.hhs.gov

Start My Family Health Port... 9:13 AM

9A2. BWH Public Website

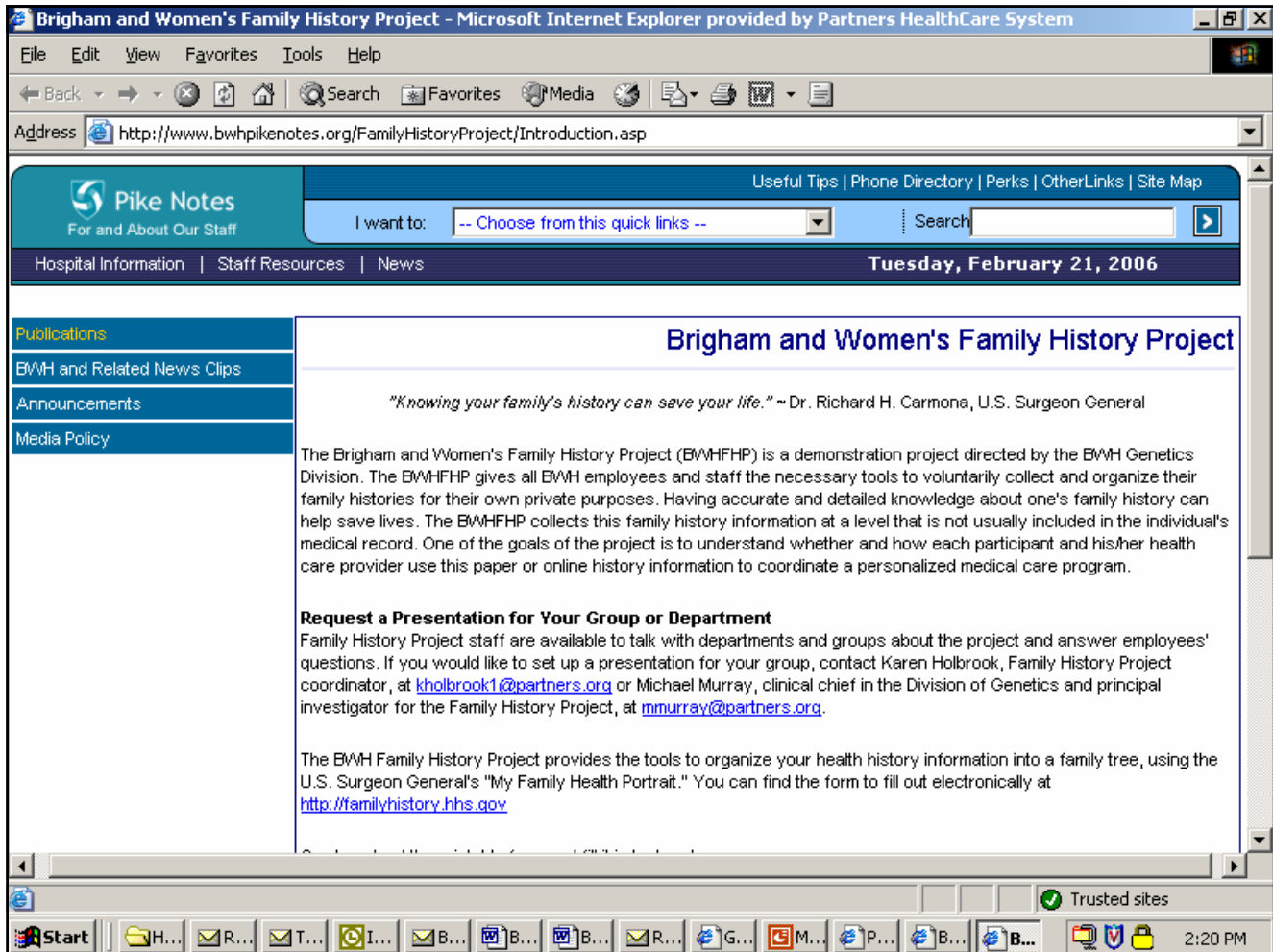
Brigham and Women's Hospital Launches National Family Health Initiative

Brigham and Women's Hospital was proudly chosen by the National Human Genome Research Institute at the National Institutes of Health to be the first site in the United States to launch the newest phase of a nationwide Family Health Initiative.

Joining Brigham and Women's Hospital (BWH) in a community celebration, Francis S. Collins, MD, PhD, a physician-geneticist and Director of the National Human Genome Research Institute, nationally launched an updated version of the "My Family Health Portrait" tool designed to help families voluntarily gather and manage

Francis Collins, MD, PhD, director of the

9A3. BWH Intranet Page - Pike Notes



9A4. BWH Gene Talk


Gene Talk - Microsoft Internet Explorer provided by Partners HealthCare System

File Edit View Favorites Tools Help

← Back → Search Favorites Media


Address http://www.houseof9.com/gene_talk/0201/

Home Family Health History Genetics Education About Us Contact Us

 BRIGHAM AND WOMEN'S HOSPITAL
Family History Project

*"Knowing Your Family's History
Can Save Your Life."*

– U.S. SURGEON GENERAL, DR. RICHARD H. CARMONA –



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http://www.houseof9.com/gene_talk/0201/history.html Local intranet

Start H:\B... RE: ... This... Inbo... BWH ... BWH ... BWH ... Re: ... Gene... 2:17 PM



Appendix 10A. Family History and Hard to Reach Populations

Project staff recognized that not all individuals are able to obtain family health history from their relatives due to family relationships or in cases of adoption. In an effort to address these challenges, staff created “Approaches to special circumstances”.

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10A. Family History and Hard to Reach Populations

FAMILY HEALTH HISTORY: Approaches to Special Circumstances

I. "Adoption: When a Family History is not available"

a. A Personal Viewpoint [Kris DeGraw Danna, BWH Director of Volunteer Services]]

It seems simple enough. Diverse media outlets and community organizations throw messages and events your way requesting participation in or a celebration of your racial and ethnic heritage. You may not know the biological origins of your existence, yet you receive daily requests to share this unknown information. Family members ask for faithful participation in the observance of certain holidays. Peers and colleagues ask you to act consistently with an assured set of characteristics. Even applications for school and work ask you. And now your doctor wants to know.

Although you are not able to complete the Surgeon General's Family Health Portrait, you can accomplish the mission of creating a medical tool. You do not have access to your relatives' health history, therefore cannot know what screenings in which to participate, BUT:

- *Be savvy, not obsessed, about early stages of chronic illnesses, their symptoms, and possible environmental igniters. Use your common sense. If you feel you or your child(ren) display appropriate signs of early stages, don't wait. Talk to your doctor or health provider immediately. Be proactive about informing these providers of your unknown family history.*
- *If you suspect that any portion of your biology is tied to a certain background or ancestry, learn more. Take notes. Become observant and aware of facts and research in these particular areas. Chances are your intuition may be closer to reality than you know or are able to uncover.*
- *Be healthy! Don't risk the arrival of a health condition due to lifestyle decisions such as smoking, drinking, sun exposure or unhealthy eating habits.*
- *Keep a record of your own medical history. Pay close attention to detail since you are the first in line. Talk openly with your children and/or parents about what you would like to accomplish.*

If you are interested in state and federal laws regarding finding an adoptee's birthparent or support for an adoptee, your state government's health department has easily accessible written and online resources.

RELATED LINKS

Adoption Journeys of Massachusetts
1-800-972-2734
<http://www.adoptionjourneysma.org>

The Center for Adoption Research
<http://www.centerforadoptionresearch.org>

Mass Adoption Resource Exchange, Inc. (MARE)
(800) 54-ADOPT
<http://www.mareinc.org>

Open Door Society
<http://www.odsacone.org>

The Center for Family Connections
(617) 547-0909
<http://www.kinnect.org/>

10A. Family History and Hard to Reach Populations

- b. A Medical Viewpoint [Dr. Michael Murray, Director of the BWH Family History Project]

Obtaining and maintaining a “family health history” is but one task within the larger undertaking of promoting the health of yourself and your family (biological or adoptive). As someone who has been involved in promoting the use of this old medical tool (i.e. the family health history), I regret that anyone has to experience these efforts as a reminder of separation from biological relatives through adoption (or other forms of estrangement). However there are many other things that can and should be done to promote one’s health, and Kris’ comments set the stage for focusing on some of those other things.

As a physician I think about health as really coming down to the combined impact of two great forces, they are **genes and environment** (or more classically **nature and nurture**). One of the reasons for the renewed focus the family health history at this time is the appreciation that many families share both genes and environment. So while adoptive families don’t share genes they do share environment, and for some common health problems, like asthma and diabetes, environmental risk factors like smoking and diet are very significant. Therefore none of us should completely discount the influence of those around us on our risk for health or disease.

With all of the current interest in genes and genetics, we all need to be careful not to emphasize inherited risk for disease to the exclusion of modifiable risks for disease. For anyone interested in putting their own disease risk into a context that considers environmental risks check out the website “Your Disease Risk” (<http://www.yourdiseaserisk.harvard.edu/>) hosted by the Harvard School of Public Health.